



# Caregiver Resource Guide

Caring for a Loved One with Cancer



“

*One of my colleagues in the field of caregiving said,*

*‘There are only four kinds of people in this world:*

*Those who have been caregivers*

*Those who currently are caregivers*

*Those who will be caregivers*

*Those who will need caregivers’*

**ROSALYNN CARTER**

***HELPING YOURSELF HELP OTHERS: A BOOK FOR CAREGIVERS***

## WHAT IS THE PURPOSE OF THIS CAREGIVER RESOURCE GUIDE?

The *American Cancer Society Caregiver Resource Guide* is a tool for people who are caring for someone with cancer. It can help you:

- Learn how to care for yourself as a caregiver.
- Better understand what your loved one is going through.
- Develop skills for coping and caring.
- Take steps to help protect your health and well-being.
- Find important resources for getting help and support.

Information about a specific cancer diagnosis and its course of treatment can be found on our website, [cancer.org](https://www.cancer.org), or you can call and speak to one of our caring, trained staff at **1-800-227-2345**. Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*. Refer to [cancer.org/caregivers](https://www.cancer.org/caregivers) to download this Guide or visit [cancer.org/caregiverguide](https://www.cancer.org/caregiverguide) for the interactive version.

The *American Cancer Society Caregiver Support Video Series* is available to help you with anything from self-care tips to training you in the physical care of your loved one. Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch.

## A RESOURCE THAT'S RELEVANT TO YOUR NEEDS

The *Caregiver Resource Guide* is not intended to be followed like a book you read from beginning to end. Rather, it can be referenced as needed for each topic that is **relevant to your care experience**. There are tabbed sections and places for you to take notes to help you organize your information, based on each of these topics:

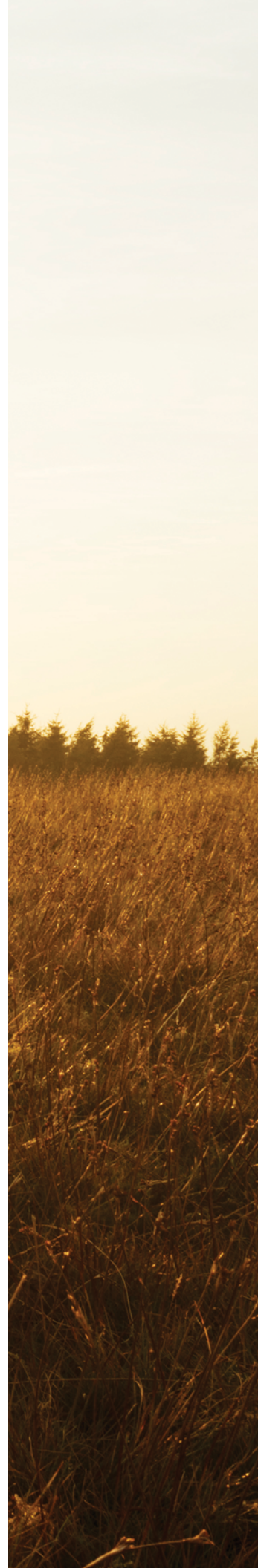
- **Cancer Caregiving:** provides information about what caregivers do and how your role is important in the cancer journey; also provides tips for being an effective caregiver
- **Caregiver Self-Care:** provides information about healthy lifestyle choices with guidelines to support physical activity and nutrition
- **Communication:** tools to better express thoughts and feelings about cancer to the patient as well as to the cancer care team
- **Cancer Information:** provides the basics about what cancer is, how it develops, common cancer myths, how cancer is treated, and how people may change both physically and mentally as a result of having cancer; addresses the financial implications of cancer
- **Cancer Treatment:** briefly describes surgery, chemotherapy, and radiation and their respective side effects; also provides resources in the event that treatment stops working
- **Patient Nutrition:** describes how eating the right kinds of foods before, during, and after treatment can help patients feel better and stay stronger
- **Coping:** describes the most common psychosocial concerns around cancer (i.e., anxiety, fear, and depression) and how caregivers can help patients cope with them
- **Caregiver Resources:** describes support groups and resources available in multiple on-line environments offered through the American Cancer Society and beyond, as well as in-person support groups offered in various communities nationwide

# AMERICAN CANCER SOCIETY CAREGIVER RESOURCE GUIDE

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# Cancer Caregiving

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## CARING FOR A LOVED ONE WITH CANCER

### WHAT IS A CANCER CAREGIVER?

Caregiver is defined in this guide as the person who most often helps the person with cancer and is not paid to do so. In most cases, the main (primary) caregiver is a spouse, partner, parent, or an adult child. When family is not around, close friends, coworkers, or neighbors may fill this role. The caregiver has a key role in the patient's care. Good, reliable caregiver support is crucial to the physical and emotional well-being of people with cancer.

Today, most cancer treatment is given in outpatient treatment centers. This means someone is needed to provide part of the day-to-day care of the person with cancer and that sicker people are being cared for at home. As a result, caregivers have many roles, which change during and after cancer treatment.

As a caregiver, you have a huge influence on how the cancer patient deals with their illness. Your encouragement can help the patient stick with a demanding treatment plan and take other steps to get well, like eating healthy meals or getting enough rest.

Here, we will give you some idea of what to expect in the role as caregiver for a person with cancer. We will also offer some tips on ways to take care of yourself during this time.

### WHAT DOES A CAREGIVER DO?

You may serve as a home health aide and companion. You may help feed, dress, and bathe the patient. You may arrange schedules, manage insurance issues, and provide transportation. You may be a legal assistant, financial manager, and housekeeper. You may have to take over the duties of the person with cancer, and still meet the needs of other family members.

On top of the normal day-to-day tasks, such as meals, cleaning, and driving or arranging transportation, as a caregiver, you'll also become an important part of the cancer care team. This busy schedule could leave you with no time to take care of your own needs. You also may feel the need to turn down job opportunities, work fewer hours, or even retire early to meet the demands of being a caregiver.

## Caregivers solve problems

The person with cancer faces many new challenges. As the caregiver, you can help the patient deal with these challenges and get through any problems that come up. The best way to prioritize and manage problems is first to try to understand the problem, as well as the desired results. Caregivers who are realistic, but positive; careful, but creative; and focused, but flexible are sources of strength and security for people with cancer.

### Good communication with the person you are caring for is the most important part of your role. Here are some things you can try to do to keep the patient involved:

- Help them live as normal a life as possible.
- Encourage them to share feelings, and support their efforts to share.
- Let your loved one know you're available, but don't press issues.
- Remember that people communicate in different ways.
- Take your cues from the person with cancer.
- Be realistic and flexible about what you hope to talk about and agree on.
- Respect the need to be alone. Sometimes, we all need time alone – even you.

For example, suppose the patient's white blood counts drop, they develop a fever, and as a result, need to be in the hospital. This can be very upsetting and may be seen as a setback by the family and the patient. You can:

- Help address their concerns by pointing out that the patient will need to be in the hospital for only a short time until an antibiotic treatment has the infection under control.
- Make sure that the patient has everything they need while in the hospital, including doctor's prescriptions for non-cancer-related medicines taken at home, such as thyroid or blood pressure medicine.
- Call all the doctors involved in the patient's care and tell them about the infection and that the patient is in the hospital.
- Ensure that arrangements have been made for the patient to stay on the antibiotics at home or as an outpatient after leaving the hospital. If daily visits to the outpatient clinic for IV (intravenous) antibiotics are needed, you can coordinate people to help the patient get there and back each day.





These kinds of tasks may be too much for your loved one to tackle while fighting an infection. This kind of help is valuable. It's a reassuring sign for them that this short-term problem can be managed and solved.

### **Caregivers are part of a cancer care team**

You are part of a cancer care team made up of the patient, other family and friends, and the medical staff. As a caregiver, you may find yourself working closely with the cancer care team, doing things like:

- Giving drugs
- Managing side effects
- Reporting problems
- Trying to keep other family members and friends informed of what's happening
- Helping to decide whether a treatment is working

As part of the team, you'll help coordinate the patient's care. You may have to keep track of prescriptions, know which tests are to be done, and make sure all doctors involved know what's going on. You may find yourself preventing mix-ups and keeping track of paperwork.

A good caregiver is a vital health care resource. In many cases, the caregiver is the one person who knows everything that's going on with the patient. Don't be afraid to ask questions and take notes during doctor visits. Learn who the members of the cancer care team are, and know how to contact them. Getting the right support and information can help both you and your loved one with cancer.

### **Caregivers involve the patient**

Good communication with the person you are caring for is the most important part of your role. It may be hard for the patient to take part in daily planning and decision making because they're dealing with the physical, emotional, and social effects of cancer and treatment. Your job is to involve the patient as much as possible, so they know they're doing their part to get better. Here are some things you can try to do to keep the patient involved:

- Help them live as normal a life as possible. To do this, you might start by helping them decide what activities are most important. They may need to put aside those that are less important in order to do the things they enjoy the most.

- Encourage them to share feelings, and support their efforts to share. For instance, if they begin talking to you about their feelings about cancer, don't change the subject. Listen and let them talk. You might want to share how you're feeling, too.
- Let your loved one know you're available, but don't press issues. For example, if they're trying to do something, such as dress themselves – they might be struggling, but it's important for them to be able to do this. You may want to do it for them, but don't. Let them decide when they need help.
- Remember that people communicate in different ways. Try sharing by writing or by using gestures, expressions, or touch. Sometimes, it may be really hard to say what you're feeling, but a gesture such as holding hands might show how you feel.
- Take your cues from the person with cancer. Some people are very private while others will talk more about what they're going through. Respect the person's need to share or their need to remain quiet.
- Be realistic and flexible about what you hope to talk about and agree on. You may need or want to talk, only to find that your loved one doesn't want to do it at that time.
- Respect the need to be alone. Sometimes, we all need time alone – even you.

You might find that the person you're caring for is acting different – angry, quiet and withdrawn, or just sad. If you get the feeling that they aren't talking to you because they want to spare your feelings, make sure they know that you are always open to listening, even about tough topics. If they keep acting very sad or withdrawn, you might want to talk



to the cancer care team about what could be causing it and what can be done. Go to [cancer.org](https://www.cancer.org) and read *Anxiety, Fear, and Depression* to learn more.

### Caregivers take care of day-to-day tasks

There are other day-to-day tasks you might do as a caregiver. Here are a few things you might help the person with cancer do, or in some cases even do for them:

- Shop for and prepare food
- Eat
- Take medicines
- Bathe, groom, and dress
- Use the bathroom
- Clean house and do laundry
- Pay bills
- Find emotional support
- Get to and from doctor's appointments, tests, and treatments
- Manage medical problems at home
- Coordinate cancer care
- Decide when to seek health care or see a doctor for new problems

All of this work costs time and money. There may also be a cost to your health and well-being, but you may find that you just keep doing what needs to be done and may suffer in silence.

You may be glad to put the well-being of the person with cancer above your own well-being. And your love for this person may give you the energy and drive you need to help them through this difficult time. Still, no matter how you feel about it, caregiving is a hard job! And many caregivers are there for their loved one 24 hours a day for months or even years.

### WHAT DOES IT FEEL LIKE TO BE A CAREGIVER?

Despite the sadness and shock of having a loved one with cancer, many people find personal satisfaction in caring for that person. You may see it as a meaningful role that allows you to show your love and respect for the person. It may also feel good to be helpful and know that you're needed by a loved one.

You might find that caregiving enriches your life. You might feel a deep sense of satisfaction, confidence, and accomplishment in caring for someone. You may also learn about inner strengths and abilities that you didn't even know you had, and find a greater sense of purpose for your own life.

The caregiving role can open up doors to new friends and relationships, too. Through a support group, you can get to know people who have faced the same kinds of problems. Caregiving can also draw families together and help people feel closer to the person who needs care.

Caregiving can also be frustrating and painful. People caring for very sick patients may notice their own feelings of severe sadness and emotional distress. You may feel sadness and grief over your loved one's illness and may also feel overwhelmed or frustrated as you try to manage many difficult problems.

Caregivers can develop physical symptoms, like tiredness and trouble sleeping. This is more likely to be a problem if you aren't able to get the support you need and don't take care of yourself – especially if you try to press forward alone, even as your own quality of life suffers.

### WHAT IF YOU DON'T WANT TO BE A CAREGIVER?

It's quite normal to feel overwhelmed, burdened, and even trapped at times while caregiving. If your family has had troubled relationships in the past, you may wonder "why me?" You may feel that the caregiver role was dumped on you without your consent. You may feel unprepared or even unable to manage the responsibilities and feelings that go with it. You may feel pressure from family members, friends, and members of the cancer care team to provide care, despite having little or no desire or ability to do so.





If you became a caregiver because of other people's wishes, you need to think about how you feel about being pressured into caregiving. Mixed feelings at the onset of this role can lead to a greater sense of frustration later on. You should decide on your limits and make them known as soon as you can – before the demands of caregiving become a problem. It's not easy to do this when others resist the change, and it can take a lot of courage to do it. If you know you're going to face resistance, talk with the patient's cancer care team first. Or you can ask their doctor about a referral so you can talk with someone about the caregiver problem.

Addressing the problems early can help you and the patient get the help you need, and if you have to, make other plans for care. In situations like this, it might be helpful to find someone to help you with caregiving so that you know from the start that the role will be shared. It also may be better to find someone else to act as the primary caregiver.

## **YOU'LL NEED TO TAKE CARE OF YOURSELF, TOO**

It's hard to plan for a major health problem like cancer. Suddenly you've been asked to care for the person with cancer, and you're also needed to help make decisions about medical care and treatment. None of this is easy. There will be times when you know you've done well, and times when you just want to give up. This is normal.

There are many causes of stress and distress in cancer caregivers. Dealing with the crisis of cancer in someone you love, the uncertain future, financial worries, difficult decisions, and unexpected and unwanted lifestyle changes are just a few of them. Fear, hopelessness, guilt, confusion, doubt, anger, and helplessness can take a toll on both the person with cancer and the caregiver. And while the focus tends to be on the patient, all of this will affect your physical and mental health, too.

By taking care of yourself, you will be better able to take care of your loved one. You can start by setting limits on what you can expect from yourself. Know that caring for someone

with cancer can be an overwhelming job. It pays to ask for help before stress builds up. Here are some ways to take care of your own needs and feelings:

### Plan things that you enjoy

There are three types of activities that you need to do for yourself:

- Those that involve other people, such as having lunch with a friend
- Those that give you a sense of accomplishment, like exercising or finishing a project
- Those that make you feel good or relaxed, like watching a funny movie or taking a walk

### Get professional help if you think you need it

It's normal to feel overwhelmed sometimes by caregiver responsibilities. But if it becomes a constant problem, you may need to see a mental health professional. Below is a list of serious signs of trouble. Get professional help if you:

- Feel depressed, physically sick, or hopeless
- Feel like hurting yourself or hurting or yelling at the people you care for
- Depend too heavily on alcohol or recreational drugs
- Fight with your spouse, children, stepchildren, or other family members and friends
- Are no longer taking care of yourself

## TAKE A BREAK OR TIME FOR YOURSELF

Most caregivers hesitate to take a break from their caregiving responsibilities, even for a short time. In fact, most would probably feel guilty if they did this. But no one can be a caregiver every day, 24 hours a day, for many months and even years. Try to get out of the house and away from your loved one every day – even if it's only to take a short walk or shop for food. If you can't leave the patient alone and don't have friends or family to relieve you, you might want to look into getting help from a respite care program.

### Respite care provides a much-needed break

Respite care is the term used to describe short-term relief for those who are caring for family members who might otherwise need professional care. Respite is a short break from the exhausting challenges of being a caregiver. It's been shown to help family caregivers stay healthy and improve their sense of well-being.

In most cases, the respite caregiver comes to the home and gets to know the patient, the family routine, and things like where medicines are stored. Sitter-companion services are one respite option. This is sometimes offered by local civic groups, church or religious groups, and other community organizations. A regular sitter-companion can provide friendly respite care for a few hours, once or twice a week. Be sure that the sitter-companion knows what to do if there's an emergency while you are gone.

Another type of respite care uses a specialized local facility where the patient may stay for a few days or even a few weeks. This gives you a chance to take a break from caregiving and



catch your breath, whether or not you they leave town.

Depending on your state, Medicaid or Medicare may help cover respite care costs. Also, check with the patient's health insurance to see what kind of respite help might be offered.

## KNOW YOUR LIMITATIONS

Most importantly, don't try to do it all yourself. Caregiving alone for any period of time is not realistic. Reach out to others. Involve them in your life and in the things you must do for your loved one.

Some caregivers feel they have to do it all alone. They may believe that, as the partner, sibling, son, or daughter they're responsible for the sick loved one. It's painful for them to admit that they can't do it all and still keep their own health and sanity. They'll bend over backward to meet their loved one's every need. Some feel guilty if they can't do it all and say they feel "selfish" if they ask for help.

Set realistic limits on what you can do. For instance, if you have a back injury, and or if your loved one is too big for you to lift, you may be able to help them roll over in bed, but don't try to lift them alone or catch them when they fall. You may end up seriously injured and become unable to help anyone. There are ways you can safely help a person sit up or walk but you have to learn to do it without hurting yourself. This is where expert help is needed; home care nurses or physical therapists can show you how to do it safely. They can also help you get special equipment, if needed.

Your own health and safety must come first if you want to keep helping your loved one.

When you need help, reach out to others, including professionals. Talk with the cancer care team about what you're doing and where you need help. Involve them in your life and your loved one's care.

## FINDING SUPPORT FOR YOURSELF

The support of friends and family is key to both the person with cancer and the caregiver. There are many kinds of support programs, including one-on-one or group counseling and support groups. A support group can be a powerful tool for both people with cancer and those who care about them. Talking with others who are in situations like yours can help ease loneliness. You can also get useful ideas from others that might help you.

Talk with a nurse or social worker or contact the American Cancer Society at **1-800-227-2345** to learn about services in your area. Talking with other caregivers can help you feel less alone. If you can't visit a group in person, the American Cancer Society Cancer Survivors Network® provides a safe online connection where cancer patients and caregivers can join chat rooms and build their own support network among other members. Visit <https://csn.cancer.org> to learn more.



***Human connections  
can help you stay strong.  
Let people know what  
you need, and ask for help.***

Other organizations have internet-based groups and even online counseling, too. Through online or in-person support groups, people can share their stories, offer practical advice, and support each other through shared experiences.

Religion can be a source of strength for some people. Some members of the clergy are specially trained to help people with cancer and their families. People who are not religious may find spiritual support in other ways. Meditation, journaling, and being outside in nature are examples of different ways a person may feel they're part of something greater than themselves.

## **ASK OTHERS TO HELP**

Caregivers need a range of support services to stay healthy, be good caregivers, and stay in the caregiving role. But they often don't know where to go for help or how to accept it.

Caregivers have been shown to have less distress and feel less burdened when they have social support. Human connections can help you stay strong. Let people know what you need, and ask for help. You cannot – and should not try to – be responsible for all the caregiving by yourself.

You need to know whom you can talk to and count on for help. Families facing cancer can become stronger. If family members don't offer help, or if you need more help than they can give you, you may be able to set up a circle of friends to help you. Members at your place of worship, neighbors, and others may be willing to help. Include them in "family meetings." Share information with them on the patient's condition, needs, and care.

Allowing others to help can take some of the pressure off and give you time to take care of yourself. Often family and friends want to help but may not know how or what you need. Here are some tips for including family and friends:

- Look for situations where you need help. Make a list or note them on a calendar.
- Hold regular family meetings to keep everyone involved. Use these meetings as updates and care-planning sessions. Include the patient.
- Ask family and friends when they can help and what jobs they think they can do. You may also contact a person with a certain request. Be very clear about what you need.
- As you hear back from each person, note it on your list to make sure they have taken care of what you needed.

There are many online resources that can help you manage your job as caregiver. Some sites offer support for people caring for a loved one who has cancer. Other sites have features like group calendars to organize helpers and areas to create personal websites that concerned people can access for updates.

For tips on how to cope with being a caregiver, visit [cancer.org/caregivers/videos](https://www.cancer.org/caregivers/videos) to watch a video on Stress Management.



Visit [caringbridge.org](https://www.caringbridge.org), [lotsahelpinghands.com](https://www.lotsahelpinghands.com), and [mylifeline.org](https://www.mylifeline.org) for a few examples. Some of these also allow others to sign up for specific tasks when help is needed. Taking full advantage of the resources available to you is another way you can take care of yourself.

### **CARING FOR YOUR CHILDREN DURING THIS TIME**

If you have young children, you'll need to figure out how to take care of them and their needs while you're caring for the person with cancer. Juggling children's schedules and trying to keep their lives as normal as possible often requires a great deal more help from friends and family members. As you're setting up care for the person with cancer, you might also need to tap into other parents and trusted friends and neighbors for help with your children.

Children can sense stress in their family members and notice that there's less time for them. They may start to have trouble in school or act like they did when they were younger. Even though your time is limited, you'll need to take time to check in with them to learn about their fears and concerns.

For more information, see *Helping Children When a Family Member Has Cancer* on [cancer.org](https://www.cancer.org).

### **BEING A CAREGIVER, AND KEEPING YOUR JOB**

Caregiving itself can be a full-time job, but many caregivers already have paying jobs. This can lead to work-related issues like missed days, low productivity, and work interruptions. Some caregivers even need to take unpaid leave, turn down promotions, or lose work benefits. The stress of caring for someone on top of worrying about keeping your job can be overwhelming. Dealing with these issues is important to both the employer and the employee.

There will be times when there will be more demands on the caregiver, for instance, when the patient is diagnosed, getting cancer treatment, getting treatment for recurrence, or nearing the end of life. The employed caregiver may end up having to take time off from their paying job for caregiving.

For people in certain types of jobs (temps, freelancers, consultants, entrepreneurs), this is very difficult. If they don't work, they don't get paid. For those with traditional jobs in larger companies, there may be benefits to help you take time off and still keep your job.

Some people find that there's no one else to care for the patient on a long-term basis, and cut back to working part time. Some feel that they have to quit their jobs entirely. If you need to keep your job but the interruptions and time off are creating problems, you might want to look into a different schedule to fit the times your loved one needs you most. Some companies allow you to take some paid leave if you are caring for a spouse or close relative. For example, you might be able to work half-days or split shifts, or take off one day a week for doctor visits.

If you need some time away from work, speak with your boss or benefits office. If your workplace has an Employee Assistance Program, look into what it offers. Some offer free or reduced-cost counseling services for money concerns, stress, and depression.



The Family and Medical Leave Act (FMLA) guarantees up to 12 weeks off per year to take care of a seriously ill family member (spouse, parent, or child). It only applies to larger companies, and not every employee qualifies for it. If you can't – or don't want to – stop working, you might be able to take unpaid time off under FMLA.

See *Family and Medical Leave Act* on [cancer.org](https://www.cancer.org) for more general information about FMLA and to link to fact sheets posted on the US Department of Labor website.

## KEEPING YOUR HEALTH INSURANCE IF YOU HAVE TO QUIT YOUR JOB

When caregivers quit their jobs, they usually lose their employer's health insurance coverage as well as their source of income. It's very important for you to still have some type of health care coverage. If you're able to pay for your own insurance, COBRA (Consolidated Omnibus Budget Reconciliation Act) will allow you to be covered for some months after you leave your job. Another option might be insurance from the Health Insurance Marketplace.

See *Understanding Health Insurance* on [cancer.org](https://www.cancer.org) for detailed information about managing insurance coverage, including COBRA.

Call **1-800-227-2345** to get referrals to programs that offer financial assistance related to prescription drug coverage and co-pay assistance.

## IF YOU MAKE MISTAKES

No matter what you do, you will very likely come to a point where you feel that you've failed in some way. It seems obvious that as a caregiver, you do the best you can. You try to include the patient, other concerned family members, and close friends in important discussions. You always try to make decisions that are in the patient's best interest – decisions that you and the patient can live with. But sometimes you'll feel that you could have handled a situation better or done something a better way.

At these times, it's important not to blame yourself. Find a way to forgive yourself and move on. It helps to keep in mind that you will keep making mistakes, just like everyone else. Try to keep a sense of humor about it. And try to recognize those things that you do well, too. These things are often easy to overlook. It also helps to keep in mind why you chose to take on this often difficult and stressful job.

As a caregiver, you have an important and unique role in helping your loved one through their cancer experience. The American Cancer Society can offer you information, day-to-day help, and emotional support. Call us at **1-800-227-2345** if you need help for yourself or your loved one.

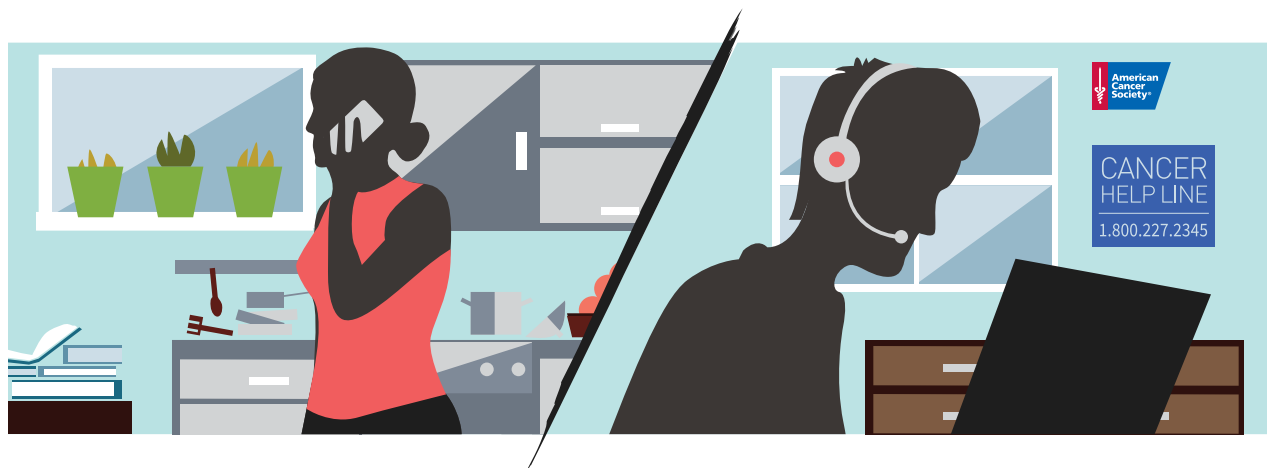
## MAKING HEALTH DECISIONS AS A CANCER CAREGIVER

The cancer care team will always discuss major health decisions with a person with cancer if they can think clearly and share their thoughts. Your loved one's decisions will be followed as long as they don't create safety issues.

Sometimes what your loved one wants is not what others want or will do for them. When patients need help carrying out their wishes, it can be hard on those who want something different from what the patient wants.

### How do I know what my loved one wants?

Everyday choices are easier to make if you understand your loved one's preferences, habits, and values. What's most important in your loved one's life? Everyday choices include deciding what to wear, when to bathe or eat, and what else to do after that. But when you're dealing with cancer even those simple choices can be overwhelming and hard to make. Sometimes even a small crisis can make the patient unable to express what they want or need. As much as possible, honor the patient's wishes, but be realistic about the limits on what you and other caregivers can do.





### *What if my loved one won't do things for themselves?*

This can be frustrating for a caregiver. You feel sure that your loved one can do some things for themselves, but you do all of them because they won't. Sometimes there are medical or emotional causes for the problem, such as severe tiredness (fatigue) or clinical depression. If you're not sure, get the patient to the doctor and state the problem clearly. The cancer care team can help you figure out what may be going on.

It's not always needed and may seem hard to do, but sometimes you might have to set limits. For example:

- Try to figure out what self-care tasks the patient can safely do, such as bathing, dressing, and going to the bathroom. If you don't know what your loved one can do, get the cancer care team to evaluate them. Social workers and occupational health professionals may be able to help with this.
- Encourage the patient to do self-care as much as possible.
- Encourage the patient to talk about things they enjoy so the conversation isn't always about cancer and illness.

- Let the patient make as many personal choices as they can. If they're overwhelmed with decisions, give them simpler choices by saying, "Would you prefer chicken or fish for dinner?" or "Would you rather wear your blue pants or the brown ones?"
- Get others involved if the patient is avoiding treatments or doing things that can cause harm. Family members can be a strong source of influence. Rally them for support. Once a decision is made, accept it and move on. And if you disagree with the decision that was made about the patient's treatment, remember that it's the patient's decision to make. Congratulate them for being able to make a decision.

Remember that professional help is available to you. It's normal to feel frustrated, upset, and stressed when caring for someone with cancer. Use the resources and services of the cancer care team when you need them. They can help you find the support you need, such as mental health counselors, home care services, or financial assistance, so that both you and the patient have the help you need.



### *What if there's abuse in the family?*

A diagnosis of cancer can worsen abusive behaviors in families that are already strained. The crisis of a cancer diagnosis can take a toll on both the caregiver and the patient. Taking care of yourself and getting the support you need can help you be a good, effective caregiver.

Patients are more commonly seen as victims of abuse, but what if the patient is the abuser? Again, the stresses of cancer may make your relationship more difficult. If abusive behavior starts after cancer treatment, the doctor should check to see if there are medical reasons for it. Don't accept abuse just because the patient is sick.

There may be times of misunderstanding, tension, hurt, and anger, but not all the time. Emotions need to be expressed and accepted. Patients and caregivers should treat each other with respect, and should not fear emotional, verbal, physical, or sexual abuse. Talk to someone on the cancer care team if you need help.

### **When do I call the doctor?**

Sometimes it's hard to know if something is "bad enough" to call the doctor after hours or in the middle of the night. The best way to know when to call is to ask. Ask the doctor or nurse what problems you should call about right away, no matter what time it is. This may be a fever or new pain, or some other problem. You can also ask what can wait until the next day or the next appointment.

Also be sure you know whom to call after hours, on weekends, and on holidays. If you don't have 24-hour access to someone on the cancer care team, find out what you should do if there are problems. Should you call your pharmacist if there are problems with the medicines? Should you go to the ER? It often seems like problems come up when the doctor's office is closed, so be sure you have an emergency plan in place.

### **What if the patient needs to be moved or relocated?**

Open and honest discussion with the patient and other family members is the first step in deciding whether the patient needs to live somewhere else for a time. Cancer and its treatment can cause confusion and forgetfulness, and may worsen the symptoms of other conditions such as dementia. Patients can endanger themselves by forgetting medicines, not eating, leaving the house, or losing track while cooking. Patients can be a danger to themselves and others if they start to hit, bite, or throw things at caregivers or family members. In such cases, the cancer care team needs to know about these behaviors. The patient may need to be hospitalized, if whatever is causing the problem can be treated. For less

severe problems, such as mild forgetfulness, unsteady walking, and occasional minor confusion, there may be other options. Again, tell the cancer care team about these problems to find out if there's a medical reason for them and if treatment is needed.

Sometimes the less severe problems can be managed at home if someone can stay with the patient at all times. But these problems deserve special discussion by the family. Otherwise, other family members might assume that the caregiver will be the one to stay home and provide 24-hour care.

Family meetings with the patient, spouse, children, siblings, and other key people can allow everyone to share their thoughts and can help you decide what to do. Sometimes these talks can be very difficult and emotional, but certain topics will need to be covered.

- The amount or type of care needed. For instance, does your loved one need 24-hour supervision? What can they safely do without help?
- What other living arrangements are available? Can the patient move in with another family member? An apartment closer to the primary caregiver? A smaller house? An independent retirement community?

This discussion can be tricky if your loved one gets confused or fearful at times. It helps to have the doctor or an occupational therapist assess the patient's needs. For example, if their professional opinion is that the patient cannot be alone at all, and the only caregiver has to work full time to make the house payment, something else must be done. An occupational therapist's assessment can also tell you if the patient can be kept safely in the home if certain modifications are made. Ask the doctor if a referral to an occupational therapist is the right thing for the patient. This may be easier if the patient is in a hospital or extended-care facility. Ask the doctor or nurse about getting an occupational therapist evaluation before the patient leaves.

### ***Is a nursing home or extended care facility an option?***

There may come a time when your loved one needs extended care or nursing home care. Even though you might not be with the person all day, you'll still find that you're a caregiver. It just may look different, since you're no longer providing all of the hands-on care. But you'll still be talking with the staff at the facility, visiting the patient, and staying in touch with those who are providing care.





***It may help to have a family meeting with at least some members of the cancer care team so that you can get their input and support.***

You'll also be the first one called if there are problems. Your caregiving experience will help you deal with the situations that may come up. You'll also know whom to call if more help is needed.

***What if the patient refuses to leave home?***

Sometimes the person with cancer decides they don't want to live elsewhere. They may resist leaving home. It's a very emotional thing to leave home, even if it's only for a short time and emotions are already high. Patients may feel that they'll no longer be able to set the rules or control their own lives, or they may be afraid of losing their independence. Maybe they don't want to feel they are a burden on others. And if they've lived in the same place for a long time, they probably have strong ties to the community, family, friends, and health care providers, as well as social lives and daily routines.

In some cases, you have to be firm, especially if the present situation is unhealthy or unsafe. If you have to act against the wishes of the person with cancer, be direct and explain what you're going to do. In other cases, there's room to negotiate. All of you – the patient, the family, and you, the caregiver – will need to be sure you've covered all options.

You'll also need to talk about each person's concerns. For instance, things like your loved one's safety, convenience, finances, and the care needed should be discussed. Clear plans must be outlined. It helps to check out the physical setting and set up a timeline of their needs. For example, are there just certain times during treatment when someone needs to be with the patient? Where will the patient sleep? How about getting up and down the steps inside or outside the house?

If this still isn't working, a social worker may be helpful in exploring options and setting plans in motion. It may also help to have a family meeting with at least some members of the cancer care team so that you can get their input and support.

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.



# Caregiver Self-Care

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## Don't Forget to Take Care of Yourself

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## DON'T FORGET TO TAKE CARE OF YOURSELF

No one plans for a major health problem like cancer. Suddenly you've been asked to take care of the person with cancer, and you're also needed to help make decisions about medical care and treatment. None of this is easy.

The work of caregiving costs both time and money. There may also be a cost to your health and overall well-being, but often caregivers just keep doing what needs to be done and may suffer in silence.

Surveys have shown that caregivers often forget to make their own health a priority and do not eat right or exercise. We encourage you to start making healthy lifestyle changes today – for yourself and for the sake of your loved one with cancer.

Taking care of yourself can make a big difference in how you feel about your role and how well you can do the things you need to do. Here are some things that can help you feel better, reduce stress, and remind you to enjoy life.

Remember that as a caregiver you must take care of yourself in order to give good care.

To learn more about healthy lifestyle behaviors for caregivers, visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch videos on Healthy Eating, Physical Activity, and Relaxation.

### EAT WELL

Choose foods and beverages in amounts that help you get to and stay at a healthy weight.

- Read food labels to become more aware of serving sizes and calories. Be aware that your portion size – the amount you serve yourself – may be larger than the serving size listed and, therefore, have more calories.
- Eat smaller portions of high-calorie foods.
- Choose vegetables, fruits, and other low-calorie foods instead of calorie-dense foods such as French fries, potato and other chips, ice cream, doughnuts, and other sweets.
- Limit your intake of sugar-sweetened beverages such as soft drinks, sports drinks, and fruit-flavored drinks.
- When you eat away from home, be especially mindful to choose food low in calories, fat, and added sugar, and avoid eating large portion sizes.

- Limit your intake of red meats (beef, pork, lamb) and processed meats, such as bacon, sausage, lunch meats, and hot dogs.
- Choose fish, poultry, or beans as an alternative to red and/or processed meats.
- If you eat red meat, select lean cuts and eat smaller portions.
- Prepare meat, poultry, and fish by baking, broiling, or poaching rather than by frying or charbroiling.

Eat more vegetables and fruits each day.

- Eat a variety of vegetables and fruits each day. In general, focus on the ones that have the most color. They tend to have the most health-promoting nutrients.
- Include vegetables and fruits at every meal and for snacks.
- Fresh, frozen, canned, and dried vegetables and fruits can all be good choices. If you choose frozen, look for vegetables without added sauces like cheese and butter, and fruits without added sugar. If canned, look for vegetables labeled low- or reduced-sodium, or no salt added. Choose fruits packed in water, 100% juice, or light syrup (drain and rinse those). Dried fruits are high in calories, so watch the amount that you eat.
- If you drink vegetable or fruit juice, choose those that are 100% juice.
- Limit your intake of *high-calorie* creamy sauces, dressings, and dips with vegetables and fruits.

Choose whole grains instead of refined-grain products.

- Choose whole-grain foods such as whole-grain breads, pasta, and cereals (such as barley and oats) instead of breads, pasta, and cereals made from refined grains, and brown rice instead of white rice.

- Limit your intake of other refined carbohydrate foods, including pastries, candy, sugar-sweetened breakfast cereals, and other high-sugar foods.

## LIMIT ALCOHOL USE

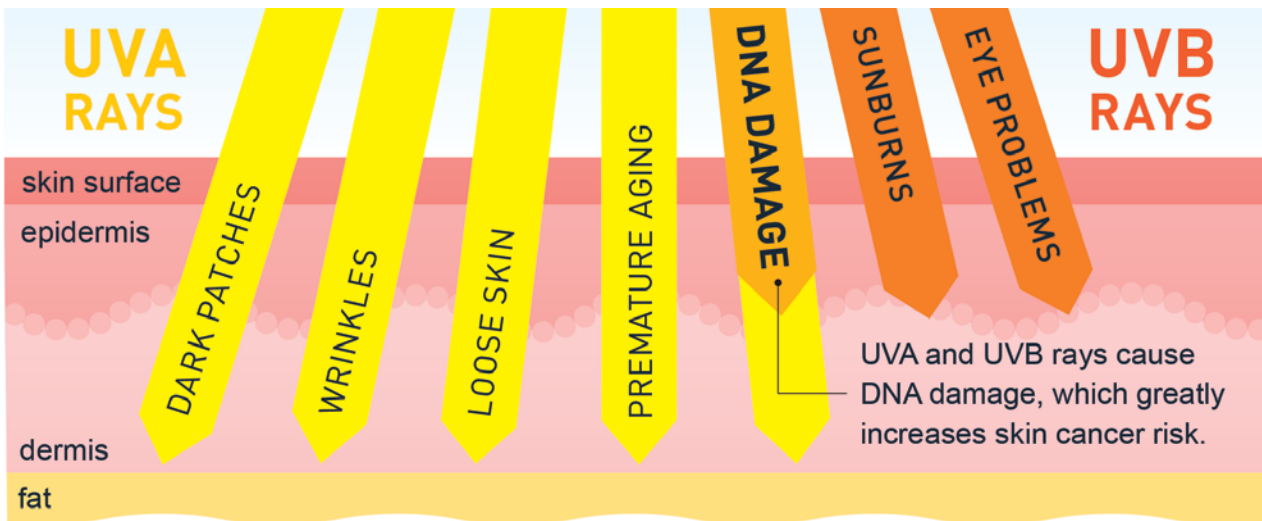
Drinking alcohol can increase your cancer risk, and the risk increases with the amount of alcohol consumed. If you choose to drink at all, men should have no more than 2 drinks per day, and women should have no more than 1 drink per day.

- A drink is 12 ounces of regular beer, 5 ounces of wine, or 1½ ounces of 80-proof distilled spirits.
- Alcohol increases your risk of developing several types of cancer (including female breast, mouth, throat, pharynx, larynx, esophagus, liver, colon, and rectum cancers) and several other health problems.

## EXERCISE

No matter when you start, exercise improves your health and can help you feel good. As a caregiver, making physical activity a priority is a great way to help reduce stress and anxiety during this challenging time.

- Adults should engage in at least 150 minutes of moderate-intensity or 75 minutes of vigorous-intensity activity each week, or an equivalent combination, preferably spread throughout the week.
- Children and adolescents should engage in at least 1 hour of moderate- or vigorous-intensity activity each day, with vigorous-intensity activity occurring at least 3 days each week.
- If you have children, being active with them is a great way to help reduce your stress, and help your kids promote their health, too.



- Limit sedentary behavior such as sitting, lying down, watching television, or other forms of screen-based entertainment.
- Doing some physical activity above usual activities, no matter what one's level of activity, can have many health benefits.

## PROTECT YOUR SKIN

Most skin cancers could be prevented with proper sun protection. Follow these steps to reduce your risk:

- Try to avoid the direct sun between 10 a.m. and 4 p.m. Instead, seek the shade.
- When you are in the sun, cover up with protective clothing.
- Use broad-spectrum sunscreen with an SPF of at least 30, even on hazy or overcast days.
- Cover your head with a wide-brimmed hat that shades your face, ears, and neck. If you choose a baseball cap, remember to protect your ears and neck with sunscreen.
- Wear sunglasses with 99% to 100% UV absorption to protect your eyes and the surrounding skin.
- Know your skin. Be aware of all moles and spots on your skin, and report any changes to your health care provider right away.

## STAY AWAY FROM TOBACCO PRODUCTS

There's no safe form of tobacco. If you smoke or chew tobacco, stop! Smoking e-cigarettes can also be harmful. This is also known as vaping or JUULing. Although e-cigarettes do not contain tobacco, they are classified as "tobacco" products and contain nicotine and other harmful substances. Encourage the people around you to quit. Smoking increases cancer risk for smokers and everyone near them.

Caregivers all want to do what is best for their loved ones, and this includes not exposing them to secondhand or "third-hand" smoke. Secondhand smoke is the toxic smoke emitted by a cigarette and inhaled by bystanders. Third-hand smoke is the toxic residue that remains on clothing, furniture, hair, and carpeting many hours after the last cigarette has been put out.

Cigarette smoke can cause lung cancer and many other types of cancer, as well as trigger asthma attacks and worsen other health problems. Exposure to any form of cigarette smoke can even be life-threatening to cancer survivors.

A caregiver who smokes must be aware of these risks, and also practice self-care. This means finding ways to relieve stress, exercising regularly, and trying hard to quit smoking. This isn't easy, especially for caregivers experiencing emotional or physical stress. It helps to look for and practice healthy ways to reduce stress.



If you're ready to quit smoking, we can help you. Please call **1-800-QUIT-NOW** (1-800-7848-669) for information, support, and quit resources near you.

## GET YOUR CANCER SCREENING TESTS

You should get your usual medical check-ups, which include things like screenings for heart problems, high cholesterol, or diabetes, as well as flu and pneumonia shots. You also need to get your cancer screening tests. Talk to your doctor about your cancer risk and the screening tests that are best for you. The American Cancer Society recommends these screening guidelines for most adults at average cancer risk.

### Cancer screening for women

#### *Breast cancer*

- Women ages 40 to 44 should have the choice to start annual breast cancer screening with mammograms (x-rays of the breast) if they wish to do so.
- Women ages 45 to 54 should get mammograms every year.
- Women 55 and older should switch to mammograms every 2 years, or can continue yearly screening.

- Screening should continue as long as a woman is in good health and is expected to live 10 more years or longer.
- All women should be familiar with the known benefits, limitations, and potential harms linked to breast cancer screening. They also should know how their breasts normally look and feel and report any breast changes to a health care provider right away.

Some women – because of their family history, a genetic tendency, or certain other factors – should be screened with MRIs along with mammograms. (The number of women who fall into this category is very small.) Talk with a health care provider about your risk for breast cancer and the best screening plan for you.

#### *Cervical cancer*

- Cervical cancer testing should start at age 21.
- Women between the ages of 21 and 29 should have a Pap test done every 3 years. HPV testing should not be used in this age group unless it's needed after an abnormal Pap test.
- Women between the ages of 30 and 65 should have a Pap test, plus an HPV test (called “co-testing”), done every 5 years. This is the preferred approach, but it's OK to have a Pap test alone every 3 years.
- Women over age 65 who have had regular cervical cancer testing in the past 10 years with normal results should not be tested for cervical cancer. Once testing is stopped, it should not be started again. Women with a history of a serious cervical pre-cancer should continue to be tested for at least 20 years after that diagnosis, even if testing goes past age 65.

- A woman who has had her uterus and cervix removed (a total hysterectomy) for reasons not related to cervical cancer and who has no history of cervical cancer or serious pre-cancer should not be tested.
- All women who have been vaccinated against HPV should still follow the screening recommendations for their age groups.

Some women – because of their health history (HIV infection, organ transplant, DES exposure, etc.) – may need a different screening schedule for cervical cancer. Talk to a health care provider about your history.

### Cancer screening for men

#### *Prostate cancer*

The American Cancer Society recommends that men make an informed decision with a health care provider about whether to be tested for prostate cancer. Research has not proven that the potential benefits of testing outweigh the harms of testing and treatment. We believe that men should not be tested without first learning about what we know and don't know about the risks and possible benefits of testing and treatment.

Starting at age 50, men should talk to a health care provider about the pros and cons of testing so they can decide if testing is the right choice for them.

If you are African American or have a father or brother who had prostate cancer before age 65, you should have this talk with a health care provider starting at age 45.

If you decide to be tested, you should get a PSA blood test with or without a rectal exam. How often you're tested will depend on your PSA level.

### Cancer screening for men and women

#### *Colorectal cancer*

For people at average risk for colorectal cancer, the American Cancer Society recommends starting regular screening at age 45 using either a stool-based test or visual exam.

#### Stool-based tests

- Highly sensitive fecal immunochemical test (FIT) every year\*, *or*
- Highly sensitive guaiac-based fecal occult blood test (gFOBT) every year\*, *or*
- Multi-targeted stool DNA test (MT-sDNA) every 3 years\*

#### Visual (structural) exams of the colon and rectum

- Colonoscopy every 10 years, *or*
- CT colonography (virtual colonoscopy) every 5 years\*, *or*
- Flexible sigmoidoscopy (FSIG) every 5 years\*

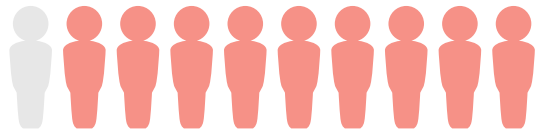
*\*If a person chooses to be screened with a test other than colonoscopy, any abnormal test result should be followed up with colonoscopy.*

There are some differences between these tests to consider, but the most important thing is to get screened, no matter which test you choose. Talk to your health care provider about which tests might be good options for you, and to your insurance provider about your coverage.





## COLORECTAL CANCER: CATCHING IT EARLY



# 9 out of 10

**5-YEAR SURVIVAL RATE**  
IF FOUND AT THE LOCAL STAGE



# 4 out of 10

**DIAGNOSED AT AN EARLY STAGE**  
PARTLY DUE TO LOW TESTING RATES

People who are in good health and with a life expectancy of more than 10 years should continue regular colorectal cancer screening through the age of 75.

For people ages 76 through 85, the decision to be screened should be based on a person's preferences, life expectancy, overall health, and prior screening history.

People over 85 should no longer get colorectal cancer screening.

### **Lung cancer**

The American Cancer Society recommends annual lung cancer screening with a low-dose CT scan (LDCT) for certain people at higher risk for lung cancer who meet the following conditions:

- Are ages 55 to 74 years and in fairly good health,  
*and*
- Currently smoke or have quit within the past 15 years,  
*and*
- Have at least a 30 pack-year smoking history. (A pack-year is 1 pack of cigarettes per day per year. One pack per day for 30 years or 2 packs per day for 15 years would both be 30 pack-years.)

Before getting screened, you should talk to your health care provider about:

- Your risk for lung cancer
- How you can quit smoking, if you still smoke
- The possible benefits, limitations, and harms of lung cancer screening
- Where you can get screened

You should also talk with your insurance provider about your coverage.

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.





# Communication

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## Communicating with Your Loved One

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## COMMUNICATING WITH YOUR LOVED ONE

When your loved one starts to talk about cancer, do you change the subject? Do you stand in silence, worried that you'll say the wrong thing? If so, you're not alone. Many people don't know what to say to a person who has cancer.

### HOW DO YOU TALK TO SOMEONE WHO HAS CANCER?

When talking with your loved one, the most important thing is just to listen. Try to hear and understand how they feel. Don't judge, or try to change the way they feel or act. Try to put your own feelings and fears aside. Let them know that you're open to talking whenever they feel like it. Or, if they don't feel like talking right now, that's OK, too. You can offer to listen whenever they're ready.

Here we will share some ideas about how to be supportive and helpful when you talk with someone who has cancer. You can learn how to make your loved one know that you are someone they can truly count on. We call this kind of communication "listening with your heart."

### ABOUT CANCER

The word "cancer" itself is upsetting. It often makes people think about death. But death is not the outcome for many people with cancer. Millions of people who have been diagnosed with cancer are alive today. And more and more cancers are being found early – when they're small and may be easier to treat. So the fear you might feel when you learn that someone you care about has cancer can and should be mixed with hope. Most cancers can be treated, and researchers are finding new and better ways to find and treat the disease every day.

Some people live with cancer for many years. This means they may have to "fit" cancer into their everyday lives. They also may have to adjust to different types of treatment and different stages of the disease. Family and friends must also adjust to these changes and try to keep giving support and hope along the way.

In many cases, cancer doesn't have a clear beginning, middle, and end. There may be a beginning and an end to a treatment plan, and maybe a time when there's no sign of cancer.

But for some people, the cancer comes back after treatment. And sometimes treatment goes on for years just to keep the cancer under control; it never really goes away.

## WAYS PEOPLE DEAL WITH A CANCER DIAGNOSIS

### Common feelings and experiences

These are some of the more common responses people have when diagnosed with cancer.

#### *Venting anger and frustration*

People with cancer sometimes take out their anger and frustration on those around them. This can upset family members and friends. It may help to remember that people often vent their feelings onto those close to them. They do this because these people are safe outlets. They know you'll still be there for them, even if they behave badly or create tension.

In most cases, the person is really frustrated and angry about the cancer and the losses it brings, but this can be hard to put into words. So the person with cancer may take out angry feelings on family, friends, or anyone who happens to be around at the time.

#### *Acting passive*

Sometimes a person with cancer seems to become childlike and passive, looking to others for direction. It can be very hard for an adult child to see a parent act this way. Try to understand that this is one way of acting out how helpless and weak they feel. These are normal feelings to have when a person has cancer.

Though the disease may limit their ability to do some things, it's usually best for the

person with cancer to keep living as normally as possible. Continuing to be a responsible adult can give them a sense of meaning, confidence, and control. Giving in to feelings of dependence may make them feel even more helpless and out of control – more like a victim. You may feel the need to overprotect your loved one, but in the long run that probably isn't helpful.

#### *Fear and anxiety*

The cancer diagnosis and treatment phase is usually an anxious and uncertain time. There's fear about the many changes that come with cancer – money and job changes, body changes, and even changes in personal relationships. Because they have so much anxiety in their lives, your loved one with cancer may seem upset or frightened for no reason that you can see. Sometimes this anxiety may come across as harshness or meanness. You may find that you have fights when you only want to help.

#### *The “blame game”*

Sometimes people with cancer blame themselves for getting the disease because of something they did or did not do. As a



***Give them time to adjust. Try to put yourself in their shoes. Think about how scared you would be if this were happening to you.***

caregiver, you may also feel guilty or you may blame them, too, and you may express this by changing the way you act toward your loved one. Other family members may have these same feelings.

### **How you can respond to these ways of dealing with cancer**

Try not to react emotionally to the changes your loved one is dealing with. Yes, this can be very hard to do! Understand that this will likely last only a short time, and it comes from all of the fear and anxiety that's part of having and dealing with cancer.

Blaming yourself and each other can be barriers to a healthy relationship. Try not to play the "blame game." Encourage others, especially the patient, not to blame themselves for what's going on. Moving forward is the only option.

During this time, you will need to overlook some of these types of behavior and be ready to offer your loved one extra forgiveness, understanding, and support. Give them time to adjust. Try to put yourself in their shoes. Think about how scared you would be if this were happening to you. This can help you to let go of minor arguments and troubles and move on.

## **COMMUNICATION**

One of the key ways to help keep open lines of communication is not only to ask "How are you feeling?" but also "What are you feeling?" If you think about it, "How are you?" is one of the most common questions we ask, but it can be a rather thoughtless one. The expected response is "Fine" or "Good." It doesn't allow for much discussion. When you ask, "What are you feeling?" you're digging a little deeper. Asking this helps your loved one feel like you want to know how they're really doing.

When you ask, "What are you feeling?" be prepared to hear anything. Your loved one may be thinking a lot about death or be worried about what the future holds for their family. Be ready to really listen to whatever answer you get. You don't have to reply, but you must be ready to hear the pain or unpleasant thoughts that the question might bring up.

People with cancer sometimes like to get the opinions of those closest to them about their illness, treatment, and treatment outlook. Be open and honest, but don't try to answer questions that you don't know the answers to. Your loved one will sense your honesty and appreciate it.

### **TIPS FOR CANCER CAREGIVERS**

Good communication lets you express yourself, help others understand your limits and needs, and understand the limits and needs of the person with cancer. You'll need to be able to talk to your loved one, the cancer care team, friends, family, and even people you barely know who are concerned about the patient. This can be hard to do. And when you need information from the cancer care team,

you might not be able to get it without signed permission from the patient.

### A few tips to help you communicate clearly:

- Respect your own feelings, needs, and desires, as well as those of the patient.
- Speak out about your feelings while being sensitive to those of others.
- Try to use “I” statements rather than “you” statements. For instance, say, “I need a break” instead of “You never help me!” Beware of statements like, “I feel you ignored me,” which says to your loved one that they did something wrong. Instead, try “I didn’t hear you answer when I mentioned \_\_\_\_\_,” or “I need help with this problem.”
- Focus on the present rather than bringing up old patterns or hurts.

When you talk to your loved one, assure them that they are your main concern. Let them know you want to be there for them and want and need to be included in their care. Try something like:

- “This is a scary time for both of us, but I want to be here for you to help you get through this. You’re not alone.”
- “I’ll do whatever I can to help you through this. I might do the wrong thing sometimes, or not know what to do, but I’ll do my best.”
- “We can do this together. Let’s try to be open with each other and work with each other no matter what happens.”

It’s good to set a goal of openness and sharing right from the start. Sometimes it may be hard. Remind each other that you’re

“on the same team.” Share your fears and worries. You’ll disagree and maybe even fight, but openness will help you deal with the conflict. It will also help you keep supporting each other and reduce distress and anxiety. Acceptance and sharing will help keep your relationship strong.

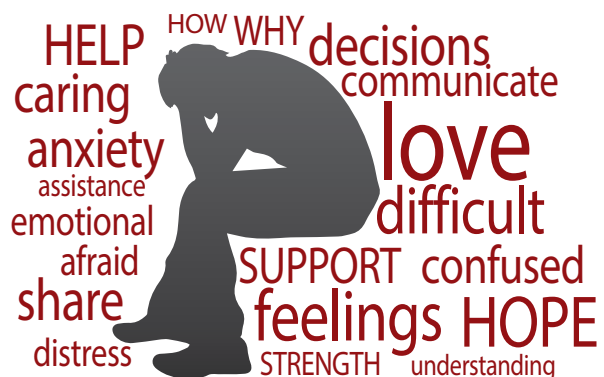
Contact us at **1-800-227-2345** to learn more about how to talk with the person with cancer.

### What do I do when the patient won’t share information with me?

It’s normal to want to protect the people you love and care about. But sometimes this can become a problem. For instance, if your loved one is having certain symptoms or worsening symptoms that they don’t tell you or the doctor about.

Try to understand the patient’s reasons for withholding information. Is your loved one normally a very private person? Are they trying to protect you or other loved ones? Are they scared and trying to deny what’s happening?

You may want to start gently; keep in mind that the patient is probably already distressed. Sit down with your loved one. Ask if there’s something that they would like to tell you. If the answer is no, ask if there’s something they don’t want to tell you. Give your loved



one a moment to consider it. Point out that you've noticed signs of a new problem or worsening symptoms. Remind them that this could be a serious problem, or just a new symptom that may be easy for the doctor to address. Mention how the problem is affecting both of you. If you're having trouble handling it, say so; and share any concerns about needing help with it. If the problem is affecting others as well, say so.

If the patient still denies the problem or refuses to discuss it, get help from other loved ones the patient trusts. Or you can call the doctor to share your concerns and find out if there's something else you can do.

You can't give the best care unless you know what's going on and how to handle it.

### **What if we can't agree on something important?**

It's good to know that you and your loved one don't always have to agree. Some of the decisions and problems that come with a cancer diagnosis can be very tough and very emotional. Remember to let the person with cancer make decisions about their care whenever possible.

Here are some things you can do to help them make the best choice:

- Explain your needs and wants clearly, and let the patient do the same. For example, you may need to do this when deciding whether to give certain treatments, such as IV antibiotics, at home or in an infusion center. Your loved one may want to do this at home, but will need your help. You might need to say "This is too scary for me. I don't think I can do this at home, but I can make sure you're at the clinic every

day." Look for common ground: you both want the patient to get the best possible care, which includes antibiotics, but you feel strongly that you cannot safely give IV drugs at home.

- Offer choices or a time limit when decisions need to be made. A change in medicines is a good example. "Let's try this sleeping pill for a few nights and see if it helps you get some rest. If not, we'll talk to Dr. Smith about trying something else."
- Focus your energy and influence on the issues that are important. Let the patient make as many choices as possible. For example, arguing over what clothes to wear probably isn't the best use of anyone's energy. But not taking medicines or not following activity restrictions may be issues that you can't ignore. If reasoning with your loved one doesn't work, explain that you'll talk to the cancer care team and get their help – then do it.

Open communication with the person you're caring for is the most important part of your role. Speak up for the patient and their needs. Help your loved one get needed information. Get input from other team members, then offer your support and encouragement.







## How do I talk with the cancer care team?

### *First, get the patient's consent*

The caregiver is often the link between the patient and the cancer care team. In general, the cancer care team can share information with you anytime you are with the patient. But there are laws that protect private health information. These laws affect what medical information your loved one's cancer care team can talk to you about when the patient isn't present. The simplest and most common way is for the patient to sign a release form that lets the doctor discuss their care with you.

Talk to the doctor about what steps need to be taken so that the cancer care team can talk to you about your loved one's care. Then be sure there's a copy of the form in the patient's records and keep the release form up to date. It's also a good idea to keep a back-up copy for your files. When you call the doctor's office, you may need to remind them that they have the form and they can discuss the patient's care with you.

If you don't have a form like this completed yet, you probably won't be able to get certain kinds of information. But you can still share

information with the doctor. You can tell the office staff that you're giving information rather than asking for it. Even without the patient's consent, you can try asking for general information about problems the patient has. For example, "Is vomiting one of the side effects of the chemotherapy that Joe got this week?" Or you can ask for advice; for instance, "If Joe has been vomiting for 2 days, should we come in to see you?" Even though you may not get details of Joe's care, you may be able to get some help in deciding what to do next.

Keep in mind that there are different forms that are signed for different purposes. Here we are talking about a release form that allows the doctor to share medical information with you. Doctor's offices may call this a "HIPAA form." However, this type of release does not give you permission to make decisions about the patient's care.

To learn more about informed consent, decision making, or other forms that may affect treatment decisions, visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch a video on Communication.

### ***Which doctor do I talk to?***

Cancer treatment often involves more than one doctor. There may even be a team of doctors, nurses, and other people taking care of your loved one. You might get information from many of these people, but it's a good idea to pick one doctor to be the one you go to with questions. Most people choose the doctor they see most often. In choosing a doctor as your main contact, some things you may want to ask are:

- Will you be the one to coordinate care?
- Will you keep the other doctors updated on what's going on?

Your loved one should feel at ease with the doctor, and you should, too. But sometimes, it takes a little time and work before this happens. Take the time to ask your questions and make your concerns known. The doctor should also take the time to answer your questions and listen to your concerns. If you, the patient, and the doctor feel the same way about sharing information and making choices, you'll probably have a good relationship and you can get what you need.

### ***Should I go to doctor visits with the patient?***

Going to see the doctor with your loved one is a good way to learn more about their cancer experience. This can be very helpful when caring for your loved one later on. At these visits you can also help the patient if they forget to mention problems to the doctor and/or come home without the information you need.

### ***How do I best use time with the doctor?***

The average time spent with the doctor is about 10 to 15 minutes or even less, so it helps to be ready for each appointment.

You and your loved one should figure out the most important things you need to talk about before you go. For instance:

- What symptoms do we need to tell the cancer care team about?
- When did these symptoms start?
- Does anything help make them better?

The American Cancer Society has a downloadable list of specific questions on [cancer.org/questions](https://www.cancer.org/questions), where you can find information about cancer types, treatment, and side effects. Print one of these lists and take it with you. That way you can prioritize the questions you want to ask, and you won't forget anything important.

Don't leave the office until the doctor answers all your questions and you both understand what to do next. Nurses can also be great sources of information, and you might get to spend more time with them than the doctor.

Take notes on what's said to you. This will help you keep track of what you should remember. If your loved one is getting back test results, be sure you understand the results before you leave. If blood work or other tests were done, find out when and how you'll get the results. Also, ask who will tell you what the results mean.

A voice recorder can also be a useful tool. Most doctors and nurses are comfortable with their patients using one, but be sure to ask before you do.

### **Family meetings can help**

Today's families are very busy, and it can be hard to keep everyone up to date on what's happening with the patient. Family members may feel frustrated and left out. They may not

understand the medical condition, especially if the patient is having problems. They also might not know that their help and ideas are needed, or how best to help.

One way to keep everyone informed is to have family meetings. When planning a family meeting, it's important to include everyone who is or will be part of the home caregiving team. This could include a family friend, neighbor, or paid caregiver; and don't forget the patient! If it's hard to get everyone together, a conference call or speaker phone might help solve the problem. Some of the things that may be covered are:

- The latest report from the doctor: How things are going; what to expect next
- Sharing feelings and concerns
- What the person with cancer wants and needs
- How much time each family member has to help out or visit
- Ways each person can help, and what other help might be available
- Financial concerns about caregiving
- How much work family members can afford to miss
- Other financial help available
- Help for you – the main caregiver (help with meals, shopping, cleaning, laundry, yard work, child care, etc.)
- How to get breaks from caregiving from time to time
- Emotional support for you and your loved one by phone or email
- Who can help with medical care, like taking the patient for treatment or to doctor's appointments
- Who can help with sharing news and updates on the patient's condition so that you don't have to spend time repeating the news each day

Every family has a history. This history affects each person's role within the family, how members relate to each other, how they feel toward the person with cancer, and how they deal with illness. There are unspoken rules about what can be expressed and what emotions are OK. It may be hard to hold family meetings if your loved one's condition requires the group to discuss these taboo topics. If you think this will be a problem, you might want to think of ways to defuse the situation beforehand. Sometimes a wise family member can help you, or you might want to ask a social worker or other professional how to bring up delicate subjects.

Try to get everyone to focus on the issues at hand. You might even want to write up a list of issues or questions and have everyone look at it and add their own. That way there's a specific agenda for the family meeting.

## LIVING WITH CANCER

### Be prepared for the long term

Cancer is often a disease that lasts a long time, and people may get treatment for many years. Sometimes people close to the person with cancer are very involved at first, but grow distant as the treatment goes on over months or even years. It's understandable that you can become "burned out," too. Still, you and your loved one need emotional support through the course of the illness.

## CONSULTATION



## CANCER TREATMENT



## REHABILITATION IS OFTEN PART OF CANCER TREATMENT



Remember that encouragement and support can help a person with cancer regain hope, even when they feel beaten down by cancer and/or its treatment. Also, the support of family and friends helps both of you have as normal a life as the illness allows. If you're going to be a support person for someone with cancer, try to hang in there for the long term. Being there and then pulling back can be very painful for the person who needs you, and may even be worse than never being there at all.

### Living a “normal” life

It's often hard to know if you are crossing boundaries or treating the person with cancer too much like a “cancer patient” and not like your family member or friend. Encourage your loved one to let you know if you cross this line. Every person with cancer appreciates the family member or friend who remembers that they used to be a person without cancer – that they had, and still have, strengths and weaknesses, interests, and parts of life that have nothing to do with cancer. Sometimes being the person in the cancer patient's life who remembers the whole person is a special gift.

### REHABILITATION

Rehabilitation (or rehab) is often a part of cancer treatment. It helps people who have had cancer do as much as they can on their own. Among the many specialists who help with rehab are the patient's doctor, nurse, social worker, physical therapist, and occupational therapist. Think of these experts

as problem solvers that you and your loved one can turn to when problems come up.

Rehab can help a person return to day-to-day functions after going through a serious illness. Rehab can help with things like job training, homemaker services, prostheses (such as a replacement of a limb or body part), or exercise programs.

Rehab can be a long process. Results may come slowly, and it's often frustrating. Sometimes people feel their efforts are useless or that it's just too hard. Encourage the patient to be an active participant in any rehab program, and offer your support along the way. One way of putting your support into action would be to go with the patient to the appointments, or do the exercises with the patient. If rehab has not been suggested and you think your loved one might benefit from it, go ahead and discuss it with the doctor.

### SUPPORTING YOUR LOVED ONE

Everyone, no matter how emotionally strong they are, can use support. Encouraging and supporting your loved one does not mean you act like a cheerleader, or that you try to make them feel good when they're feeling bad. It's important to allow them to express anger, frustration, and sad feelings. You can encourage them by saying things like, “I'm sorry you're feeling so bad. I can't imagine how you feel, but I am here to listen anytime you need to talk.” Or maybe, “You have one more round of chemo. Maybe when that's over, you'll start feeling a little better.”



In fact, just listening and not talking is probably more helpful than saying the wrong thing. Some of the wrong things to say are “I know how you feel,” when you clearly don’t; or “It will be better tomorrow,” when you can’t be sure of that either. Even though you may say these things with the best of intentions, your loved one may feel like you really don’t understand and decide that it doesn’t help to talk to you. You must listen with your ears and your heart. As one person with cancer put it, “A long illness is so discouraging. You need people to get you through it.” Having a good support system means the person does not have to face cancer alone.

### **CONCERN FOR YOU, THE CAREGIVER**

Just as people with cancer should not spend all their time thinking about their illness, neither should family members and friends spend every spare minute thinking about or being with their loved one. Caregivers need relief and rest to stay emotionally and physically fit and be able to help the person with cancer.

Don’t forget to plan time for yourself. Ask friends or other family members for help. Tell them exactly what they can do to help. Many times they are just waiting to be asked.

Many caregivers feel guilty when they take time for themselves, but even a brief time away can serve to restore you and allow you to “recharge your batteries.” Just a couple of hours may make a big difference; ask for help.

It’s hard to see a loved one in pain or suffering through the side effects of cancer treatment. If you need help coping with your feelings about their illness, know that help is available. The social services department at the hospital or doctor’s office may be able to help you or direct you to someone who can. They may be able to suggest support groups in your area for friends and families of people with cancer. Sometimes the hospital chaplain or your own clergy can help. Asking around to find good counselors can be another way to get the support and help you need. Helping yourself may be the best way to help your loved one.

For information about coping with being a caregiver, visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch a video on Stress Management.

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.



# Cancer Information

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## QUESTIONS AND ANSWERS ABOUT CANCER AND ITS IMPACT

### WHAT IS CANCER?

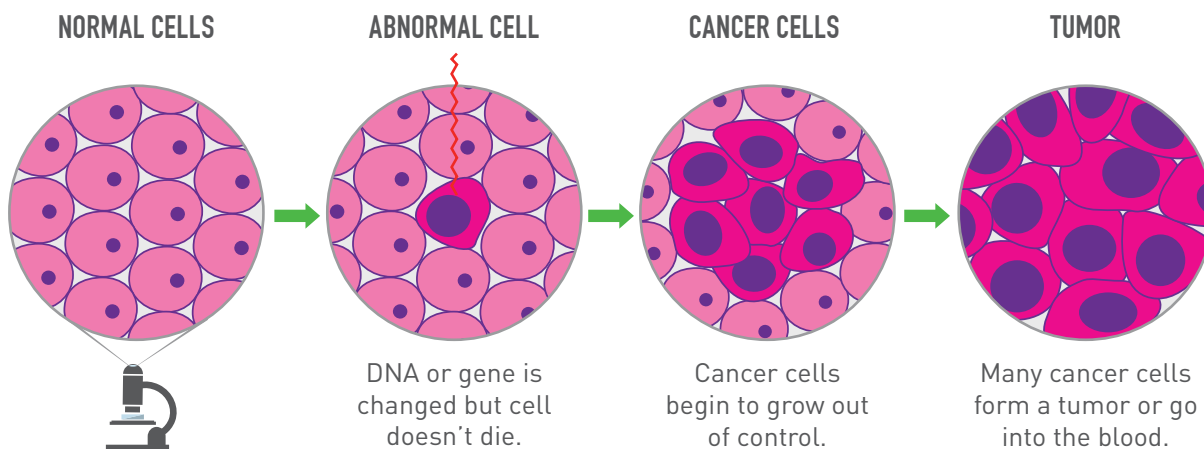
The body is made up of trillions of living cells. Normal body cells grow, divide into new cells, and die in an orderly way. During the early years of a person's life, normal cells divide faster to allow the person to grow. After the person becomes an adult, most cells divide only to replace worn-out or dying cells or to repair injuries.

Cancer starts when cells in a part of the body start to grow out of control. There are many

kinds of cancer, but they all start because of out-of-control growth of abnormal cells.

Cancer cell growth is different from normal cell growth. Instead of dying, cancer cells continue to grow and form new, abnormal cells. Cancer cells can also invade (grow into) other tissues, something that normal cells can't do. Growing out of control and invading other tissues are what makes a cell a cancer cell.

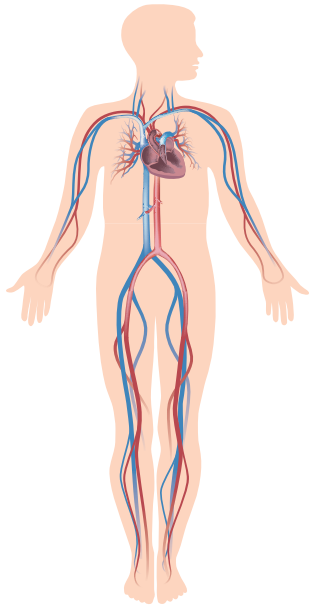
### WHAT CANCER LOOKS LIKE UNDER A MICROSCOPE





## PATHS THROUGH WHICH CANCER CAN SPREAD

### BLOOD VESSELS

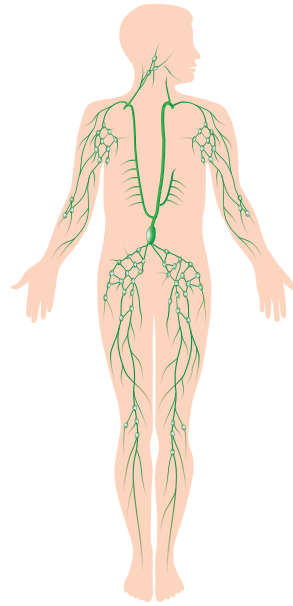


Cells become cancer cells because of damage to DNA, which is in every cell and directs all its actions. In a normal cell, when DNA gets damaged the cell either repairs the damage or dies. In cancer cells, the damaged DNA is not repaired, but the cell doesn't die like it should. Instead, this cell goes on making new cells that the body doesn't need. These new cells will all have the same damaged DNA as the first cell does.

People can inherit damaged DNA, but most DNA damage happens when the normal cell is reproducing or is caused by something in our environment. In most cases, no clear cause is found.

Cancer cells often form a tumor. But some cancers, like leukemias, rarely form tumors. Instead, these cancer cells involve the blood and blood-forming organs and circulate through other tissues where they grow.

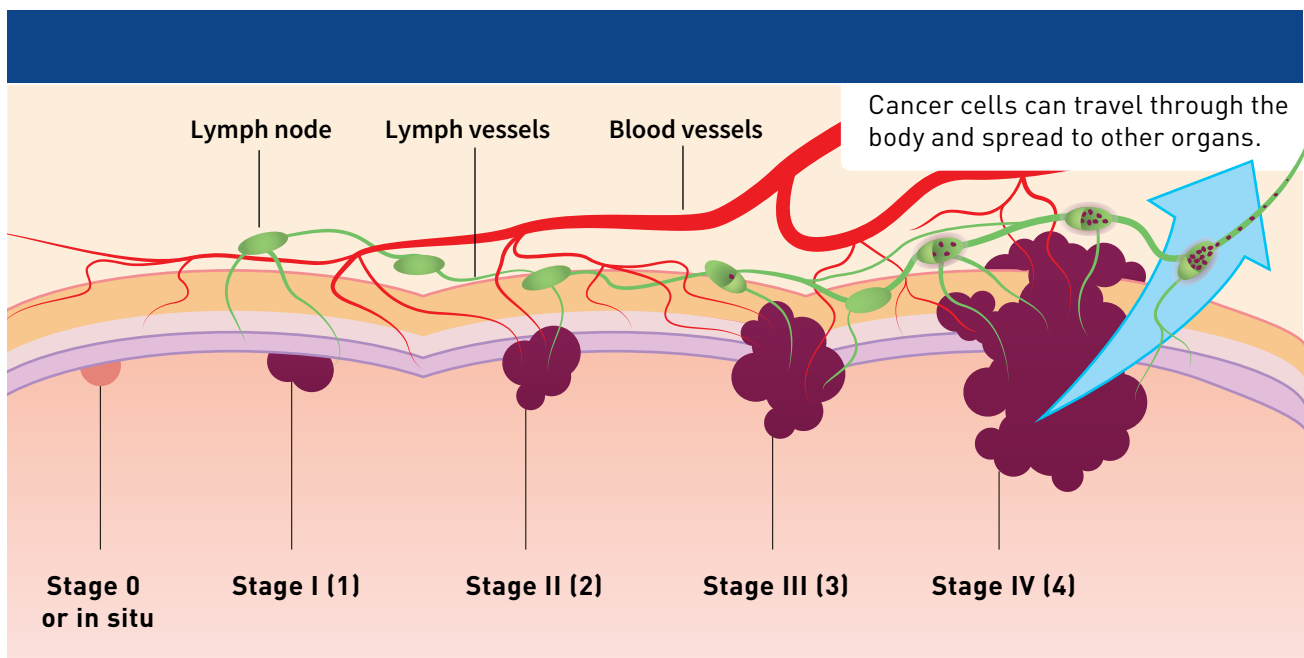
### LYMPH SYSTEM



Cancer cells often travel to other parts of the body, where they begin to grow and form new tumors that replace normal tissue. This process is called metastasis (meh-TAS-tuh-sis). It happens when the cancer cells get into the bloodstream or lymph vessels of our body.

No matter where a cancer may spread, it's always named for the place where it started. For example, breast cancer that has spread to the liver is still called breast cancer, not liver cancer. Likewise, prostate cancer that has spread to the bone is metastatic prostate cancer, not bone cancer.

Different types of cancer can behave very differently. For example, lung cancer and colon cancer are very different diseases. They grow at different rates and respond to different treatments. That's why people with cancer need treatment that's aimed at their kind of cancer. To learn more about specific cancer types and treatments, please visit [cancer.org](https://www.cancer.org) or call us at **1-800-227-2345**.



Not all tumors are cancer. Tumors that aren't cancer are called benign (be-NINE). Benign tumors can cause problems; they can grow very large and press on healthy organs and tissues. But they can't grow into (invade) other tissues. Because they can't invade, they also can't spread to other parts of the body (metastasize). These tumors are almost never life threatening.

## HOW DO WE ADJUST TO THE DIAGNOSIS?

With time, the patient and loved ones will start to adjust to the cancer diagnosis. This is a time of change and action. Everyone is getting used to the unexpected and scary situation that they now find themselves in. Even with all the activity, some people go through their days feeling numb and disengaged. Others may be sad, edgy, or angry. Emotions may change from minute to minute as everyone copes in their own way.

It's important to get accurate, reliable information in writing to be ready when you or others must ask questions or coordinate care. Ask:

- What is the exact name and location of the cancer?
- What's the stage of the cancer?
- What treatments are recommended? How are they done, and how long do they take?
- Will the patient need to be in the hospital? When and for how long?

The American Cancer Society has a downloadable list of specific questions on [cancer.org/questions](https://www.cancer.org/questions), where you can find information about cancer types, treatment, and side effects. Print one of these lists and take it with you. That way you can prioritize the questions you want to ask, and you won't forget anything important.

After you know the name and stage of the cancer, you can get more information about it by calling **1-800-227-2345** and talking with one of our caring, trained staff. You can also visit [cancer.org](https://www.cancer.org) to get information online.

Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch a video on Communication.

## IS CANCER CONTAGIOUS?

No, cancer is not contagious. In the past, people often avoided those who had cancer. They were afraid of all kinds of diseases, and didn't know enough about illness to understand that they were in no danger. Even today, families, friends, and coworkers of people with cancer sometimes shy away from them when they learn about the disease. As a result, people with cancer often say they feel isolated and alone. You don't have to stay away from someone with cancer; you cannot catch it from them. In fact, that person could probably use your company more than ever.

## IS CANCER CAUSED BY STRESS?

Many studies have looked for a link between personality, stress, and cancer. Careful reviews of scientific evidence do not show that someone's personality can increase their cancer risk. Study findings do not always agree, but the feeling of being stressed does not appear to be a strong predictor of cancer. Major life stressors, such as divorce or the death of a loved one, may raise cancer risk slightly. Also, poverty is linked to higher cancer risk, but this may be more related to health behaviors and poor access to medical care than to poverty itself. Of interest, many studies have shown that people who are socially isolated are more likely to die of all causes, including cancer.

We do know that social support can improve the quality of life of people with cancer and their loved ones. These things also help people with cancer cope better with their diagnosis, treatment, and recovery.

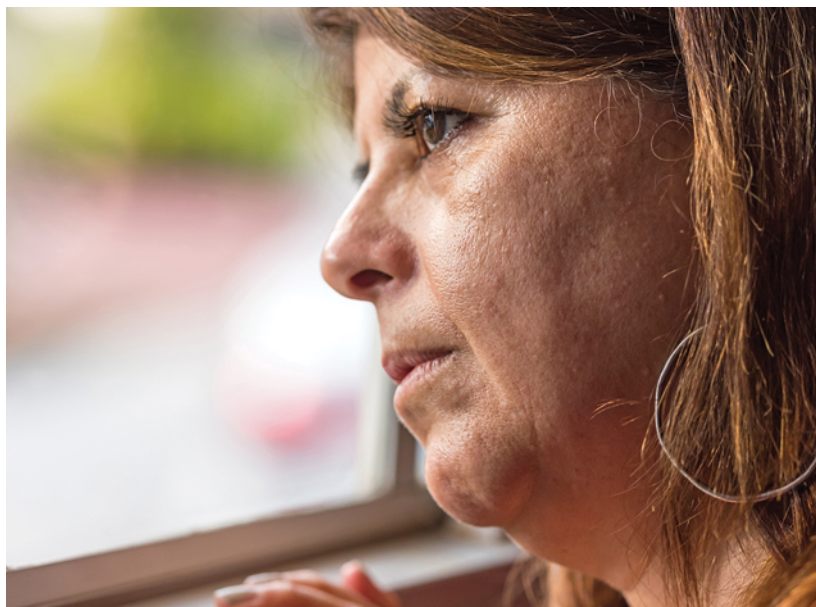
## DOES CANCER ALWAYS CAUSE PAIN?

Pain is one of the main reasons people fear cancer. If someone you know has the disease, it's normal to be worried about seeing them in pain. But there are some cancers that cause no physical pain at all. When a person with cancer does have pain it can be caused by a number of things. Some people have pain because of the growth of a tumor, while others may have pain from surgery or the side effects of treatment.

You should also know that the cancer care team can treat and manage almost any kind of pain. A great deal of progress has been made in pain control, so pain can be reduced or relieved in almost all cases.

You may also be concerned that someone taking pain medicine for cancer will become addicted to it. But the evidence shows that, in general, people who take prescribed drugs for cancer pain according to the doctor's directions do not become addicted. For more on this, read *Get Help for Cancer Pain* on [cancer.org](http://cancer.org). You can also get a free copy of the booklet by calling 1-800-227-2345.

For tips on controlling your loved one's pain, visit [cancer.org/caregivervideos](http://cancer.org/caregivervideos) to watch a video on Pain Management.





## WILL MY LOVED ONE HAVE PHYSICAL CHANGES?

There are some common physical changes shared by many people with cancer. The cancer itself causes some of these changes, and others are the result of side effects of cancer treatment. Keep in mind that each cancer journey is different. The person with cancer may or may not have any of the following:

- Hair loss, including eyebrows and eyelashes
- Weight loss or weight gain
- Appetite loss or increase
- Changes in how things taste or smell
- Extreme tiredness (called fatigue)
- Pale skin and lips, or changes in skin color
- Disfigurement (for example, the loss of a limb or a breast after cancer surgery)
- Nausea and vomiting
- Problems with sleep
- Poor concentration (sometimes called chemo brain)

For many people with cancer, the hardest side effect to deal with is fatigue. People report that fatigue can be overwhelming, and they are surprised at how tired they can feel long

after treatment ends. It can take a long time to heal after surgery, and people can feel tired for months after an operation. Chemotherapy can involve many weeks of strong medicines that worsen fatigue as the body heals. People getting radiation treatment also report extreme fatigue. Someone with cancer may also experience stress and emotional concerns, which add to exhaustion. Fatigue can go on for many months after treatment is over.

Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch a video on Managing Your Loved One's Side Effects from Treatment.

## HOW WILL MY LOVED ONE'S EMOTIONS BE AFFECTED?

Each person reacts in their own way to cancer and its treatment. It's normal to feel sad and grieve over the changes that a cancer diagnosis brings. The person's emotions and mood can change from day to day, even from hour to hour. This is normal. A person with cancer may go through any or all of the following emotions and thoughts:

- Uncertainty
- Anger

- A sense of lack of control
- Sadness
- Fear
- Frustration
- Guilt
- Mood swings
- Much stronger and more intense feelings
- A sense of being disconnected or isolated from others
- Loneliness
- Resentment
- Grief

Over time, the person may discover some changes that are good:

- A greater sense of resilience or strength
- Peace, or a feeling of being at ease
- A clearer idea of their priorities in life
- More appreciation for their quality of life and the people they care about

Cancer can be very unpredictable. Someone with the disease can feel good one day and terrible the next. Expect that they will have good days and bad days. Learning to live with uncertainty is part of learning to live with cancer, both for the patient and for the people around them.

There may be times when the uncertainty and fear cause the person with cancer to seem angry, depressed, or withdrawn. This is normal and is a part of the process of grieving what was lost to the disease (things like health, energy, time). Over time, most people are able to adjust to the new reality in their lives and go forward. Some may need extra help from a support group or a mental health

professional to learn to deal with the changes cancer has brought into their lives. See *Anxiety, Fear, and Depression* on [cancer.org](http://cancer.org) for more information.

## HOW DOES SOMEONE COPE WITH CANCER?

People develop all kinds of coping styles during their lives. Some people are quite private, while others are more open and talk about their feelings. Some people use humor and find it to be a relief from the serious nature of the illness, while others may become withdrawn and isolated from family and friends. A cancer diagnosis creates a lot of change. People often try to maintain as much control as they can in order to feel more secure. Some people become very angry or sad. They might be grieving the loss of their own healthy self-image, or the loss of control over their own lives.

Some people find it helps to simply be hopeful and do what they can to maintain that hope. Hope means different things to different people. And people can hope for many things while facing cancer.

You might assume that someone who is positive and optimistic must be denying the fact that they have cancer. If the person seems upbeat and unaffected by having the disease, don't assume they're in denial. Making the most of every day may simply be their way of coping. As long as they're getting medical care, they're probably not in denial, and their way of coping with cancer should be respected.

More information about coping with the cancer experience can be found in the Coping tab, page 95, of this guide.

## WHAT SHOULD I SAY TO MY LOVED ONE WITH CANCER?

You're not alone if you don't know what to say to the person with cancer. Sometimes the simplest expressions of concern are the most meaningful. And sometimes just listening is the most helpful thing you can do.

While it's good to be encouraging, it's also important not to show false optimism or tell the person with cancer to always stay positive. Doing these things might seem to discount

their very real fears, concerns, or sad feelings. It's also tempting to say that you know how the person feels. But while you may know this is a trying time, no one can know exactly how any person with cancer feels.

Using humor can be an important way of coping. It can also be another approach to support and encouragement. Let the person with cancer take the lead; it's healthy if they find something funny about a side effect, like hair loss or increased appetite, and you can certainly join them in a good laugh.

### Basic dos and don'ts when someone you know has cancer:

#### DO:

- Take your cues from the person with cancer. Respect the person's need to share or their need for privacy.
- Respect their decisions about how their cancer will be treated, even if you disagree.
- Include the person in usual projects, plans, and social events. Let them be the one to tell you if the commitment is too much to manage.
- Listen without always feeling that you have to respond. Sometimes a caring listener is what the person needs the most.
- Expect the person with cancer to have good days and bad days, emotionally and physically.
- Keep your relationship as normal and balanced as possible. While greater patience and compassion are called for during times like these, your loved one should continue to respect your feelings, as you respect theirs.

#### DON'T:

- Offer advice they don't ask for, or be judgmental.
- Feel you must put up with serious displays of temper or mood swings. You shouldn't accept disruptive or abusive behavior just because someone is ill.
- Take things too personally. It's normal for the person with cancer to be quieter than usual, to need time alone, and to be angry at times.
- Be afraid to talk about the illness.
- Always feel you have to talk about cancer. Your loved one may enjoy conversations that don't involve the illness.
- Be afraid to hug or touch your loved one if that was a part of your relationship before the illness.
- Be patronizing. (Try not to use a "How sick are you today?" tone when asking how the person is doing.)
- Tell your loved one, "I can imagine how you must feel," because you really can't.
- Be around your loved one with cancer if you are sick, or have a fever or any other signs of infection.

This can be a great way to relieve stress and take a break from the more serious nature of the situation. But never joke unless you know the person with cancer can handle it and appreciate the humor.

If they look good, let them know! Avoid making comments when their appearance isn't as good, such as "You're looking pale," or "You've lost weight." It's very likely that they're acutely aware of it, and they may feel embarrassed if others comment on it.

Remember that your loved one with cancer may find it hard to ask for help or may be worried about seeming weak or vulnerable. Telling a person, "You're so brave," or "You're so strong," can put pressure on them to act strong when they may not feel up to it. Families can put subtle pressure on people with cancer by expecting or needing them to be strong all the time.

## HOW DO I GET OVER FEELING UNCOMFORTABLE AROUND MY LOVED ONE WITH CANCER?

Feeling sorry for them or feeling guilty for being healthy yourself is a normal response. But by turning those feelings into offerings of support you make the feelings useful. Asking how you can help can take away some of the awkwardness. Cancer is a scary disease. It can create a great deal of uneasiness for people who don't have experience dealing with it. Don't be ashamed of your own fears or discomfort. Be honest with the person about how you feel. You might find that talking about it is easier than you think.

Cancer often reminds us of our own mortality. If you are close in age to the person with cancer or if you are very fond of them, you

may find that this experience creates anxiety for you. You might notice feelings a lot like those of the person who has cancer: disbelief, sadness, uncertainty, anger, sleeplessness, and fears about your own health.

## HOW DO WE DEAL WITH THE UNCERTAINTY?

When a person has cancer, they go through different stages. Your understanding and your care will change over time, too. There will be times when you don't know what will happen next, and with an illness as serious as cancer, that's a scary place to be. But there are no guarantees in cancer care. There's no way to know for sure whether treatment will work. No one can predict the side effects or problems your loved one will have during treatment. And even after successful treatment, there's still the chance that cancer will come back. There can even be a new, different cancer sometime in the future.

Research has shown that caregivers sometimes experience higher levels of fear of the cancer returning than the patients themselves. Visit [cancer.org/caregiver/videos](https://www.cancer.org/caregiver/videos) to watch a video on Fear of Recurrence to learn about tips for coping with this feeling.

Some ideas that have helped others deal with uncertainty and fear and feel more hopeful are:

- Learn what you can do to keep your loved one as healthy as possible, and learn about the services available to you. This can give you a greater sense of control.
- Know that you don't have control over some aspects of the cancer. It helps to accept this rather than fight it.



- Try to let go of your fears, but don't deny them. It's normal for these thoughts to enter your mind, but you don't have to keep them there. Some people picture them floating away or being vaporized. Others turn them over to a higher power to handle.
- Express feelings of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions help many people feel less worried. People have found that when they express strong feelings, like fear, they're better able to let go of these feelings.
- Use your energy to focus on wellness and what you can do now to stay as healthy as you can. Remember to take care of yourself, as well as your loved one with cancer.
- Find ways to help yourself relax.
- Make time for regular exercise, and be as active as you can.
- Control what you can. Keeping your life as normal as possible and making changes in your lifestyle are just a few of the things you can control.

You play an important role in the health of the person you are caring for, but you cannot control how they are doing physically or mentally. Be careful not to look at your loved

one's progress and good days as proof of your caregiving skills. If you do this, you'll be more likely to blame yourself when they have bad days and setbacks. Uncertainties and highs and lows are part of dealing with cancer; no one, not even the best caregiver, can control them.

## **CAN MY LOVED ONE KEEP WORKING DURING TREATMENT?**

Your loved one with cancer may want to keep working through treatment. In some cases, it's possible. In others, it doesn't work well. Still, an employee with cancer who wants to keep their job may be able to take some time off during treatment, using either company benefits or the Family and Medical Leave Act (FMLA). FMLA can be used by the person with a serious illness, as well as by their caregiver.

Taking leave under FMLA is usually much better for the person with cancer than quitting, because they can keep their health insurance. If the person with cancer later learns that they must leave their employment permanently, they may be able to use COBRA (Consolidated Omnibus Budget Reconciliation Act) to extend health insurance coverage even further.

Your loved one may also benefit from the Americans with Disabilities Act (ADA). This federal law requires employers to make "reasonable accommodations" for an employee with a long-term or permanent disability. But the person must be able to do the main job functions in order to qualify for this protection. And it doesn't apply to every employer.

If the patient with cancer had to quit their job during or after treatment, and is ready to go back to work, the ADA offers some legal protections against job discrimination.



If your loved one would like more information about how cancer may affect their ability to work and legal issues related to employment, have them go to [cancer.org](http://cancer.org) and see *Working During and After Treatment*.

## HOW IMPORTANT IS WORKING TO A PERSON WITH CANCER?

Facing cancer often brings with it an increased sense of the importance of work in a person's life. Working can boost self-worth and help the person focus on what they're able to do rather than on their illness. Work can be a safe haven away from the medical world and can help a person balance the feeling of being out of control.

Work is also a source of stability because it has a routine and is familiar. In addition, work provides contact with other people. Cancer can be isolating, and being around people can be a great comfort. It may be very important for your loved one to be at work as much as possible and be as productive as possible. Financial and insurance issues may also affect the decision to work during treatment.

## WHAT DO WE NEED TO KNOW ABOUT THE PATIENT GOING BACK TO WORK AFTER TREATMENT?

As treatment winds down, the patient may be given the "all clear" to go back to work. Or it may be that your loved one needs to increase their work duties slowly; this will depend on their physical condition and the type of job they have.

You may need to help get the letters from the doctor that will be needed to clear the patient for full work duties when the time comes. And even when your loved one starts working a more normal schedule, there may be days of

extreme tiredness in which your help will still be needed. It may take some time to get past this phase, and you may still need your circle of helpers so that you, too, can start getting back to a more normal schedule.

This may be a time when the ADA can be helpful to some patients. If the patient can still do the essential part of their job, the ADA can be used to negotiate for special equipment or a different work schedule. See *Americans With Disabilities Act* on [cancer.org](http://cancer.org) for more information.

## WHAT DO I NEED TO KNOW ABOUT MY LOVED ONE'S HEALTH INSURANCE?

Cancer is a very costly illness. Even if the patient has health insurance, it surprises many people to learn how much they have to pay out of pocket for cancer care. And your loved one is probably going to need help keeping track of it all, figuring out what's covered and what isn't, and paying deductibles and copays.

You or someone else will probably need to help set up a system for tracking costs, comparing insurance statements, and keeping careful records. Your loved one will need to stay in touch with their insurance plan in



case there are reimbursement problems. The patient may need to give permission to the insurance company to talk about problems and disputes with the person chosen to help with insurance.

Having a health insurance plan that covers needed cancer treatments is important.

As a caregiver, it's especially important to know these things about health insurance:

- *Do not* let your loved one's health insurance lapse.
- Pay health insurance premiums and other costs in full and on time. New insurance can be hard to get. Your loved one doesn't get a special enrollment period to buy marketplace insurance if they lost coverage because they didn't pay premiums.
- If they are changing insurance plans, they shouldn't let one policy lapse until the new one goes into effect. This includes switching to Medicare.
- Know the details of your loved one's individual insurance plan and its coverage. Ask the plan administrator for a Summary of Benefits and Coverage. This is an easy-to-understand description of a plan's benefits and the costs they will have to pay. If you think the patient might need more coverage than a plan offers, ask the insurance carrier if it's available.
- When possible, call the insurer to make sure that any planned medical service (such as surgery, procedures, or treatments) does not require prior authorization.
- If a bill looks odd or wrong, make sure to call or email the insurer to avoid being mistakenly charged more than you should.
- Submit claims for all medical expenses, even when you're not sure if they're covered.
- Keep accurate and complete records of all claims submitted, pending (waiting), and paid.
- Keep copies of all paperwork related to claims, such as letters of medical necessity, explanations of benefits (EOBs), bills, receipts, requests for sick leave or family medical leave (FMLA), and correspondence with insurance companies.
- Get a caseworker, a hospital financial counselor, or a social worker to help if finances are limited. Companies or hospitals can often work with you to make special payment arrangements for your loved one if you let them know about the situation.
- Send in bills for reimbursement as you get them. If you become overwhelmed with bills or tracking your loved one's medical expenses, get help from trusted family members and/or friends.
- Contact local support organizations, such as your American Cancer Society or your state's government agencies, for extra help.

***Having a health insurance plan that covers needed cancer treatments is important.***

### **Renewing or selecting a new plan**

Most work-based insurance plans have an open enrollment period once a year. This is when your loved one can look at all health plans offered at work. They can also change plans or add a new family member to the plan at this time.

Sometimes there's an option to keep the same plan, but sometimes that plan is going away or changing. When this happens, someone needs to look carefully at the new options and how they will cover the cancer treatments the patient needs. If the plan is through the state health marketplace, it's important to select a plan early enough so that it starts before the old plan lapses.

If the patient has Medicare, you can visit their Open Enrollment Center online at <https://www.cms.gov/outreach-and-education/reach-out/find-tools-to-help-you-help-others/medicare-open-enrollment.html>, or you can call them at 1-800-633-4227. The same general rules apply when comparing plans.

If the patient has Medicaid, complete the eligibility/renewal forms for them right away. Most states mail these out each year to be sure the requirements for coverage are still met. If the patient moves, give the new address to the Health Department right away so they get the annual renewal forms. Keep copies of the completed forms for reference, and so that you'll know when they're due next. That way someone can call if the renewal forms don't come on time.

### Getting answers to insurance-related questions

Questions about insurance coverage will often come up during your loved one's treatment. Here are some tips for dealing with insurance-related questions:

- Speak with the insurer or managed care provider's customer service department.
- Ask the cancer care team social worker for help.
- Hospitals, clinics, and doctors' offices often have someone who can help fill out claims for insurance coverage or reimbursement. Ask the case manager or a financial assistance counselor to help guide you through what can be a complex process.
- Talk with the consumer advocacy office of the government agency that oversees the insurance plan.
- Learn about the insurance laws that protect the public. Call your American Cancer Society at 1-800-227-2345.

See *Understanding Health Insurance* section on [cancer.org](https://www.cancer.org) for more information about health insurance.

### HOW CAN CANCER AFFECT A PERSON'S FINANCIAL SITUATION?

Cancer often causes money problems. The patient may lose pay by being absent from work during and just after treatment. Their pay may drop if shorter hours are worked while getting treatment or not feeling well. The patient may also need to pay more of their insurance premium if they work fewer hours or take time off for treatment. In some cases, health coverage may be stopped or decreased if they go to a part-time schedule. A lot depends on the workplace policies. It's important for someone with cancer to understand in advance how schedule changes will affect their insurance, salary, and other benefits.

Frequent medical visits can also be a financial drain because of prescription costs and insurance copays (the part of treatment that insurance doesn't pay). Copays can reach burdensome amounts. There are also parking fees, gasoline, and the costs of other services



and equipment not covered by insurance. The costs add up very quickly.

Call **1-800-227-2345** to get referrals to programs that offer general financial assistance and copay assistance.

### **HOW DO I DEAL WITH ALL THE MONEY ISSUES?**

If you lost your income because you had to quit your job to be a full-time caregiver, financial problems can become overwhelming very quickly. Contact us at **1-800-227-2345** or visit [cancer.org](https://www.cancer.org) for more information on dealing with money issues.

If you are still working, your loved one with cancer may need extra help – someone to check in on them while you're at work. Some caregivers may be able to check in by phone as long as their loved one can do some of their own basic care. Others may need to pull family and friends together to find people who can be there or check in while you're at work. If there's a need for skilled nursing care, the patient may be able to get home health visits through their health insurance.

A few people may be able to get paid for time spent caregiving. Some states may have programs that directly pay some caregivers. You can find out whether your state has a program by contacting your local Medicaid office, social services, or health department.

### **WHAT ARE COMMON LEGAL ISSUES?**

It may be hard to talk about, but legal issues can be a huge source of stress for caregivers, patients, and families. Common worries include who will manage your loved one's money and who will make important health care decisions if they are unable to do so. It's important to raise these issues with the patient while they are still able to make choices, so that you and the rest of the family can be clear about what your loved one wants.

#### **If the person with cancer becomes unable to manage their own money**

There are surrogate decision-making tools that may help you and your loved one. One example is the durable power of attorney, which allows the patient to choose the person who can make financial decisions on their behalf. This is quite different from the durable



***A durable power of attorney for health care has nothing to do with money or finances, only health care decisions.***

power of attorney for health care, which is discussed below. The durable power of attorney does not affect health decisions.

**If the person with cancer becomes unable to make health care decisions**

A durable power of attorney for health care has nothing to do with money or finances, only health care decisions. It allows the patient to choose someone to make health care decisions if they become unable to do so. Many times, this is a close family member, partner, or spouse who is aware of the patient's health condition and their wishes. The caregiver is a logical choice in many cases, given their knowledge of the patient and their condition.

But it becomes more difficult when the patient and the caregiver have different goals and values. For instance, if the patient is nearing the end of life and wishes to stop treatment, and the caregiver is still looking for a cure, it may not work the way the patient wants.

See *Advance Directives* on [cancer.org](https://www.cancer.org) for more information on living wills and durable powers of attorney.

You should also find out about things you can do to protect your loved one and family, both legally and financially, during the cancer experience. See *Understanding Financial and Legal Matters* on [cancer.org](https://www.cancer.org) to learn about laws that protect rights and professionals who can help navigate the legal and financial systems.

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.



# Cancer Treatment

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## UNDERSTANDING THE CANCER TREATMENT PROCESS

### WHAT DO I NEED TO KNOW ABOUT TREATMENT?

Cancer treatment varies a lot depending on the type and stage of the cancer. The most common treatments for cancer are surgery, chemotherapy, and radiation. Treatment may mean time in the hospital or making many trips to a clinic. Your loved one may be able to go to some treatments on their own. For other treatments, someone may need to drive or go along. Your loved one may need more than one type of treatment, and each type comes with its own challenges.

You'll want to be sure that you understand the treatment options chosen by the patient and doctor since you probably will be helping plan how to make it happen. Treatment can be long or fairly short, but even short treatments tend to disrupt a person's life for several weeks. As the caregiver, your life and your family's lives may be disrupted, too.

During treatment, you'll want to learn about general cancer information, treatment effects, and how to manage side effects.

Our *Caregiver Support Video Series* can help you with – among other things – Drain Care, Lifting, Identifying Signs of Infection, and Managing Your Loved One's Medications, Pain, and Treatment Side Effects. Visit [cancer.org/caregivervideos](https://cancer.org/caregivervideos) to watch.

Some questions that you may want to discuss with the cancer care team ahead of time are:

- What symptoms do we need to tell you about right away? Which ones can wait?
- How do we reach you after office hours? On weekends? Holidays?
- What can we do to manage side effects?
- How will we know if the treatment is working?

The American Cancer Society has a downloadable list of specific questions on [cancer.org/questions](https://cancer.org/questions), where you can find information about cancer types, treatment, and side effects. Print one of these lists and take it with you. That way you can prioritize the questions you want to ask, and you won't forget anything important.



Again, you'll want to write this information down and keep it handy. This can really help if you or someone else runs into problems later.

## HOW DO WE DEAL WITH MEDICAL DELAYS?

### Lab result delays

Sometimes it can take awhile to get back lab results. This can be even harder to deal with when you're waiting to get test results to see if it's cancer or if the disease has come back. It's scary to find out about a change in blood counts, or find a new mass or lump and not know if it's cancer.

Waiting for these results can be a frightening time, and people can go through some strong emotions, including disbelief, anxiety, fear, anger, and sadness. It's important to know that it's normal for you and the patient to have these feelings. Some people find comfort in talking with other people about what's going on, while others wish to keep it very private. Try to respect your loved one's wishes during this time.

### Treatment delays

Planning cancer treatment takes time. Most people want to start treatment right away. They worry that the extra time taken to do tests or make decisions will take up precious time that could be spent fighting the cancer.

Cancer treatment should start very soon after diagnosis, but for most cancers, it won't hurt to wait a few weeks to begin treatment. This gives the person with cancer time to talk about all their treatment options with the cancer care team, family, and friends, and then decide what's best for them.

Your loved one might also want to get a second opinion on what's the best treatment. This is often a good idea, especially if the patient can see a doctor experienced in treating their type of cancer. A second opinion can give your loved one more information and help them feel more confident about choosing a treatment plan. See *Seeking a Second Opinion* on [cancer.org](http://cancer.org) to learn more.

Your loved one might also want or need time to prepare to put their normal activities "on hold" while getting treatment. For instance, arrangements for work or child care may be needed, and taking care of these things ahead of time can help the patient better focus on dealing with treatment. See *Family and Medical Leave Act* and *Helping Children When a Family Member Has Cancer* on [cancer.org](http://cancer.org) to learn more about these topics.

If you or your loved one is worried that treatment isn't starting right away, discuss your concerns with the cancer care team and be sure that any delays will not cause more problems.

## SURGERY

Cancer surgery can be used in a lot of ways. Here are some:

- To take out a small piece of something that might be cancer to check it for cancer cells (This is called a biopsy [pronounced BY-op-see].)
- To look in your loved one's body to see how much cancer there is and how far it has spread (This is called staging.)
- To take out all of the cancer
- To take out most of the cancer to help other treatments like chemotherapy or radiation work better (This is called debulking.)

***When surgery is used to take out a cancer, other treatments like chemotherapy or radiation may be used after it.***

- To treat problems caused by the cancer, such as opening a bowel blocked by a tumor
- To put in devices that will help with cancer treatment, such as an IV access tube or a feeding tube
- To help replace or fix a body part after cancer treatment, such as putting in a new part to replace a bone that was removed
- To try to help keep a person from getting cancer, such as taking off a woman's breasts if she is at a high risk for breast cancer, even though she doesn't have cancer

### **Will surgery be the only cancer treatment?**

When surgery is used to take out a cancer, other treatments like chemotherapy or radiation may be used after it. These treatments help kill any cancer cells that may be left behind. Chemotherapy or radiation may also be used before surgery. It may help shrink a tumor so it's easier to take out.

### **What's it like to have cancer surgery?**

#### ***Getting ready for surgery***

The surgeon (the doctor who will do the surgery) will talk with you and your loved one about the planned surgery. After all of the details have been discussed, your loved one will sign a consent form. This tells the surgeon that your loved one wants them to do the surgery.

Your loved one will also talk to an anesthesiologist (pronounced AN-es-**THEE**-zee-AHL-uh-jist). This is the doctor or nurse who will give the drugs that help the patient relax or go into a deep sleep during the surgery so they don't feel pain. They also watch your loved one during surgery to keep them safe.

The person you're providing care for may need to get blood tests or other tests to make sure they're healthy enough for surgery. Be sure they tell their doctors about all the medicines they take. Tell them about over-the-counter drugs, vitamins, and other supplements. This is to make sure your loved one isn't taking anything that could affect the surgery.

Your loved one will be told what they need to do the day before surgery. They may be told not to eat after a certain time, or they may need to shower with a special soap the doctor gives them.

#### ***After cancer surgery***

After the surgery is done, your loved one will be put back on a stretcher and taken to a recovery room. They will be watched closely as they wake up. They will be given medicine to treat pain. With some types of surgery, they might be taken to a hospital room for one or more nights.

For the first few days after surgery, your loved one will have pain. Make sure they take their pain medicine. They need to be able to take deep breaths, cough, and move as they heal. Pain can keep them from doing these things. Tell the doctor if the medicine isn't working.

Your loved one may have tubes coming out of their body for a few days. A catheter is a tube

put into the bladder so that urine goes into a bag outside of the body. A drain is a tube put into the wound during surgery to help let extra fluid drain out. As the caregiver, you will be taught how to deal with these tubes. The patient may have bowel problems. Talk with the doctor about what your loved one can do to help this.

### **Recovering at home**

Your loved one may feel tired or weak for a while. The amount of time it takes to feel better is different for each person.

When your loved one gets home, they can do some things they used to, but not everything. The doctor or nurse will tell them what can and can't be done. Be sure to ask when your loved one can take off any bandages, when they can shower or take a bath, and what needs to be done to take care of the wound. Also ask when they can drive.

### **What about surgery risks and side effects?**

All surgery has risks. Some of the more common risks and side effects are:

- A lot of bleeding
- Pain
- Infection
- Damage to internal organs
- Blood clots
- Nerve damage
- Scar tissue buildup

The chance of having side effects depends on overall health, the type of surgery, and other factors. Talk with your loved one's cancer care team about any problems you are worried about and if they might happen to them. Keep in mind that the team can only tell you

what they think will happen. No one can tell you for sure that the person you're providing care for won't have problems during or after surgery. But even if the surgery causes problems, the "good" will likely outweigh the "bad" of the side effects.

Many side effects go away over time as healing occurs. How long it takes is different for each person. Some side effects can take longer to go away than others. Some, like nerve damage, might not go away at all. If your loved one starts to feel upset or sad about their side effects, encourage them to talk to their doctor. The cancer care team can help with side effects.

### **Follow-up care**

No matter what type of cancer your loved one has, after surgery they will still need to see their cancer care team. This part of treatment is called follow-up care. They will check how the patient is doing and help them deal with any problems they may have. The surgeon will take out any drains, stitches, or staples, and check to see how things are healing.

After surgery, your loved one may need more cancer treatment. The cancer care team will talk about what this will be like and when the treatments will start.

See *Treatments and Side Effects* on [cancer.org](https://www.cancer.org) for more detailed information about surgery, its side effects, and specific questions to ask the doctor.

Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch videos on Identifying Signs of Infection and Managing Your Loved One's Medications, Pain, and Treatment Side Effects.

## CHEMOTHERAPY

Chemotherapy is the use of strong drugs to treat cancer. You will often hear chemotherapy called “chemo” (KEY-mo), but it’s the same thing. The chemo drugs your loved one will receive have been tested many times. Research shows they work to help kill cancer cells.

### What does chemo do?

There are more than 100 chemo drugs used today. Doctors choose what drugs to give based on the kind of cancer and how much cancer is in the body (the stage). Your loved one’s doctor will talk about the goals of chemo before they start treatment.

Chemo may be used to:

- Keep the cancer from spreading.
- Make the cancer grow slower.
- Kill cancer cells that may have spread to other parts of the body (metastasized – meh-TAS-tuh-sized).
- Make side effects from cancer better, like pain or blockages.
- Cure cancer.

### Will chemo be the only cancer treatment?

Sometimes chemo is the only cancer treatment needed. More often, it’s part of a treatment plan that can include surgery and/or radiation therapy (RAY-dee-A-shun THER-uh-pee).

Here’s why:

- Chemo may be used to shrink tumors before surgery or radiation.
- It may be used after surgery or radiation to help kill any cancer cells that are left.
- It may be used with other treatments if the cancer comes back.

### How does chemo work?

Chemo kills cells that grow fast, like cancer cells. It can affect normal cells that grow fast, too, like the cells that make hair or blood. But most normal cells can fix themselves.

Your loved one will probably get more than one chemo drug. This is called combination chemotherapy. The drugs work together to kill more cancer cells.

## WAYS TO PREPARE FOR CHEMO DAY



Clean house, and do laundry.



Grocery shop the day before.



Make 1-2 meals, and freeze for later.



Your loved one should wear warm clothes, and bring a pillow and blanket.



Bring books, laptop, cards, movies, etc.



Pack healthy snacks and coconut water.



If possible, get your loved one to complete blood work the day before.



Pick up all prescription medications before your loved one’s appointment.



Ask for an IV bag of antinausea medicine after your loved one’s chemo.

## How is chemo given?

Most chemo drugs are given in one of these ways:

- Sometimes chemo is a pill or liquid. You just swallow it. You can take it at home, but you must be careful to follow the directions.
- Chemo can be given like a flu shot. The shots may be given in a doctor's office, a hospital, a clinic, or at home.
- Most often, chemo drugs are put into the blood through a tiny plastic tube called a catheter (CATH-it-ur) that's put in a vein. This is called IV (intravenous – in-truh-VEEN-us) chemo.
- Other types of chemo can be put right into the spine, chest, or belly (abdomen), or rubbed on the skin.

Your loved one may get chemo once a day, once a week, or even once a month. It may all be given in 1 day, or they may need to get it for a few days in a row. It depends on the type of cancer and the drugs.

Chemo is usually given with breaks between treatment cycles. The breaks give the body time to rebuild healthy new cells and help renew strength. How long between chemo depends on the type of cancer your loved one has, their treatment goals, and how the cancer and their body work with the drugs.

## What about chemo side effects?

Chemo drugs are very strong. They kill any cell that's growing fast, even if it's not a cancer cell. So, some normal, healthy cells that grow quickly can be harmed. This can cause side effects. Ask the cancer care team what side effects your loved one may expect from the chemo they receive.

If the person you're providing care for has bad side effects, blood tests may be done to find out if they need a lower dose of chemo, or if they need longer breaks between doses. Keep in mind that even if chemo causes problems, the "good" will likely outweigh the "bad" of the side effects.

For most people, side effects go away over time after treatments end. How long it will take is different for each person. Some side effects can take longer to go away than others. Some might not go away at all. If your loved one starts to feel upset or sad about their side effects, encourage them to talk to their doctor. The cancer care team can help with side effects.

## Common chemo side effects

### *Nausea and vomiting*

Some chemo drugs can cause nausea (feeling sick to your stomach) and vomiting (throwing up). These symptoms often start a few hours after treatment and last a short time. In some cases, they may last for a few days. Be sure to ask the cancer care team if chemo might cause this and what can be done about it.

If your loved one's doctor gives them a drug to help nausea and vomiting, be sure they take it. Tell the cancer care team right away if the drug isn't working. Call the doctor if your loved one has been vomiting for more than 1 day or can't keep liquids down.

### *Hair loss*

Some chemo can make hair fall out. Your loved one may lose the hair on their head, face, arms, armpits, and groin. They may lose hair slowly or almost overnight. Not all chemo drugs have this effect. Some only cause the

hair to thin out. The cancer care team can tell you what to expect from the chemo drugs your loved one is getting. In most cases, hair grows back after chemo. But it may not be the same color or may be different in other ways.

Ask the cancer care team for tips on taking care of your loved one's hair and scalp during chemo. Some people choose to wear head covers, such as caps, scarves, turbans, or wigs and hairpieces. Many health plans cover at least part of the cost of a wig or hairpiece. Also, these costs can be deducted from your income taxes.

The American Cancer Society helps women address the appearance-related side effects of cancer. Our **“tlc” Tender Loving Care® publication**, offers affordable hair loss and mastectomy products, as well as advice on how to use those products. Visit [tlcdirect.org](http://tlcdirect.org) or call **1-800-850-9445** to order products or a catalog.



### **Bone marrow changes**

The bone marrow is the liquid inner part of some bones. It's where blood cells are made (red blood cells, white blood cells, and platelets). It's often affected by chemo, which can cause blood cell counts to drop.

- **Red blood cells (RBCs)** carry oxygen from the lungs to all parts of the body. Not having enough red blood cells is called anemia (uh-NEE-me-uh). This can make your loved one feel short of breath, weak, and tired. It can also make the skin, mouth, or gums look pale.
- **White blood cells (WBCs)** fight infection. Low numbers of white blood cells make a person less able to fight infections. Your loved one's cancer care team may suggest ways to stay safer from infection, such as staying away from people with colds or fevers, staying away from crowds of people, and washing hands often.
- **Platelets (PLATE-lets)** form blood clots that stop bleeding from cuts or bruises. If your loved one's bone marrow can't make enough platelets, they may bleed too much, even from small cuts. If their platelet count is very low, they will need to be very careful. For instance, even brushing their teeth too hard could make their gums bleed. So, you might need to buy your loved one a soft-bristle toothbrush or one made from foam. Check with the cancer care team about flossing.

These effects on the bone marrow will not last long. Blood tests will be done to see when the bone marrow is making new blood cells again. And there are treatments that can be used if your loved one's blood cell counts get too low.

### ***Mouth and skin changes***

Some chemo drugs can cause sores in the mouth and throat. Good mouth care is a key part of treatment. Be sure your loved one brushes their teeth and gums after each meal. Encourage them to see a dentist before starting chemo. A dentist can show them the best ways to take care of their teeth and gums during treatment.

Some people have skin problems while having chemo, such as redness, itching, peeling, dryness, and acne. Most skin problems are not bad, but some need to be treated. Some people are allergic to chemo. This can cause hives (or skin welts), itching, or trouble breathing. Chemo is usually given in the doctor's office or clinic where a nurse can watch for this type of problem. These problems must be treated right away.

Ask the cancer care team for tips on taking care of the mouth and skin while getting chemo. If your loved one has any side effects, tell the cancer care team about them right away. There are often things they can do to help and keep the problems from getting worse.

### ***Sex life changes***

Sometimes sexual desire is low or even gone for some time, but it comes back when treatment ends. Most patients can have sex during treatment, but some don't feel like it. This does not mean that something is wrong.

See *How Cancer Affects Sexuality* on [cancer.org](http://cancer.org) to learn more about the sexual effects of cancer treatments and how to deal with them.

Most chemo can cause birth defects if a woman gets pregnant during treatment. Some chemo can affect a man's sperm, which may cause problems if he gets a woman pregnant while he is in treatment. Ask the doctor about this, and find out if and what kind of birth control should be used and for how long.

### ***Fertility problems***

Some chemo drugs can leave your loved one unable to have children. This effect does not always go away after treatment ends. If the person you're providing care for wants to have children someday, encourage them to talk to their doctor about this before starting treatment.

See *Fertility and Women With Cancer* or *Fertility and Men With Cancer* on [cancer.org](http://cancer.org) to find out more about this.



### Memory changes

Cancer and its treatment can affect your loved one's memory and thinking. This may be called "chemo brain" or "chemo fog." In rare cases, it can last for a long time after treatment.

If you notice this, talk to your loved one's doctor. There are health care workers who can help them with thinking exercises and other types of treatment to help deal with these effects.

### Emotional changes

Chemo and cancer can affect a patient's emotions. Chemo changes normal life and can make it harder to get things done. Your loved one may feel sad or scared. There may be some strain on how they get along with others. But there are ways to cope with these things. Encourage your loved one to talk to their cancer care team about counseling, support groups, and things they can do to help be less stressed.

Refer to the Coping tab, page 95, in this guide for more information about this.

### Can chemo side effects be prevented and treated?

There are ways to stop most chemo side effects or make them better. Be sure to talk to the cancer care team if your loved one has side effects.

Remember that not everyone gets the same chemo drugs. Some chemo drugs cause more side effects than others. Your loved one's overall health and fitness will also affect how their body reacts to chemo. Some people are able to go on with everyday life while getting chemo. But others need to be in the hospital during treatment. Most people have to change

***Some chemo drugs can cause more side effects than others.***

their work hours to get chemo. Ask the cancer care team what your loved one will be able to do during treatment – on chemo days and in between treatments.

See *Treatments and Side Effects* on [cancer.org](https://www.cancer.org) for more detailed information about chemotherapy, its side effects, and specific questions to ask the doctor.

Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch a video on Managing Your Loved One's Medications, Pain, and Treatment Side Effects.

## RADIATION

Radiation (RAY-dee-A-shun) therapy (THER-uh-pee) is the use of radiation to treat cancer and other problems. There are different types of radiation. One that you may know about is x-rays. If you've ever had an x-ray of your chest or any other body part, you've had some radiation. Radiation is used in much higher doses to treat some cancers.

### How does radiation therapy work?

Special equipment sends high doses of radiation to cancer cells or tumors. This kills the cancer cells and keeps them from growing and making more cancer cells. Radiation can also affect normal cells near the tumor. But normal cells can repair themselves; cancer cells can't.





Sometimes radiation is the only treatment needed. Other times it's used along with chemo or surgery.

Sometimes radiation can cure cancer. Other times the goal may be to slow the cancer's growth to help your loved one feel better. Be sure to talk to your loved one's cancer care team about the goal of their treatment.

### How is radiation given?

Radiation can be given in 3 ways. They are:

- External beam radiation
- Internal radiation
- Systemic radiation

Some people get more than 1 type of radiation.

### *External beam radiation therapy*

Radiation that comes from outside the body is called external beam radiation. A big machine sends high-energy beams to the tumor and some of the area around the tumor.

### How long does the treatment take?

For most people, treatments are given 5 days a week for 1 to 10 weeks. The number of treatments needed depends on the size and

type of cancer, where the cancer is, how healthy your loved one is, and what other treatments they're getting. Most people get a break on weekends so their normal cells can recover.

### What happens during each treatment visit?

External radiation therapy is like getting an x-ray. There's no pain and only takes a few minutes. But it takes time to get the machine set up, so it may take 15 to 30 minutes to get each treatment. It's often given in a walk-in clinic, so your loved one doesn't have to be in the hospital.

Your loved one will lie flat on a treatment table under the radiation machine. The radiation therapist may put special shields or blocks between the machine and other parts of the body. These protect other body parts from the radiation. The patient will need to stay still during the treatment, but they don't have to hold their breath.

Once everything is all set and the machine is ready, the therapist goes into a nearby room to run the machine. The therapist can see and talk to your loved one the whole time. While the machine is working, there will be clicking, whirring, and something that sounds like a

vacuum cleaner as the machine moves around to aim the radiation. The radiation therapist controls this movement and checks to make sure the machine is working the way it should. It will not touch your loved one.

If your loved one is worried about anything happening while the machine is on, encourage them to talk to the radiation therapist. If they start to feel sick or scared, they should let the therapist know right away. The machine can be stopped at any time.

### ***Internal radiation therapy***

When a radiation source is put inside the body, it's called internal radiation therapy. Internal means inside. This lets the doctor give a large dose of radiation right to the cancer cells and/or tumor.

The radioactive source is called an implant. It might look like a wire, pellet, or seeds. The implant is put very near or right into the tumor, and the radiation travels only a very short distance. The implant can be left in place forever or just for a short time.

### **How are implants put in the body?**

Some implants are put in the body with needle-like tubes. This might be done in an operating room, and drugs may be used to make a person relax or sleep. Other implants are put in a body opening, like the uterus or rectum. These are only left in for a short time.

### **Some implants are left in.**

If your loved one has implants that will be left in their body, they may not be allowed to do some things, such as be close to children or pregnant women, for a certain period of time. But they can go back to the other normal

things they do right away. The implants give off less and less radiation over time. They stop giving off radiation after a few weeks to a few months. Once the radiation is gone, the implants just stay in and cause no harm.

### **Some implants are taken out**

Some implants are taken out after they have been in for many hours or days. While the implants are in place, your loved one will stay in a private hospital room. Doctors and nurses will provide care, but they'll need to limit how much time they spend with your loved one.

Many times, these implants are taken out right in the hospital room. The treated area may be sore for some time, but most people get back to normal quickly.

### ***Systemic radiation therapy***

Systemic (sis-TEM-ick) radiation uses radioactive drugs to treat certain types of cancer. These drugs can be given by mouth or put into a vein (IV or intravenous) to kill the cancer cells.

### **Safety issues**

Because systemic radiation uses a radioactive liquid that goes through the whole body, some radiation will be in your loved one, making these fluids radioactive. They may need to stay in the hospital for a few days.

Your loved one's cancer care team will tell you what needs to be done to be safe until their body no longer contains radiation that might affect others. What you must do depends on the radioactive drug used. Be sure you understand what they need to do to protect the people around them.

## What about radiation side effects?

Some people have no side effects at all, while others do. Side effects depend on the part of the body being treated. For instance, if radiation is given to the head, there might be hair loss. Or if radiation is given to the chest, it might cause a cough or sore throat.

Most side effects go away in time. But there are ways to feel better. If your loved one has bad side effects, the doctor may stop their treatments for a while, change the schedule, or change the type of treatment they're getting. Tell your loved one's cancer care team about any side effects so they can help with them.

## Common radiation side effects

### *Fatigue*

Fatigue (fuh-TEEG) means feeling very tired. It can last for a long time and keep a person from doing the things they want and need to do. It's not like the fatigue a person feels at the end of a long, hard day. That kind gets better after a good night's sleep. The fatigue caused by cancer and/or cancer treatment is worse and causes more problems. Rest does not always make it go away.

Cancer fatigue is very common. By knowing about fatigue, one can cope with it better. No lab tests or x-rays can show fatigue or tell how bad it is. Only your loved one will know if they have fatigue and how bad it is.

If your loved one has fatigue, be sure to talk to the cancer care team about it. Fatigue can be described as mild, moderate, or severe. Or, a scale from 0 to 10 can be used. A 0 means no fatigue, and a 10 means the worst fatigue ever.

This weak or weary feeling will go away over time after treatment ends. Until then there are some things you can encourage your loved one to do to help reduce fatigue:

- Do the things that need to get done when they feel their best.
- Ask for help, and let people help.
- Put things that they use often within easy reach.
- Set up a daily routine.
- Try to relax to reduce stress. Many people feel better with deep breathing, prayer, talking with others, reading, listening to music, and painting, among other things.
- Balance rest and activity. They should not spend too much time in bed, which can make them weak. But they shouldn't let rest or daytime naps keep them from sleeping at night. A few short rest breaks are better than one long one.
- Talk to the cancer care team about how to keep pain and nausea – if these are a problem – under control.



- Depression can make a person feel more tired. Talk with the doctor about treatment if your loved one seems depressed. Some signs of depression include feeling sad or worthless, losing interest in life, thinking about death a lot, or if they're thinking about hurting themselves.
- Encourage the patient to get some exercise each day. Talk to the cancer care team before starting.
- They may be told to eat a special diet. If so, help prepare it. It's good to include protein (meat, milk, eggs, and beans). It's also good for your loved one to drink about 8 to 10 glasses of water a day.
- Let the cancer care team know about the fatigue and talk with them if:
  - It doesn't get better, keeps coming back, or gets worse.
  - The patient seems more tired than usual during or after an activity.
  - Their fatigue doesn't get better with rest or sleep.
  - They become confused or can't think.
  - The patient can't get out of bed for more than 24 hours.
  - They can't do the things they need or want to do.

### ***Skin changes***

Skin over the part of the body being treated may look red, swollen, blistered, sunburned, or tanned. After a few weeks, your loved one's skin may become dry, flaky, itchy, or it may peel. Be sure to let the cancer care team know about any skin changes. They can suggest ways to ease the discomfort, help keep it from getting worse, and try to prevent infection.

Most skin changes slowly go away after treatment ends. In some cases, though, the

treated skin will stay darker and might be more sensitive than it was before. Your loved one needs to be gentle with their skin. Here are some things you can remind them to do:

- Wear loose clothes made from soft, smooth fabrics.
- Do not rub, scrub, scratch, or use tape on treated skin. If their skin must be covered or bandaged, use paper tape or other tape for sensitive skin. Try to put the tape outside the treatment area, and don't put the tape in the same place each time.
- Do not put heat or cold (such as a heating pad, heat lamp, or ice pack) on the treated skin.
- Protect the treated area from the sun. It may be extra sensitive to sunlight. Protect the skin from the sun even after radiation therapy ends. Wear clothes that cover the skin, or use sunscreen with an SPF of at least 30.
- Use only lukewarm water and mild soap. Just let water run over the treated area. Do not rub. Also be careful not to rub away the ink marks needed for radiation therapy.
- Do not use a pre-shave or after-shave lotion or hair-removal products. Use an electric shaver to shave, but first check with your cancer care team.
- Ask the cancer care team before using anything on the skin in the treatment area. This includes powders, creams, perfumes, deodorants, body oils, ointments, lotions, or home remedies during treatment and for several weeks afterward.

### ***Eating problems***

Your loved one may not feel like eating during treatment. Eating may be more of a problem if radiation is given to the stomach or chest. Even if they don't feel like eating, they should try to eat foods high in protein and calories.

Patients who eat well can better handle cancer treatment and side effects. There are many recipe books for patients who need help with eating problems. The American Cancer Society has one book that's particularly useful called *What to Eat During Cancer Treatment, Second Edition*. Visit [cancer.org/bookstore](https://www.cancer.org/bookstore) to purchase the book.

If your loved one has trouble swallowing, tell their cancer care team. If they have pain when chewing and swallowing, they may be told to try a soft or liquid diet. Liquid nutrition drinks come in many flavors. They are available in grocery stores and drug stores, or they can be made at home. They can be mixed with other soft-textured foods (applesauce, gelatin, or soups) or added to milk shakes and smoothies.

Here are some tips to help when your loved one doesn't feel like eating:

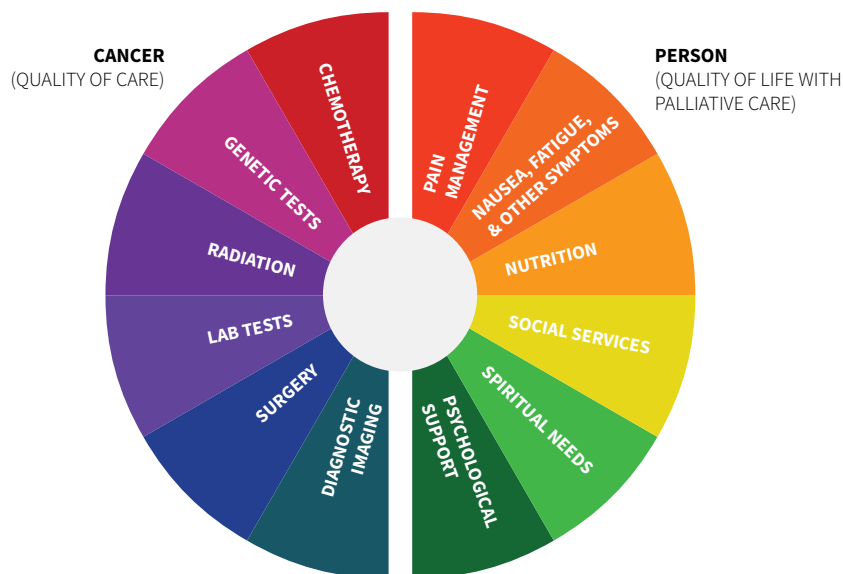
- Have them eat when they're hungry, even if it's not mealtime.
- Offer 5 or 6 small meals during the day rather than 2 or 3 large ones.

- Try to have them eat with family or friends, or turn on the TV or radio.
- If your loved one drinks alcohol, ask the cancer care team if it's OK during treatment. Ask if alcohol will affect any medicines they are taking.
- Keep healthy snacks close by.
- If others offer to cook, let them. Don't be shy about telling them what your loved one wants to eat.
- Add calories to their diet by having them drink milk shakes or liquid supplements, adding cream sauce or melted cheese to vegetables, and mixing canned cream soups with milk or half-and-half instead of water.

See *Treatments and Side Effects* on [cancer.org](https://www.cancer.org) for more detailed information about radiation, its side effects, and specific questions to ask the doctor.

Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch a video on Managing Your Loved One's Medications, Pain, and Treatment Side Effects.

## PALLIATIVE CARE: TREATING THE PERSON, NOT JUST THE DISEASE



## WHAT IS PALLIATIVE CARE?

Palliative care is care for adults and children with serious illness that focuses on relieving suffering and improving quality of life for patients and their families. It is not intended to cure the disease itself. Palliative care focuses on helping people get relief from symptoms caused by cancer – things like nausea, pain, fatigue, or shortness of breath. Palliative care looks to help with emotional and spiritual problems, too.

In the past, the term palliative care was mainly used to describe the act of promoting comfort when aggressive treatment was no longer working – the care given at the end of life. Today, palliative or supportive care is used to describe treatment given throughout the cancer experience, whenever the person is having symptoms that need to be controlled.

No matter what it's called, palliative or supportive care has long been recognized as an important part of cancer treatment. For decades it was simply considered to be part of cancer treatment. But more recently, it's getting much more attention and study. It has grown into a specialized field of knowledge, as well as being a standard part of care given by doctors and cancer care teams.

### Who should get palliative care and when?

Any person diagnosed with a serious illness who is having symptoms should get palliative care. People with complex medical problems, such as someone with heart failure, diabetes, and cancer, should get palliative care.

This supportive care should be available from the time of diagnosis until it's no longer needed – at any stage and in any care setting.

### Who delivers palliative care?

Palliative care is most often begun by the cancer care team, and referrals to or visits with palliative care specialists may happen later.

The oncologist (cancer doctor), oncology nurse, and other members of the cancer care team usually treat and help manage symptoms. For instance, they may prescribe medicines to help control or prevent nausea and vomiting or to help relieve pain. Oxygen and other measures may be used to help with breathing problems. All of these treatments are palliative care.

Palliative care can also be given by a team of doctors, nurses, and other specialists who work with the oncologist to help treat symptoms. This option may be considered for people with symptoms that are hard to manage (like severe pain), family distress, or complex medical problems. In this case, the doctor might ask a palliative care team to see the patient.

The palliative care team typically includes a palliative care doctor (who may be board-certified in hospice and palliative medicine), a palliative care nurse, a social worker, a patient navigator, and maybe a person with a spiritual role such as a pastoral counselor or chaplain. Many hospitals and oncology clinics have these teams as part of the services they provide. They can send the team to patients in intensive care units, emergency rooms, or hospital wards to talk with the patient and family and help with palliative care.

Even though the palliative care team is often based in a hospital or clinic, it's becoming more common in the outpatient setting. And most of the actual care happens at home.

At home, medicines may be taken and other methods may be used as prescribed by the team, or the patient may need help from family members and loved ones. The team provides education and support to the patient as well as to their caregiver.

## WHAT HAPPENS WHEN TREATMENT ENDS?

After treatment most patients go into a stage of healing and recovery. Less time is spent in the clinic, and your loved one sees the cancer care team less often. Patient stress may go down, but caregiver stress may not. Day-to-day care for and monitoring of the patient continues to be your job as the caregiver, and not seeing the cancer care team as often may leave you feeling alone and without back-up or support. The caregiver plays a key role during this time, and there can be many responsibilities.

Ask the doctor these kinds of questions, and write down the answers for later:

- What kind of follow-up visits are needed? How often and for how long?
- Are there any symptoms we should let you know about? Whom should we call for other problems?
- When will the patient be able to go back to a regular work schedule (if they have been off work or working fewer hours)?
- How will we know if the cancer has come back?

After treatment is over, be sure that your loved one has copies of their medical information. Some people collect this information as they go through treatment instead of waiting until the end. Either way, once all of this information is collected, be sure to keep

copies for the patient. These records are important in the event that questions come up later, the patient needs to see a different doctor in the future, or the cancer comes back.

Ideally, patients will receive an individualized survivorship care plan from their doctor that includes guidelines for monitoring and maintaining their health. Many groups have developed various types of care plans to help improve the quality of care of patients as they move beyond their cancer treatment. Visit [cancer.org/survivorshipcareplans](https://www.cancer.org/survivorshipcareplans) to see a sample of these plans.

### When can the patient go back to normal activities?

In most cases, your loved one can slowly increase their activities at home. How quickly they can do this will depend on their physical condition and the type of cancer treatment they had. Still, with patience and time, most people can get back to their “normal” lives after cancer treatment.

It’s possible that potentially lifesaving treatments may have affected the patient in ways that won’t ever go away. For some people, long-term effects mean permanent life changes, so that they can’t go back to the life they had before treatment. It’s normal for the patient and sometimes loved ones to

***With patience and time, most people can get back to their “normal” lives after cancer treatment.***



grieve whatever might have been lost due to treatment. Accepting these losses can take time for both you and the patient.

As the caregiver, you may find yourself continuing to do the things you did when the patient was in treatment. But it's important that, over time, you let the patient go back to doing the things they can and should do on their own. This may take place over a period of months as the patient gets stronger.

Check in every week or so to see what you're doing that the patient can start doing, either alone or with a little help. If there are things that the patient can't quite do, talk with the doctor about a referral to a physical therapist or occupational therapist. These professionals may be able to maximize your loved one's abilities by helping build muscle strength and/or offering assistive devices.

### **WHAT IF TREATMENT DOESN'T STOP?**

Sometimes treatment doesn't end at the expected time. For some patients, cancer is treated as a chronic illness – a disease that they live with and manage on a day-to-day basis, much like diabetes or heart disease.

This can be a very demanding situation for a caregiver. You're helping your loved one as they get treatment, so there are ongoing side effects and frequent appointments to deal with. The difference is that in this case, you don't really know how long it will last. Living with this uncertainty can be an extra challenge.

Some patients are able to go back to work during long-term treatment, though they may need extra help just after treatments. They may also need help with home responsibilities, family, and bills. In other cases, less frequent chemo treatments and better management of side effects mean that the caregiver can work a more normal schedule. In some cases, both you and the patient go back to outside jobs. Still, chemo or other treatments usually mean that some schedule changes will be needed.

Even if everyone goes back to their jobs, someone will still need to keep up with the treatment plan, the medical records, and the bills. This can be demanding for you and your loved one. You may both need support with the amount of work that's needed on top of working and dealing with cancer. And



emotional support may be needed to help you, the patient, and other family members cope with knowing that the cancer cannot be cured.

### WHAT IF THE CANCER COMES BACK?

In some cases, the cancer may seem to be gone and then it comes back (recurs) and treatment will start again. The person with cancer may or may not react in the same way they did the first time. Again, communication is key. Many people are quite upset when they learn the cancer is back. They may feel they don't have the emotional or physical reserves to fight again. Others seem to accept a recurrence more easily. They may have expected it, or are simply ready, for whatever reasons, to fight again. By equipping yourself with the knowledge of how best to talk to your loved one, you can be most helpful to them.

Research has shown that caregivers sometimes experience higher levels of fear of the cancer returning than the patients themselves. Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch a video on Fear of Recurrence to learn about tips for coping with this feeling.

### WHEN TREATMENT STOPS HELPING – WHAT THEN?

If treatment is no longer helping and the cancer is still growing, your loved one may decide to stop treatment and choose care to help them cope with symptoms. This is a time when it helps to know what's most important to your loved one. What makes their life worth living? It helps if the patient can put this into words and share it with others who are close to them.

The patient will have to decide things like, “When do I stop trying to beat the cancer and

enjoy the rest of my life?” or “Would I rather spend the next 2 months spending time with my grandchildren or dealing with side effects?” Knowing what's most important to the patient helps the caregiver and family members understand these decisions.

Sometimes caregivers can help patients clarify their highest priorities so that they can focus on them before the chance is lost. Other times it may take someone on the cancer care team or a mental health professional to help the patient figure out what's most important to them, and what can be expected from further treatment. This is a difficult time for everyone, and help from the cancer care team may be needed to fully understand the situation and figure out what's best for the patient.

### WHAT DO I DO IF THE PATIENT DECIDES TO STOP CANCER TREATMENT?

There are times when you and the person with cancer will not agree on decisions that are made. One of those times may be when they decide that treatment aimed at fighting the cancer is no longer worth the physical and emotional cost. They want to let the disease run its course. You may feel like they're giving up, and that can be very upsetting and frustrating. You may feel sad or angry that they have decided not to seek further treatment. This is not the outcome either of you hoped for. You are both upset.

Once the decision to stop curative treatment (treatment aimed at producing a cure) has been made, make sure that other family members and loved ones understand and can support your loved one's decision. It's important that you all give each other the right to feel the way you do. Try to understand

that the patient is tired of getting treatment and tired of feeling sick without seeing any clear benefits. It may be time for a family meeting where questions can be answered and concerns addressed. Be sure that other day-to-day caregivers are invited, if they're still involved in the patient's care. You may need extra help from others at this point since there's often more work for the caregiver as the end of life nears.

It's also time to talk with the doctor about focusing on palliative (comfort) care. Many things can be done to deal with symptoms of cancer, such as pain, trouble breathing, and fatigue. When these symptoms are helped, the patient often has more energy to spend time doing those things that mean the most to them. You'll want to be in close contact with the doctor to be sure that any new symptoms are quickly addressed. We have caregiver-specific information about what to expect toward the end of life, including various emotions you'll experience. See *Nearing the End of Life* on [cancer.org](https://www.cancer.org) for this information.

If your loved one is expected to live only a few months, hospice may be a good option. Hospice care is intended to relieve discomfort and make the patient better able to enjoy the time they have. In most cases, hospice care is given at home and requires that the patient have a primary caregiver. See *Hospice Care*

on [cancer.org](https://www.cancer.org) for more information on hospice and how it works.

If there are children in the family, it's important for them to understand what's going on. See *Helping Children When a Family Member Has Cancer* on [cancer.org](https://www.cancer.org) for ideas on talking with children and teens.

As you work with your loved one and help make the most of the rest of their life, it's normal to feel sad and even start to grieve. But once you stop and think about it, you may decide to let go of your wish for more time with this person and focus, instead, on the quality of time that you have left. This is probably best for both of you. You might even have to talk about how the two of you will "agree to disagree" but still love and care about each other.

You'll want to continue with your circle of support and any spiritual outlets you have. A support group or mental health professional may also help as you go through this time. See *Coping With the Loss of a Loved One* on [cancer.org](https://www.cancer.org) to find out more.

## IF YOUR LOVED ONE REFUSES CANCER TREATMENT

There are people who choose not to get any cancer treatment. This can be very hard for family and friends who may not agree with this choice. But for the most part, people who are able to make decisions for themselves have the right to refuse any and all treatment.

As someone who cares about and supports the person with cancer, you may wonder why they would make this choice. Maybe the person has health problems that make cancer treatment harder or more risky. Maybe they feel that with their age and life history, it's just "their time."



*Even after a person refuses cancer treatment, it's important to make sure they fully understand their options.*

Sometimes the person's religious beliefs come into play. There are many reasons why people choose not to get cancer treatment.

It's OK to ask your loved one about their reasons for refusing cancer treatment. Even though the answer may be hard to hear, the choice to refuse treatment is the patient's – no one else's. Often, the reasons make sense and give you a better idea of what's going on. It's also OK to tell the patient what you think. You may say something like, "I hadn't thought about it that way, and I'm glad you shared your point of view with me." Or, "I wish you would talk to a doctor about treatment options, but I'll support your choice and help you through this time the best that I can."

Even after a person refuses cancer treatment, it's important to make sure they fully understand their options. You may want to ask your loved one to talk with a doctor about the decision and whether any treatments might help. Some patients will agree to talk with a doctor, and others won't. But don't be surprised if, after talking with a doctor, your loved one still refuses treatment. Again, they have the right to make their own choices, just as you have the right to feel the way you do. Try to see it from their point of view, and continue to offer your love and support.

Supportive care can help anyone with cancer – even those who are sure that they don't want treatment for the cancer itself. Sometimes called palliative care, supportive care helps keep people with cancer from having severe pain, nausea, or other symptoms. It's care that aims to treat symptoms, not cancer. It helps the person feel as good as possible for as long as possible.

The person who refuses cancer care may be open to hospice care. Hospice workers give palliative or supportive care so that symptoms can be controlled as the cancer runs its course. They also try to help the family and the patient make the most of the time they have left. A patient who is able to make their own decisions may choose to refuse this care, too. This can be hard on the family and loved ones, watching the person suffer while knowing that supportive care could ease the pain and other symptoms. If this happens, loved ones usually do the best they can, but should keep offering hospice and palliative care as an option. This care will be needed even more as the patient's condition gets worse; the time may come when the family and loved ones cannot manage without help.

#### HOW DOES HOSPICE CARE HELP?



Patients receiving hospice care live 29 days longer on average.



A patient's pain level is brought to a comfortable level within 48 hours of initial assessment.



Patients enrolled in hospice care report higher quality of life than those not in a hospice program.



## ADVANCE DIRECTIVES AND LIVING WILLS

This section covers the basics about advance directives and living wills. See *Advance Directives* on [cancer.org](https://www.cancer.org) or call 1-800-227-2345 to learn more about these and other agreements that cover health care wishes.

### WHAT'S AN ADVANCE DIRECTIVE?

An advance health care directive or advance directive is a kind of legal document that details a person's wishes about their health care for their doctor and their loved ones.

Advance directives can be general, with very few directions about care. For instance, it may just name a substitute person (proxy) to make health decisions if the patient becomes unable to do so. Or it may include instructions for the chosen proxy.

Advance directives can also be very detailed and clearly outline the different types of potentially life-sustaining treatments the patient would accept or refuse in certain situations. Some types of advance directives

are limited to certain situations, like the living will, organ or tissue donation, or their wishes not to be revived (resuscitated) if their heart or breathing stops.

No matter which kind of advance directive is used, no one will be able to control a patient's money or other property based on their advance directive.

### WHAT'S A LIVING WILL?

The living will is a formal legal document designed to control certain future health care decisions only when a person becomes unable to make decisions and choices on their own. The person must also have a terminal illness (they cannot be cured) or permanent unconsciousness (often called a "persistent vegetative state").

The living will describes the type of medical treatment the person would – or would not – want in these situations. It can describe under what conditions an attempt to prolong life should be started or stopped. This applies to treatments such as dialysis, tube feedings, or artificial life support (such as the use of breathing machines).

Some state laws include a model form for a living will. For most states the model form is optional, but others require that their form be used. Most laws say that the document must be witnessed and notarized. Usually, the witnesses cannot be spouses, potential heirs, doctors caring for the patient, or employees of the patient's health care facility.

A living will can be revoked (ended or taken back) at any time. It's important to know that a few states automatically void a living will after a certain number of years. Check out your state laws so you know if and, if so, how often a living will must be reviewed.

### **WHY IS AN ADVANCE DIRECTIVE NEEDED?**

Advance health care directives (also called advance directives) are a way for your loved one to give consent for certain situations where they might – or might not – want treatment. They can also be used to appoint someone to make decisions if your loved one can't do so for themselves. An advance directive gives them a better chance of having their wishes carried out, even if they can't talk to the doctors about what they want.

An advance directive will not affect the type or quality of care while they can voice their own decisions. It only comes into play when they can't.

### **CAN MY LOVED ONE HAVE BOTH A LIVING WILL AND A POWER OF ATTORNEY FOR HEALTH CARE?**

Yes. Your loved one can have a living will and a durable power of attorney for health care at the same time. In most cases, they can also provide extra instructions in another type of advance directive for situations not covered by the living will.

If your loved one has more than one kind of advance directive, be sure that the person named as their proxy has copies of their living will and any other advance directive.

The proxy must clearly understand what your loved one wants. It's also very important to be sure that these documents don't conflict with each other, so that there will be no confusion about their wishes if they can't speak for themselves. It's important to check your loved one's state's requirements to find out what's legally accepted in their state.

## **FACING THE END OF LIFE**

Some people have cancer that no longer responds to treatment and must face the fact that they will soon die. This is scary for the person who is sick and for those around them. Your loved one may be in pain, may be bedridden, may be able to walk only a few steps, or may be confused. It's hard to watch someone you love go through this process of decline.



## BEING THERE

No matter how hard it may be, it's still important to try to be there for your loved one. They may feel lonely even if there are people around. This is because the people nearby may not be really in tune with what's going on with the person. You can be the one who is in sync with your loved one every step of the way. Just by staying close and listening with a smile or gentle touch, you show you are there. It takes courage and extra energy to do this.

Sometimes the person with advanced cancer may pull away from people and seem to be withdrawing as death nears. This is natural and is one way of disconnecting from life. This process and what you might expect at this time is described in our information called *Nearing the End of Life* on [cancer.org](https://www.cancer.org). The best thing you can do at this time is take the person's cue – simply stay in the background and be available. Try not to take this withdrawal personally or feel hurt when the person pulls away. It likely has nothing to do with you.

## TALKING ABOUT DEATH AND DYING

Many people worry about what to say when a person talks about dying. But this is a common topic when facing cancer. Your loved one may want to talk about the dying process; they want to know what to expect. Some patients want to make sure that their wishes are followed when it comes to death; they want to be sure that machines are not used to keep them alive. Some want to know how they will die, and ask, "What will happen when I'm actually dying?" For answers to these questions and concerns, it helps to find experts in hospice care or care of the terminally ill. If you don't know the answers to specific questions, you can say, "I don't know, but we can call some

*No matter how hard it may be, it's still important to try to be there for your loved one.*

people who can help us with those answers." These professionals can guide you and your loved one by explaining the things that might happen as death gets closer.

Hospice staff members are used to answering these questions, and they are skilled in doing it in a supportive, caring way. Hospice gives expert, compassionate care for people with advanced disease. See *Nearing the End of Life* and *Hospice Care* on [cancer.org](https://www.cancer.org) if you would like to read more about end-of-life issues or hospice care.

You may be asked, "Why is this happening to me?" It's very hard to hear this question because there is no answer. And it's heart wrenching to feel the pain that lies within questions like this. In most cases, the simple answer is "I don't know." Holding your loved one's hand and letting them cry or talk about their sadness and regrets is the best you can do. Allowing a person to do this is a true help because many people avoid the subject of dying and won't allow themselves to share this pain.

Some people who know they're going to die feel the need to get some things off their chests. They may want to talk about some of the things they did in their life that they're not proud of or that they regret. They may want



to apologize for these things. They may want to give you advice about the lessons they learned or instructions about what to do for them in the future. Respectfully listening and, of course, offering forgiveness and a loving attitude are often all that's necessary. There are no magic words for the dying person, but often your presence is all that's needed, and having an open heart is priceless.

Get support. Talk about your experience with the impending death of your loved one. Don't think you are protecting your family and friends by not expressing your sadness. Ask others for what you need. Find and talk to others who have lost a loved one. Talk to the cancer care team if you need help. They can help you find resources to deal with this phase of caregiving. As with all other aspects of caring for your loved one, don't try to get through this difficult time on your own.

*You may be asked, “Why is this happening to me?” It’s very hard to hear this question because there is no answer.*

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.



# Patient Nutrition

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## NUTRITION DURING AND AFTER TREATMENT

You may find it frustrating and difficult to try to meet the nutritional needs of someone who may not want to eat at all or whose likes and dislikes may change on a daily basis. When your loved one does not feel like eating, it's important to be patient and encouraging.

Many times, 5 or 6 small meals a day may work better than 3 large meals. Don't worry if the person's diet is not as balanced as you would like; try to have good days make up for not-so-great days. Foods may not taste "normal" to someone going through cancer treatment, so don't be offended if old favorites aren't successful. If your loved one's tastes seem to have changed, encourage trying new foods. If an old favorite is not appealing, perhaps a new food will be surprisingly well received. Keep the fridge, freezer, and pantry stocked with easy-to-prepare convenience foods. Put together a basket or cooler full of snacks your loved one can keep handy to nibble on when the urge strikes.

Here are some tips that you may find helpful:

- Prepare the biggest meal of the day when they feel the hungriest. This is often in the morning.
- Offer favorite foods anytime during the day. It's OK to have a sandwich or bowl of soup for breakfast or have breakfast food anytime.
- Casseroles containing pasta, rice, and potatoes tend to be well tolerated. Many favorite casserole recipes can be easily altered to increase the amount of calories and protein they contain.
- Consider adding finely chopped meats, cheese, or hard-boiled eggs to soups, sauces, or casseroles for extra calories and protein.
- Spicy, greasy, or heavy foods may not be well tolerated on an unsettled stomach.
- Add sauces, broths, or cheese to foods to enhance flavor and make food easier to swallow.
- Package food in single-serving containers for convenient use later; large servings can seem overwhelming when the appetite is poor.

- If your loved one is sensitive to smells, prepare meals in a different room from where they'll be eaten. Consider grilling outdoors or using a slow cooker on the back porch or in the garage to keep the aroma of food from filling the house. Suggest that the person go to another room or to the opposite side of the house while food is being prepared. Serving foods cool or at room temperature also helps to lessen smells.
- Drinking is often easier than eating. If the patient does not feel like eating but is willing to drink, offer sips of hot cocoa, milk, milk shakes, smoothies, soups, and canned nutritional supplements. Soups can be sipped out of mugs, too.

Cancer treatment may reduce the person's ability to fight off infections. Keep these tips in mind when preparing food:

- Wash your hands before and after preparing meals.
- Meat, fish, poultry, and eggs should be thoroughly cooked.
- To avoid cross contamination, use different cutting boards for meats and vegetables and use a clean knife when cutting different foods.
- Check expiration dates on packaged food. If you're unsure about an item's freshness or its expiration date, don't use it.
- Wash all fruits and vegetables under cold running water before peeling or cutting, and avoid bruised or damaged produce.
- Keep hot foods hot and cold foods cold. Refrigerate leftovers within 2 hours of serving.
- Discard refrigerated leftovers after 3 days.
- Avoid foods from buffet lines and self-serve bulk bins.

- If your loved one is at a high risk for infection, ask the nurse for specific nutrition guidelines.

*Adapted from What to Eat During Cancer Treatment, Second Edition (©2019, American Cancer Society: [cancer.org/bookstore](https://cancer.org/bookstore))*

Nutrition is an important part of cancer treatment. Eating the right kinds of foods before, during, and after treatment can help your loved one feel better and stay stronger. If you have any questions or concerns, you should talk to a doctor, nurse, or dietitian about your loved one's nutritional needs. A registered dietitian can be one of your best sources of information about diet. If you're going to meet with a dietitian, be sure to write down your questions before your meeting so you won't forget anything. And be sure to ask them to repeat or explain anything that's not clear.

You can find more on nutrition before, during, and after cancer treatment in our book called *American Cancer Society Complete Guide to Nutrition for Cancer Survivors: Eating Well, Staying Well During and After Cancer*. Call us at 1-800-227-2345 or visit our bookstore online at [cancer.org/bookstore](https://cancer.org/bookstore) to find out about costs or to place an order.

Visit [cancer.org/caregivervideos](https://cancer.org/caregivervideos) to watch a video on Managing Your Loved One's Medications, Pain, and Treatment Side Effects.

## Benefits of good nutrition during cancer treatment

Good nutrition is especially important for people who have cancer because both the illness and its treatments can change the way they eat. Cancer and cancer treatments can also affect the way the body tolerates certain foods and uses nutrients.

LESS JUNK ...

MORE FRUITS  
AND VEGGIES



The nutrient needs of people with cancer vary from person to person. Your loved one's cancer care team can help identify the nutrition goals and plan ways to help you meet them. Eating well while being treated for cancer might help your loved one:

- Feel better.
- Keep up strength and energy.
- Maintain weight and the body's store of nutrients.
- Better tolerate treatment-related side effects.
- Lower risk of infection.
- Heal and recover faster.

## ONCE TREATMENT STARTS

### Eat well

Your loved one's body needs a healthy diet to function at its best. This is even more important when a person has cancer. With a healthy diet, your loved one will go into treatment with reserves to help keep up their strength, prevent body tissue from breaking down, rebuild tissue, and maintain their defenses against infection. People who eat well are better able to cope with side effects of treatment. And they may even be able to handle higher doses of certain

drugs. In fact, some cancer treatments work better in people who are well-nourished and are getting enough calories and protein.

### Try these tips:

- Try new foods. Some things your loved one may never have liked before may taste good during treatment.
- Choose different plant-based foods. Try beans and peas instead of meat at a few meals each week.
- Aim for a variety of fruits and vegetables a day, including citrus fruits and dark-green and deep-yellow vegetables. Colorful vegetables and fruits and plant-based foods contain many natural health-promoting substances.
- Limit high-fat foods, especially those from animal sources. Choose lower-fat milk and dairy products. Reduce the amount of fat in meals by choosing a lower-fat cooking method like baking or broiling.
- Try to help the patient stay at a healthy weight and stay physically active. Small weight changes during treatment are normal.
- Limit the amount of salt-cured, smoked, and pickled foods.

If your loved one can't do any of the above during this time, don't worry about it. Help is available if or when they need it. Sometimes diet changes are needed to get the extra fluids, protein, and calories needed. Tell their cancer care team about any problems they have.

Also talk to the cancer care team about food restrictions that should be followed. While not needed in every case, these can be an important part of cancer treatment.

### Snack as needed

During cancer treatment the body often needs extra calories and protein to help maintain weight and heal as quickly as possible. If your loved one is losing weight, snacks can help them meet those needs, keep up their strength and energy level, and help them feel better. During treatment they may have to rely on snacks that are less healthy sources of calories to meet their needs. Keep in mind that this is just for a short while; once side effects go away they can return to a healthier diet. Try these tips to make it easier to add snacks to your loved one's daily routine:

- Encourage them to eat small snacks throughout the day.
- Keep a variety of protein-rich snacks on hand that are easy to prepare and eat. These include yogurt, cereal and milk, half a sandwich, a bowl of hearty soup, and cheese and crackers.
- Avoid snacks that may make any treatment-related side effects worse. If they have diarrhea, for example, avoid popcorn and raw fruits and vegetables. If they have a sore throat, do not offer dry, coarse snacks or acidic foods.

If the patient is able to eat normally and maintain their weight without snacks, then don't include them.



## HEALTHY PROTEIN AND LOW-CALORIE MEALS

Snacks that can help keep strength and energy levels up



Small sandwiches (egg salad, grilled cheese, or peanut butter)

Soups (broth based or hearty)



Homemade milk shakes and smoothies

Nuts, seeds, and nut butters



Small meals daily instead of 3 big meals can help cancer patients get through treatments.

## Tips to get more calories and protein

Your loved one can:

- Eat several small snacks throughout the day, rather than 3 large meals.
- Eat their favorite foods anytime during the day. For instance, eat breakfast foods for dinner if they appeal to them.
- Eat every few hours. Don't wait until they feel hungry.
- Eat the biggest meal when they feel hungriest. For example, if they are most hungry in the morning, make breakfast their biggest meal.
- Try to eat high-calorie, high-protein foods at each meal and snack.
- Exercise lightly or take a walk before meals to increase their appetite.
- Drink high-calorie, high-protein beverages like milk shakes and canned liquid supplements.
- Drink most of their fluids between meals instead of with meals. Drinking fluid with meals can make them feel too full.
- Try homemade or commercially prepared nutrition bars and puddings.

## Some quick-and-easy snacks

- Angel food cake
- Cereal (hot or cold)
- Cheese (aged or hard cheese, cottage cheese, cream cheese, and more)
- Cookies
- Crackers
- Dips made with cheese, beans, yogurt, or peanut butter
- Eggnog (pasteurized)
- Fruit (fresh, frozen, canned, dried)
- Gelatin made with juice, milk, or fruit
- Granola or trail mix
- Homemade milk shakes and smoothies
- Ice cream, sherbet, and frozen yogurt
- Juices
- Microwave snacks
- Milk by itself, flavored, or with instant breakfast powder
- Muffins
- Nuts, seeds, and nut butters
- Popcorn, pretzels
- Puddings, custards
- Sandwiches such as egg salad, grilled cheese, or peanut butter
- Soups (broth based or hearty)
- Sports drinks
- Vegetables (raw or cooked) with olive oil, dressing, or sauce
- Yogurt (low fat or Greek)



## High-protein foods\*

### Beans, legumes, nuts, and seeds

- Sprinkle seeds or nuts on desserts like fruit, ice cream, pudding, and custard. Also serve on vegetables, salads, and pasta.
- Spread peanut or almond butter on toast and fruit or blend in a milk shake.

### Eggs

- Keep hard-boiled eggs in the refrigerator. Chop and add to salads, casseroles, soups, and vegetables. Make a quick egg salad.
- All eggs should be well-cooked to avoid the risk of harmful bacteria.
- Pasteurized egg substitute is a low-fat alternative to regular eggs.

### Meats, poultry, and fish

- Add cooked meats to soups, casseroles, salads, and omelets.
- Mix diced or flaked cooked meat with sour cream and spices to make dip.

### Milk products

- Eat cheese on toast or with crackers.
- Add grated cheese to baked potatoes, vegetables, soups, noodles, meat, and fruit.
- Use milk in place of water for hot cereal and soups.
- Include cream or cheese sauces on vegetables and pasta.
- Add powdered milk to cream soups, mashed potatoes, puddings, and casseroles.
- Add Greek yogurt, powdered whey protein, or cottage cheese to favorite fruits or blended smoothies.

## High-calorie foods\*

### Butter

- Melt over potatoes, rice, pasta, and cooked vegetables.
- Stir melted butter into soups and casseroles and spread on bread before adding other ingredients to a sandwich.

### Milk products

- Add whipping or heavy cream to desserts, pancakes, waffles, fruit, and hot chocolate; fold it into soups and casseroles.
- Add sour cream to baked potatoes and vegetables.

### Salad dressings

- Use regular (not low-fat or diet) mayonnaise and salad dressing on sandwiches and as dips with vegetables and fruit.

### Sweets

- Add jelly and honey to bread and crackers.
- Add jam to fruit.
- Use ice cream as a topping on cake.

\*Adapted from Eldridge B, and Hamilton KK, Editors, Management of Nutrition Impact Symptoms in Cancer and Educational Handouts. Chicago, IL: American Dietetic Association; 2004.

### **Don't forget about physical activity**

Physical activity has many benefits. It helps maintain muscle mass, strength, stamina, and bone strength. It can help reduce depression, stress, fatigue, nausea, and constipation. It can also improve your loved one's appetite. If they don't already exercise, encourage them to talk to their doctor about aiming for at least 150 minutes of moderate activity, like walking, each week. If the doctor approves, start small (maybe 5 to 10 minutes each day), and as they are able, work up to the goal of 150 minutes a week. The patient should listen to their body, and rest when they need to. Now is not the time to push themselves to exercise. They should do what they can when they're up to it.

### **Manage eating problems caused by surgery, radiation, and chemotherapy**

Different cancer treatments can cause different kinds of problems that may make it hard to eat or drink. Here are some tips on how to manage nutrition problems depending on the type of treatment your loved one receives:

#### ***Surgery***

After surgery, the body needs extra calories and protein for wound healing and recovery. This is when many people have pain and feel tired. They also may be unable to eat a normal diet because of surgery-related side effects. The body's ability to use nutrients may also be changed by surgery that involves any part of the digestive tract (like the mouth, esophagus, stomach, small intestine, pancreas, colon, or rectum). Be sure to talk to your loved one's cancer care team about any problems they're having so they can help manage them.

#### ***Chemotherapy***

Chemotherapy (chemo) side effects depend on what kind of chemo drugs your loved one takes and how they take them. See *How to cope with common eating problems* on [cancer.org](https://www.cancer.org), which covers many of the common side effects of chemo that can cause eating problems.

Most people get chemo at an outpatient center. It may take anywhere from a few minutes to many hours. Make sure your loved one eats something beforehand. Most people find that a light meal or snack an hour or so before chemo works best. If they'll be there several hours, plan ahead and bring a small meal or snack in an insulated bag or cooler. Find out if there's a refrigerator or microwave available to use.

Some side effects of chemo go away within hours of getting treatment. If side effects last longer, tell the cancer care team. There are things that can be done to lessen eating-related side effects. Prompt attention to eating-related side effects can help keep up your loved one's weight and energy level and help them feel better.

If they're having trouble eating and have been following a special eating plan for diabetes or some other chronic health condition, talk to the cancer care team about how best to change eating habits while they're getting chemo.



## Radiation therapy

The type of side effects radiation causes depends on the area of the body being treated, the size of the area being treated, the type and total dose of radiation, and the number of treatments.

The following chart shows possible eating-related side effects of radiation, according to the part of body being treated. Some of these side effects happen during treatment while others may not happen until after treatment.

Side effects usually start around the second or third week of treatment and peak about two-thirds of the way through treatment.

After radiation ends, most side effects last 3 or 4 weeks, but some may last much longer.

If your loved one has trouble eating and has been following a special eating plan for diabetes or some other chronic health condition, some of these general tips may not work. Talk to the cancer care team about how best to change eating habits while they're getting radiation.

Tell the cancer care team about any side effects your loved one has so they can prescribe any needed medicines. For example, there are medicines to control nausea and vomiting and to treat diarrhea.

PART OF BODY BEING TREATED	EATING-RELATED SIDE EFFECTS THAT MIGHT HAPPEN	
	DURING TREATMENT	MORE THAN 90 DAYS AFTER TREATMENT
Brain, spinal column	Nausea, vomiting	Headache, tiredness
Head or neck: tongue, voice box, tonsils, salivary glands, nasal cavity, pharynx (throat)	Sore mouth, hard to swallow or pain with swallowing, change in taste or loss of taste, sore throat, dry mouth, thick saliva	Dry mouth, damage to jaw bone, lockjaw, changes in taste and smell
Chest: lungs, esophagus, breast	Trouble swallowing, heartburn, tiredness, loss of appetite	Narrowing of the esophagus, chest pain with activity, enlarged heart, inflammation of the pericardium (the membrane around the heart), lung scarring or inflammation
Belly (abdomen): large or small intestine, prostate, cervix, uterus, rectum, pancreas	Loss of appetite, nausea, vomiting, diarrhea, gas, bloating, trouble with milk products, changes in urination, tiredness	Diarrhea, blood in urine, bladder irritation



If your loved one has eating-related side effects, see *How to cope with common eating problems* on [cancer.org](https://www.cancer.org) for tips on how to deal with them.

## NUTRITION AFTER TREATMENT ENDS

Most eating-related side effects of cancer treatments go away after treatment ends. Sometimes side effects like poor appetite, dry mouth, change in taste or smell, trouble swallowing, or weight changes last for some time. If this happens, talk to the cancer care team and work out a plan to help your loved one deal with the problem.

As your loved one begins to feel better, you may have questions about eating a healthy diet. Just as you wanted the patient to go into treatment with the best nutrient stores that their diet could give them, you'll want to do the best for them at this important time, too. Eating well will help your loved one regain their strength, rebuild tissue, and feel better overall.

Tips for healthy eating after cancer:

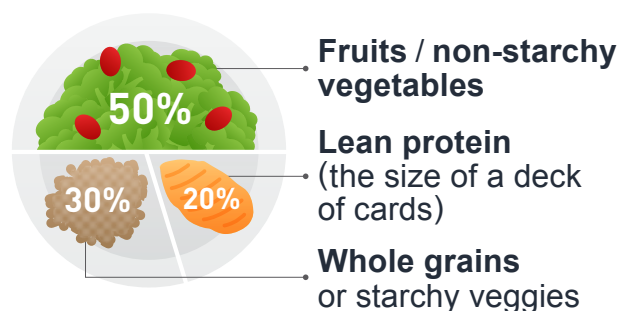
- Check with the cancer care team for any food or diet restrictions.
- Ask a dietitian to help you create a nutritious, balanced eating plan.

- Choose a variety of foods from all the food groups. Encourage your loved one to eat fruits and vegetables each day, including citrus fruits and dark-green and deep-yellow vegetables.
- Offer plenty of high-fiber foods, like whole-grain breads and cereals.
- Buy a new fruit, vegetable, low-fat food, or whole-grain product each time you shop for groceries.
- Decrease the amount of fat in meals by baking or broiling foods.
- Limit intake of red meat (beef, pork, or lamb) to no more than 3 to 4 servings a week.
- Avoid salt-cured, smoked, and pickled foods, including bacon, sausage, and deli meats.
- Choose low-fat milk and dairy products.
- If the patient chooses to drink alcohol, remind them to limit the amount to no more than 1 drink per day for women, and 2 for men. Alcohol is a known cancer-causing agent.

If your loved one is overweight, consider helping them lose weight by cutting calories and increasing activity. Choose activities that you both enjoy and get healthy with them. Be sure to check with the cancer care team before starting any exercise program.

## IF OVERWEIGHT,

### PAY ATTENTION TO PORTION SIZES.



### Nutrition and physical activity during and after treatment: Questions and answers

No single study is the last word on any subject. News reports may focus on what seem to be conflicting results because they are new or different, or they challenge conventional wisdom. And in brief news stories, reporters can't always put new research findings in their proper context.

In the questions and answers listed here, we have tried to address some common concerns that cancer caregivers have about diet and physical activity.

#### **Alcohol**

##### ***Should a person with cancer avoid alcohol during cancer treatment?***

The cancer type and stage (extent), as well as the type of treatment, should be taken into account when deciding whether to drink alcohol during treatment. Many of the drugs used to treat cancer are broken down by the liver, and alcohol, by causing liver inflammation, could impair drug breakdown and increase side effects. It's a good idea

for your loved one to drink only a little, if any alcohol during treatment to prevent interactions with the drugs used to treat cancer.

Alcohol, even in the small amounts used in mouthwashes, can irritate mouth sores and even make them worse. If your loved one has mouth sores, they may be advised to avoid or limit alcohol. It may also be best for them to avoid or limit alcohol if they are starting treatment that will put them at risk for mouth sores, such as head and neck radiation or many types of chemotherapy.

#### **Antioxidants**

##### ***Is it safe for patients to take antioxidant supplements during cancer treatment?***

Many dietary supplements contain levels of antioxidants (such as vitamins C and E) that are much higher than the recommended Dietary Reference Intakes for optimal health.

At this time, many cancer doctors advise against taking high doses of antioxidant supplements during chemotherapy or radiation. There's concern that the antioxidants might repair the damage to cancer cells that these cancer treatments cause, making the treatments less effective. But others have noted that the possible

***If your loved one is overweight, consider helping them lose weight by cutting calories and increasing activity.***

harm from antioxidants is only in theory. They believe that there may be a net benefit in helping to protect normal cells from damage caused by these cancer treatments.

Whether antioxidants or other supplements are helpful or harmful during chemotherapy or radiation treatment is a major question without a clear science-based answer. Until more evidence is available, it's best for patients getting these treatments to avoid dietary supplements except to treat a known deficiency of a certain nutrient, and to avoid supplements that give more than 100% of the Daily Value for antioxidants.

### **Organic foods**

#### ***Are foods labeled organic recommended for patients?***

The term “organic” is often used for foods grown without pesticides and genetic modifications (changes). It's also used for meat, poultry, eggs, and dairy products that come from animals that are not given antibiotics or growth hormones. The use of

the term organic on food labels is controlled by the US Department of Agriculture.

It's commonly thought that organic foods may be better for you because they reduce exposure to certain chemicals. It has also been suggested that their nutrient makeup may be better than non-organic foods. Whether this means health benefits for those who eat organic foods is unknown.

At this time, there are no studies in humans to show whether organic foods are better than other foods in terms of reducing the risk of cancer, the risk of cancer coming back, or the risk of cancer progression.

### **Physical activity**

#### ***Should patients exercise during cancer treatment and recovery?***

Research strongly suggests that exercise is not only safe during cancer treatment, but it can also improve physical functioning and many aspects of quality of life. Moderate exercise has been shown to improve fatigue (extreme tiredness), anxiety, and self-esteem. It also helps heart and blood vessel fitness, muscle strength, and body composition (how much of your body is made up of fat, bone, or muscle).

People getting chemotherapy and radiation who already exercise may need to do so at a lower intensity and build up more slowly than people who are not getting cancer treatment. The main goal should be to stay as active as possible and slowly increase the level of activity over time after treatment.



### Are there special precautions patients should consider?

Certain issues for patients may prevent or affect their ability to exercise. Some effects of treatment may increase the risk for exercise-related problems. For instance:

- People with severe anemia (low red blood cell counts) should delay activity until the anemia is better.
- Those with weak immune systems should avoid public gyms, pools, and other public places until their white blood cell counts return to safe levels.
- People getting radiation should avoid swimming pools because chlorine may irritate the skin at the treatment area.

If your loved one was not active before diagnosis, they should start with low-intensity activities and then slowly increase their activity level. Certain people should use extra caution to reduce their risk of falls and injuries:

- Older people
- Those with bone disease (cancer in the bones or thinning bones, such as osteoporosis)
- People with arthritis
- Anyone with nerve damage (peripheral neuropathy)

### Soy products

#### Should patients include soy-based foods in their diet?

Soy foods are an excellent source of protein and can be a good option for meals without meat. Soy contains many phytochemicals, some of which have weak estrogen activity and seem to protect against hormone-dependent cancers in animal studies. Other compounds in soy have antioxidant properties and may have anticancer effects.

There's a great deal of interest in the possible role of soy foods in reducing cancer risk, especially breast cancer risk. But the evidence at this time is mixed.

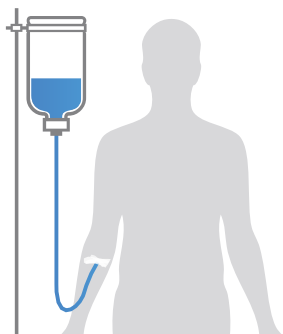
For the breast cancer patient, current research finds no harmful effects from eating soy foods. These foods may even help tamoxifen work better. There is less known about the effects of soy supplements.

### Sugar

#### Does sugar "feed" cancer?

No. Sugar intake has not been shown to directly increase the risk of getting cancer or having it get worse (progress). Still, sugars and sugar-sweetened drinks add large amounts of calories to the diet and can cause weight gain, which we know can affect cancer outcomes.

## AFTER TREATMENT, TRY LOW-INTENSITY ACTIVITIES



**150 MINUTES**  
moderate-intensity  
activity/week

(i.e., fast walking, aerobics class, tennis)

**THINGS TO AVOID:**  
public gyms and pools

(Those with weak immune systems)



There are many kinds of sugars, including honey, raw sugar, brown sugar, corn syrup, and molasses. Many drinks, such as soft drinks and fruit-flavored beverages, contain sugar. Most foods and drinks that are high in added sugar do not offer many nutrients and may replace more nutritious food choices. For this reason, limiting the intake of foods and drinks with added sugar is recommended.

### **Supplements**

#### ***Would patients benefit from using vitamin and mineral supplements?***

Your loved one should try to get the nutrients they need through food, not supplements. Dietary supplements should only be used when the doctor tells them to do so because of a deficiency of a certain nutrient. Vitamins or other supplements should not be used to get higher than recommended levels of nutrients; this may do more harm than good.

### **Vegetables and fruits**

#### ***Is there a difference in the nutritional value of fresh, frozen, and canned vegetables and fruits?***

Yes, but they can all be good choices. Fresh foods are usually thought to have the most nutritional value. But some frozen foods can

have more nutrients than fresh foods. This is because they're often picked ripe and quickly frozen, and nutrients can be lost in the time between harvesting and eating fresh foods.

Canning is more likely to reduce the heat-sensitive and water-soluble nutrients because of the high temperatures used in the canning process. Also, be aware that some fruits are packed in heavy syrup, which means a lot of sugar, and some canned vegetables are high in sodium.

It's best to choose different forms of vegetables and fruits.

#### ***Does cooking affect the nutritional value of vegetables?***

Cooking vegetables and fruits can help the body better absorb certain nutrients, like carotenoids (compounds that give vegetables and fruits their colors). Microwaving and steaming are the best ways to preserve the nutrients, while boiling, especially for a long time, can leach out the water-soluble vitamins.



***Should I juice vegetables and fruits for my loved one?***

Juicing can add variety to a diet and can be a good way to get vegetables and fruits, especially if your loved one has trouble chewing or swallowing. Juicing also helps the body absorb some of the nutrients in vegetables and fruits. But juices may be less filling than whole vegetables and fruits, and they contain less fiber. Drinking a lot of fruit juice can add extra calories to a person’s diet, too.

Buy juice products that are 100% vegetable or fruit juices and pasteurized to remove harmful germs. These are better for everyone, but are especially important for people who may have weak immune systems, such as those getting chemotherapy.

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.

**NOTES:**

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# Coping

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## Coping with Cancer

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## COPING WITH CANCER

Most patients, families, and caregivers face some degree of depression, anxiety, and fear when cancer becomes part of their lives. These feelings are normal responses to such a life-changing experience. Caregivers may have these feelings because they are afraid of losing their loved one. They may also feel angry because someone they love has cancer, frustrated that they cannot “do enough,” or stressed because they have to do more.

It’s important to remember that people can feel distress at any time after a cancer diagnosis and treatment, even many years after the cancer is treated. As health situations change, patients and caregivers must cope with new stressors along with the old, and their feelings often change, too.

People who have physical symptoms such as pain, nausea, or extreme tiredness (fatigue) also seem more likely to have emotional distress. Most of the time, these physical symptoms can be controlled with medicines, but it may take more than one try to find the right drug or combination of drugs. The cancer care team can help your loved one with these kinds of symptoms before they feel overwhelmed.

### COMMON EMOTIONS AFTER A CANCER DIAGNOSIS

#### Depression and the person with cancer

It’s normal to grieve over the changes that cancer brings to a person’s life. The future, which may have seemed so sure before, now becomes uncertain. But if a person has been sad for a long time or is having trouble carrying out day-to-day activities, they may have clinical depression. In fact, up to 1 in 4 people with cancer has clinical depression.

Clinical depression causes great distress, impairs functioning, and might even make the person with cancer less able to follow their cancer treatment plan. The good news is that clinical depression can be treated.

If the person you’re caring for has symptoms of clinical depression, encourage them to get help. There are many ways to treat clinical depression, including medicines, counseling, or a combination of both. Treatments can reduce suffering and improve quality of life.

### Symptoms of clinical depression

- Ongoing sad, hopeless, or “empty” mood for most of the day
- Loss of interest or pleasure in almost all activities most of the time
- Major weight loss (when not dieting) or weight gain
- Being slowed down or restless and agitated almost every day, enough for others to notice
- Extreme tiredness (fatigue) or loss of energy
- Trouble sleeping with early waking, sleeping too much, or not being able to sleep
- Trouble focusing thoughts, remembering, or making decisions
- Feeling guilty, worthless, or helpless
- Frequent thoughts of death or suicide (not just fear of death), suicide plans or attempts

Some of these symptoms, such as weight changes, fatigue, or even forgetfulness can be caused by the cancer itself and its treatment. But if 5 or more of these symptoms happen nearly every day for 2 weeks or more, or are severe enough to interfere with normal activities, it might be depression. If this is the case, encourage your loved one to be checked for clinical depression by a qualified health or mental health professional. If the person tries to hurt themselves, or has a plan to do so, get help right away.

#### DETECTING DEPRESSION IN LOVED ONES



Low energy



Dark or empty mood



Trouble focusing thoughts



### Things to do to help the clinically depressed person with cancer

- Encourage your loved one to continue treatment for depression until symptoms improve, or to talk to the doctor about different treatment if there’s no improvement after 2 or 3 weeks.
- Promote physical activity, especially mild exercise such as daily walks.
- Help make appointments for mental health treatment, if needed.
- Provide transportation for treatment, if needed.
- Engage the person in conversation and activities they enjoy.
- Remember that it’s OK to feel sad and grieve over the losses that cancer has brought to their life, and to yours.
- Realize that being pessimistic and thinking everything is hopeless are symptoms of depression and should get better with treatment.
- Reassure your loved one that with time and treatment, they will start to feel better – and although changes to the treatment plan are sometimes needed, it’s important to be patient.

If you suspect you may be depressed, see a doctor. Make time to get the help and support you need as a caregiver.

For ideas on how to manage your stress, check out [cancer.org/caregiver/videos](https://www.cancer.org/caregiver/videos) and watch a video on Stress Management and Coping.

### *Things not to do*

- Keep feelings inside.
- Force someone to talk when they're not ready.
- Blame yourself or another person for feeling depressed.
- Tell a person to cheer up if they seem depressed.
- Try to reason with a person whose depression appears severe. Instead, talk with the doctor about medicines and other kinds of help.

### **Anxiety, fear, and the person with cancer**

At different times during treatment and recovery, people with cancer may be fearful and anxious. Finding out that they have cancer or that the cancer has come back causes the most anxiety and fear. Fear of treatment, doctor visits, and tests might also cause apprehension (the feeling that something bad is going to happen).

It's normal to feel afraid when you're sick. People may be afraid of uncontrolled pain, dying, or what happens after death, including what might happen to loved ones. And, again, these same feelings may be experienced by family members and friends. Signs and symptoms of fear and anxiety include:

- Anxious facial expressions
- Uncontrolled worry
- Trouble solving problems and focusing thoughts
- Muscle tension (the person may also look tense or tight)
- Trembling or shaking
- Restlessness, may feel keyed up or on edge

- Dry mouth
- Irritability or angry outbursts (grouchy or short-tempered)

If your loved one has these symptoms most of the day, nearly every day, and they are interfering with their life, a mental health evaluation could be helpful. Keep in mind that sometimes, despite having all the symptoms, a person may deny having these feelings. But if your loved one is willing to admit that they feel distressed or uncomfortable, therapy can often help.

### *Things to do to help*

- Encourage, but do not force, your loved one to talk.
- Share feelings and fears that you or your loved one may be having.
- Listen carefully to their feelings. Offer support, but don't deny or discount feelings.
- Remember that it's OK to feel sad and frustrated.
- Get help through counseling and/or support groups.
- Use meditation, prayer, or other types of spiritual support if it helps.
- Encourage your loved one to try deep breathing and relaxation exercises. Starting with their toes and working up to their head, they should close their eyes, breathe deeply, focus on each body part and relax it. When relaxed they should try to think of a pleasant place such as a beach in the morning or a sunny field on a spring day.
- Encourage the person you're providing care for to talk with their doctor about using antianxiety or antidepressant medicines.

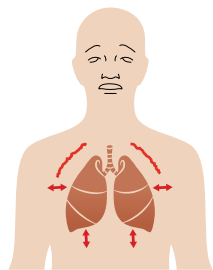
### Things not to do

- Keep feelings inside.
- Force someone to talk if they're not ready to.
- Blame yourself or another person for feeling fearful or anxious.
- Try to reason with your loved one if their fears and anxieties are severe; talk with the doctor about medicines and other kinds of help.

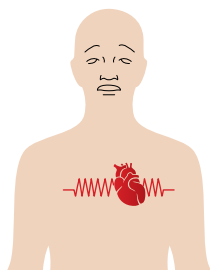
### Panic attacks and the person with cancer

Panic attacks can be an alarming symptom of anxiety. They happen very suddenly and often are their worst within about 10 minutes. The person may seem fine between attacks, but is usually very afraid that they will happen again.

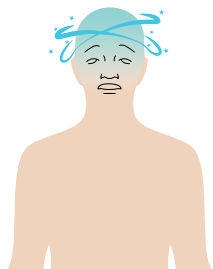
#### IF ANY OF THESE SYMPTOMS OCCUR



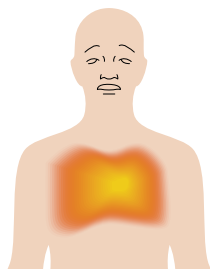
Shortness of breath  
and a feeling of choking



Racing heart



Feeling dizzy or faint



Chest pain



OR



### Symptoms of a panic attack

- Shortness of breath or a feeling of being smothered\*
- Racing heart\*
- Feeling dizzy, unsteady, lightheaded, or faint\*
- Chest pain or discomfort\*
- Feeling as if they're choking\*
- Trembling or shaking
- Sweating
- Fear of losing control or "going crazy"
- An urge to escape
- Numbness or tingling sensations
- Feeling "unreal" or "detached" from themselves
- Chills (shaking or shivering) or hot flashes (may involve sweating or facial reddening)

*\* If a person is having any of the first 5 symptoms (marked with \*), it can mean an urgent or life-threatening condition. Call 911 or the doctor right away if your loved one unexpectedly has any of these. These symptoms can be signs of other, more serious problems such as shock, heart attack, blood chemistry imbalance, collapsed lung, allergic reaction, or others. It's not safe to assume that they are panic related until diagnosed by a doctor.*

If your loved one has had panic attacks in the past, and it happens again exactly like it did before, they can often recognize it as a panic attack.

If they recover completely within a few minutes and have no more symptoms, it's more likely to have been a panic attack. If panic attacks are diagnosed by a doctor, brief therapy and medicines have been shown to be helpful.



### ***Things to do to help***

- Check with the doctor to be sure that the symptoms are caused by panic and not another medical problem.
- Stay calm and speak softly during a panic attack.
- Sit with your loved one during panic attacks until they're feeling better.
- Call for help if needed.
- After the panic attack is over, encourage the person to get treatment for the panic attacks.
- Provide transportation to treatment if needed. Your loved one may be afraid that a panic attack will happen while driving.

### ***Things not to do***

- Minimize or make light of the person's terror or fear.
- Judge your loved one for feeling scared and acting strangely.
- Try to talk the person out of their fear or other feelings.
- Hesitate to call the doctor if you have questions about what's happening.

## **PUTTING UP A FRONT**

Some people might put up a false front, or put on a “happy face,” even if they don't really feel that way. This may be their way of trying to protect the people they love, and possibly themselves, from painful feelings. Some people believe even that a person with cancer can improve their outcome by being cheerful and happy all the time, but this isn't true.

Studies of coping styles and survival or recurrence (cancer coming back after treatment) show that being cheerful has little to no effect on cancer. Still, some people with cancer feel guilty for being sad or fearful, and may try to act happy and “be positive” even when it's painful to them. If this might be happening, gently tell your loved one that you're willing to listen to their feelings, no matter what they are. The message may be something like, “I care about you, and I'm here for you whether you are happy, afraid, angry, or sad.”

## **SHARING CONCERNS WITH THE CANCER CARE TEAM**

Being able to talk with the cancer care team about concerns such as fears, pain, and other issues may help the patient feel more comfortable. Someone on the team can answer questions and talk about any concerns. They can also refer the patient to a mental health professional if needed.

Depression, anxiety, and other emotional problems can nearly always be helped with a combination of medicines, support groups, or psychotherapy. But first, a person must recognize that they need help dealing with their emotions and responses to the major changes that cancer brings to their lives.



## CAREGIVER DISTRESS AND UNMET NEEDS

When your loved one was first diagnosed with cancer and you began your journey as a caregiver, your overall quality of life likely suffered because you were trying to adjust to your new role. During the initial intensive phase of caregiving, you may have had symptoms of depression, and your physical health possibly suffered.

Research has shown that one of the main things that contributes to high distress is being afraid that your loved one's cancer will return (this is referred to as fear of recurrence). In fact, one of the most stressful events in the course of the cancer experience is being told that the cancer has come back. During this time especially, a strong support system will help you be better able to adjust.

We have asked caregivers about their needs throughout the caregiving journey, and they shared these top 5:

- Helping the patient with their emotional distress (for example, anger, anxiety, depression, fear)
- Dealing with my own emotional distress (for example, anger, anxiety, depression, fear, resentment)
- Dealing with lifestyle changes
- Getting information about the cancer my loved one was diagnosed with (for example, prognosis, treatment)
- Talking to my loved one about their concerns

Perhaps these are things you're currently dealing with as a caregiver. This guide is designed to help meet all of those needs and to be used as a practical, day-to-day tool to help get you through this experience.

If you would like to see what level of distress you may be experiencing, a Caregiver Distress Checklist is provided on the next page. Use this checklist throughout the caregiving journey when you feel your distress level change. It can help you find ways to measure and manage it. The Coping Checklist for Caregivers follows and offers information about healthy ways to deal with the distress you may be experiencing.

The *Caregiver Support Video Series* was created just for you – to help you manage the complex care experience. It includes videos on Stress Management and Coping, Fear of Recurrence, and Relaxation. Visit [cancer.org/caregivervideos](https://www.cancer.org/caregivervideos) to watch.

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.

## CAREGIVER DISTRESS CHECKLIST

Caregivers are often so concerned with caring for their loved one's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, go to the next page to do a self-evaluation.

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### During the past week or so, I have ...

- |   |   |
|---|---|
| 1. Had trouble keeping my mind on what I was doing <input type="checkbox"/> Yes <input type="checkbox"/> No                         | 12. Felt strained between work and family responsibilities <input type="checkbox"/> Yes <input type="checkbox"/> No   |
| 2. Felt that I couldn't leave my loved one alone <input type="checkbox"/> Yes <input type="checkbox"/> No                           | 13. Had back pain <input type="checkbox"/> Yes <input type="checkbox"/> No  |
| 3. Had difficulty making decisions <input type="checkbox"/> Yes <input type="checkbox"/> No   | 14. Felt ill (headaches, stomach problems, or common cold) <input type="checkbox"/> Yes <input type="checkbox"/> No   |
| 4. Felt completely overwhelmed <input type="checkbox"/> Yes <input type="checkbox"/> No   | 15. Been satisfied with the support my family has given me <input type="checkbox"/> Yes <input type="checkbox"/> No   |
| 5. Felt useful and needed <input type="checkbox"/> Yes <input type="checkbox"/> No  | 16. Found my loved one's living situation to be inconvenient or a barrier to care <input type="checkbox"/> Yes <input type="checkbox"/> No                  |
| 6. Felt lonely <input type="checkbox"/> Yes <input type="checkbox"/> No   | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress.                        |
| 7. Been upset that my loved one has changed so much from their former self <input type="checkbox"/> Yes <input type="checkbox"/> No |   |
| 8. Felt a loss of privacy and/or personal time <input type="checkbox"/> Yes <input type="checkbox"/> No                             |   |
| 9. Been edgy or irritable <input type="checkbox"/> Yes <input type="checkbox"/> No  | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. |
| 10. Had sleep disturbed because of caring for my loved one <input type="checkbox"/> Yes <input type="checkbox"/> No                 |   |
| 11. Had a crying spell(s) <input type="checkbox"/> Yes <input type="checkbox"/> No  |   |
- 

### Comments:

Please feel free to comment or provide feedback if you plan to share this with a health care professional.

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## Self-evaluation

### To determine your score

1. Count up all your “Yes” responses, *but* do not count #5 or #15 yet.
2. Now, look at questions #5 and #15. If you responded “Yes” to these questions, do *not* count these with your “Yes” count. If you responded “No” to either or both questions, add these to your “Yes” count. (For example, if you had 4 “Yes” answers on the rest of the questions, and you answered “No” to question #5 and “No” to question #15, your total score would be 6.)

### To interpret your response

#### Chances are that you are experiencing a high degree of distress:

- If you answered “Yes” to either or both questions 4 and 11; or
- If your total “Yes” score = 10 or more; or
- If your score on question #17 is 6 or higher; or
- If your score on question #18 is 6 or higher

*Source: American Medical Association. All Rights Reserved*

#### If you are having a high degree of distress

- Consider seeing a doctor for a check-up.
- Look for some relief from caregiving. (Talk to the patient’s doctor, social worker, or cancer care team about resources available in your community.)
- Consider joining a support group for caregivers. Online and phone support is available.
- Call the American Cancer Society at **1-800-227-2345** for more information and referrals.

## If your distress level is low

It isn’t unusual for caregivers to have some of these problems for a short time. But they may mean that you’re at risk for higher levels of distress. When caregivers don’t attend to their own needs and allow other pressures to take over, they may lose the ability to continue to care for their loved one. Part of caring for someone else is caring for yourself.

You may want to learn more about managing caregivers’ responsibilities. You can learn more about caregiving and resources you can use on our website.

### Now what?

Asking for help can be a good thing. You may need more than one kind of help to manage caring for your loved one. See a doctor if you have serious distress, or if you can’t accomplish your day-to-day activities. We also encourage you to print out this checklist and talk it over with a doctor, nurse, social worker, or other professional on your loved one’s cancer care team.

### Get support

American Cancer Society support programs reach cancer patients and caregivers throughout the US. Practical advice is available online to help patients and caregivers manage on a day-to-day basis and cope with physical and emotional changes. Please refer to the Resources listed at the end of this guide. You also can call us at our toll-free number, **1-800-227-2345**, for more information and support.

## COPING CHECKLIST FOR CAREGIVERS

Caring for someone with cancer, taking on new responsibilities, and worrying about the future can be exhausting at the very least, and it can quickly lead to burnout. When you're busy caring for your loved one with cancer, who's taking care of you? Check out these lists to identify strengths and weaknesses you can build on or improve.

### Healthy ways to cope

Take a moment to look at these statements. They describe some healthy situations and ways of coping. They'll give you an idea of how well you're holding up, and may help you identify areas where you need to make a few changes to take better care of yourself. The more of these statements you can agree with, the better. If you don't already have or do all of these, look for ways you can start working toward those that appeal to you. They can help you expand and strengthen your coping skills.

- I have supportive family and friends around me.
- I pursue a hobby or project for work, church, or my community.
- I take part in a social or activity group more than once a month.
- I am within 10 pounds of the ideal body weight for my height and bone structure.
- I use relaxation methods like meditation, yoga, or progressive muscle relaxation at least 5 times a week.
- I do something fun "just for me" at least once during an average week.
- During an average week, I get at least 150 minutes of moderate exercise (such as walking or yoga) or 75 minutes of vigorous activity (such as jogging or basketball).
- I eat a well-balanced, healthy meal 2 or 3 times during an average day. (A balanced meal is low in fat and high in vegetables, fruits, and whole-grain foods.)
- I have a place where I can go to relax or be by myself.
- I set priorities and manage my time every day (such as deciding what tasks are most important, how much I can – and can't – do, and getting help when needed).

It can be hard to find the time to do all these things, but they can help a lot in keeping some balance in your life during this very stressful time. If your schedule is too crowded, see whom you can ask for help. If there's no one to help you, talk to your loved one's cancer care team to find out what resources may be available in your area.

### Notes:

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### Less-healthy coping

If you use any of these strategies to help you get by, you may find that over the long term they actually lower your ability to deal with important issues in your life. They can also create health problems and worsen your relationships with loved ones. If you need help quitting tobacco, alcohol, or other drugs, please talk with your health care provider.

- I smoke cigarettes or use tobacco several times a week.
- At least once or twice during an average week, I use medicines, alcohol, or other substances to help me sleep.
- At least once or twice during an average week, I use alcohol, medicines, or other substances to reduce anxiety or help me calm down.
- I bring work home at least once or twice during an average week.

If you find it hard to cope or feel overwhelmed or sad all the time, you may want to talk with a health care provider about these feelings.

*Source: This checklist was adapted from one created by Dr. George Everly Jr. of the University of Maryland. The original appears in the U.S. Public Health Service pamphlet, "What Do You Know About Stress" (DHHS Publication No. PHS79-50097) and is in the public domain. Please give appropriate credit if you copy it.*

### HOW YOUR BODY RECOVERS AFTER YOU QUIT SMOKING

20  
minutes



Your heart rate and blood pressure drop.

12  
hours



The carbon monoxide level in your blood drops to normal.

2 to 3  
weeks months



Your circulation improves, and your lung function increases.

1 to 9  
months



Coughing and shortness of breath decrease; cilia start to regain normal function in the lungs, increasing the ability to handle mucus, clean the lungs and reduce the risk of infection.

1  
year



The excess risk of coronary heart disease is half that of a continuing smoker's.

5  
years



Risk of cancer of the mouth, throat, esophagus, and bladder are cut in half. Cervical cancer risk falls to that of a non-smoker. Stroke risk can fall to that of a non-smoker after 2-5 years.

10  
years



The risk of dying from lung cancer is about half that of a person who is still smoking. The risk of cancer of the larynx (voice box) and pancreas decreases.



# Caregiver Resources

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## American Cancer Society and Other Resources

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## AMERICAN CANCER SOCIETY AND OTHER RESOURCES

### AMERICAN CANCER SOCIETY PROGRAMS AND SERVICES

When someone is diagnosed with cancer, we are available at **1-800-227-2345** or **cancer.org** – to provide the latest cancer information, free services to help you and your family, and emotional support.

#### Cancer Survivors Network<sup>SM</sup>

The American Cancer Society Cancer Survivors Network<sup>®</sup> provides a safe online connection where cancer patients and caregivers can find others with similar experiences and interests. The site is used by a large group of caregivers who are actively engaged in conversations around care specific to treatment side effects, coping with multiple responsibilities, seeking respite care, and maintaining health and well-being as a caregiver. Go to <https://csn.cancer.org> to connect with other caregivers.

#### Lodging programs

##### *Hope Lodge<sup>®</sup>*

The American Cancer Society Hope Lodge program provides a free home away from home for cancer patients and their caregivers. More than just a roof over their heads, it's a nurturing community where patients and caregivers can share stories and offer each other emotional support. Go to [cancer.org/hopelodge](https://cancer.org/hopelodge) to find locations.

##### *Hotel Partners Program*

Through our Hotel Partners Program, we partner with local hotels across the country to provide free or discounted lodging to patients and their caregivers without a Hope Lodge facility. The program is open to cancer patients of all ages, including pediatric patients accompanied by a parent and patients traveling with children. All accommodations are provided based on eligibility requirements and are subject to availability and to restrictions imposed by the participating hotels. Requests for lodging are on a first-come, first-served basis. For more information or to request hotel lodging, call the American Cancer Society at **1-800-227-2345**.



**National Cancer Information Center:  
1-800-227-2345**

Our National Cancer Information Center provides compassionate assistance and support for everyone facing cancer. Our caring, trained staff are available by phone, or live chat on [cancer.org](https://www.cancer.org), to help those who have just been diagnosed, are in the midst of treatment, or are caring for someone with the latest cancer information, health insurance assistance, transportation, and lodging requests. We are also here with a compassionate ear anytime patients, family members, or caregivers need it.

**Reach To Recovery®**

Our Reach To Recovery program matches breast cancer patients with trained volunteers who have had similar diagnoses and treatment plans. Our volunteers offer peer-to-peer support on everything from practical and emotional issues to helping them cope with their disease, treatment, and long-term survivorship issues. Visit [cancer.org/reachtotherecovery](https://www.cancer.org/reachtotherecovery) to find out more.

**Road To Recovery®**

One of the biggest roadblocks to cancer treatment is the lack of transportation. That's why we started the Road To Recovery program. It's at the very heart of our work of removing barriers to quality health care by providing patients transportation to treatment and other cancer-related appointments through volunteers drivers, partners, or community organizations. To see if the program is offered in your loved one's area, call 1-800-227-2345 or visit [cancer.org/roadtotherecovery](https://www.cancer.org/roadtotherecovery) for more information.

**Springboard Beyond Cancer**

Developed by the American Cancer Society and the National Cancer Institute, Springboard Beyond Cancer is an online tool that helps cancer patients and their caregivers identify goals, create a plan, identify potential challenges, monitor their progress, and reassess the plan to allow them to communicate more effectively with their health care team. Visit [survivorship.cancer.gov](https://survivorship.cancer.gov) to find out more.

***“tlc” Tender Loving Care®***

The American Cancer Society *“tlc” Tender Loving Care* publication offers affordable hair loss and mastectomy products for women coping with cancer, as well as advice on how to use them. Products include wigs, hairpieces, hats, turbans, breast forms, and mastectomy bras, camisoles, and swimwear. The *“tlc”™* products and catalogs may be ordered online at [tlcdirect.org](https://tlcdirect.org) or by calling 1-800-850-9445.





## AMERICAN CANCER SOCIETY MATERIALS

The following information may also be helpful to you. These materials may be ordered free by calling our toll-free number at 1-800-227-2345.

- Advance Directives*
- Americans With Disabilities Act*
- Anxiety, Fear, and Depression*
- Cancer Immunotherapy*
- Choosing a Doctor and a Hospital*
- Distress in People With Cancer*
- Family and Medical Leave Act*
- Fertility and Men With Cancer*
- Fertility and Women With Cancer*
- Get Help for Cancer Pain*
- Helping Children When a Family Member Has Cancer*
- Hospice Care*
- How Cancer Affects Sexuality*
- How to Cope With Common Eating Problems*
- If You're About to Become a Cancer Caregiver*
- Listen With Your Heart – Talking With the Person Who Has Cancer*
- Nearing the End of Life*
- Nutrition for the Person With Cancer During Treatment*
- Seeking a Second Opinion*

- Survivorship: During and After Treatment*
- The Grieving Process*
- Treatments and Side Effects*
- Understanding Financial and Legal Matters*
- Understanding Health Insurance*
- What a Cancer Caregiver Does*
- Working During and After Treatment*

## AMERICAN CANCER SOCIETY BOOKS

The following books are just a few of the more than 40 titles available from the American Cancer Society. Visit [cancer.org/bookstore](https://www.cancer.org/bookstore) to learn more and access our catalog and bookstore. All American Cancer Society books are also available from all major book retailers such as Amazon, Barnes & Noble, and others, and are available in print and ebook formats.

- American Cancer Society Complete Guide to Family Caregiving, Second Edition*
- American Cancer Society Complete Guide to Nutrition for Cancer Survivors, Second Edition*
- Cancer Caregiving A-to-Z*
- Cancer in Our Family, Second Edition*
- How to Help Your Friend With Cancer*
- What Helped Get Me Through: Cancer Survivors Share Wisdom and Hope*
- What to Eat During Cancer Treatment, Second Edition*



## NATIONAL ORGANIZATIONS AND WEBSITES\*

Along with the American Cancer Society, other sources of information and support include:

### American Association for Marriage and Family Therapy

Phone: 703-838-9808

Website: [aamft.org](http://aamft.org)

This association has educational materials on helping couples living with illness.

### AARP

Toll-free number: 1-877-333-5885

Website: [aarp.org/caregiving](http://aarp.org/caregiving)

This caregiving resource center has tools, worksheets, and tips on how to plan, prepare, and succeed as a caregiver. They include information on caregiving options, housing, legal issues, financial matters, care for the caregiver, and more.

### American Psychosocial Oncology Society (APOS)

Website: [apos-society.org](http://apos-society.org)

Coping with a cancer diagnosis can be overwhelming, and the disease impacts all aspects of the lives of patients and caregivers. APOS is committed to helping direct them to the resources, programs, and support they may need to ease the burden of the cancer journey.

### CancerCare

Toll-free number: 1-800-813-4673

Website: [cancercares.org/caregiving](http://cancercares.org/caregiving)

CancerCare provides free, professional support services (online, telephone, and in-person) for caregivers and loved ones, as well as caregiving information and other resources.

### Cancer Hope Network

Toll-free number: 1-877-467-3638

Website: [cancerhopenetwork.org](http://cancerhopenetwork.org)

Cancer Hope Network volunteers provide free and confidential one-on-one telephone support for people with cancer, family members, and caregivers.

### Cancer Legal Resource Center

Toll-free number: 1-866-843-2572

Website: [cancerlegalresources.org](http://cancerlegalresources.org)

This resource center offers free, confidential information and resources on cancer-related legal issues to cancer survivors, their families, friends, and others coping with cancer.

### Cancer Support Community (CSC)

Toll-free number: 1-888-793-9355

Website: [cancersupportcommunity.org](http://cancersupportcommunity.org)

The CSC provides emotional and educational services for all people affected by cancer. The website provides a range of information, tools, and support to help you cope with the impact of cancer. The support community has developed a Cancer Experience Registry, a community of people impacted by cancer where patients and caregivers are experts. It is a place where you can share your voice, learn from others, and help shape new programs, research, and policy for those living with cancer. Go to [CancerExperienceRegistry.org](http://CancerExperienceRegistry.org) to find out more about the registry.

### Caregiver Action Network (CAN)

Telephone: 202-454-3970

Website: [caregiveraction.org](http://caregiveraction.org)

This organization supports and educates family caregivers, helps them connect with other caregivers, and helps them become their own advocates. CAN is a collaborative partner for Help For Cancer Caregivers, a tool that provides personalized information to help monitor, track and manage the challenges caregivers face. Go to [helpforcancercaregivers.org](http://helpforcancercaregivers.org) to learn more.

### CaringBridge

Telephone: 651-789-2300

Website: [caringbridge.org](http://caringbridge.org)

CaringBridge offers free, personalized websites to people facing various medical conditions, hospitalization, medical treatment, and/or recovery from a significant illness or procedure. It allows family members and friends to receive information about a particular individual. Visitors who are provided with an individual's personal website address (or URL) and password can read updates on the individual's condition or post messages to the family as needed.

### Eldercare Locator

Telephone: 1-800-677-1116

Website: [eldercare.gov](http://eldercare.gov)

This caregiver support program helps find services and local respite programs funded by the Administration on Aging. These programs, along with other state and community-based services, help to reduce depression, anxiety, and stress that caregivers may feel.



### Family Caregiver Alliance (FCA)/National Center on Caregiving

Telephone: 1-800-445-8106

Website: [caregiver.org](http://caregiver.org)

This organization provides information and resources for long-term caregiving, including practical skills, how to hold family meetings, decision making, assistive equipment, and online support. Search their Family Care Navigator to find state-specific resources.

### GriefNet

Website: [griefnet.org](http://griefnet.org)

GriefNet provides online grief support email groups for adults and children. A minimal monthly fee is required.

### GriefShare

Telephone: 1-800-395-5755

Website: [griefshare.org](http://griefshare.org)

GriefShare seminars and support groups are led by people who understand what caregivers are going through and want to help. The online locator will find support groups near you.

### **Job Accommodation Network (JAN)**

Telephone: 1-800-526-7234

Website: [askjan.org](http://askjan.org)

JAN provides free consulting services for individuals with physical or intellectual limitations that affect employment. Services include one-on-one consultation about job accommodation ideas, requesting and negotiating accommodations, and rights under the Americans with Disabilities Act (ADA) and related laws.

### **Lotsa Helping Hands**

Website: [lotsahelpinghands.com](http://lotsahelpinghands.com)

Lotsa Helping Hands connects caregivers who need assistance to people who want to provide help and offers tools to enable caregivers to coordinate their caregiving teams online or with a mobile app.

### **MyLifeLine**

Telephone: 1-888-234-2468

Website: [mylifeline.org](http://mylifeline.org)

MyLifeLine provides free personal websites that allow patients and caregivers to post updates, request and coordinate help from friends and family with day-to-day tasks, and collect personal donations to assist with the cost of care.

### **National Alliance for Caregiving (NAC)**

Telephone: 1-301-718-8444

Website: [caregiving.org](http://caregiving.org)

The NAC is a nonprofit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.



### **National Association for Home Care & Hospice Location Service**

Telephone: 1-202-547-7424

Website: [agencylocator.nahc.org](http://agencylocator.nahc.org)

The service has a Home Care/Hospice Agency Locator, containing the most comprehensive database of home care and hospice agencies.

### **National Cancer Institute (NCI)**

Telephone: 1-800-422-6237

Website: [cancer.gov](http://cancer.gov)

The NCI is an excellent source of up-to-date information about cancer for patients and their families. Caregivers can also search the NCI-supported clinical trials by ZIP code.

### **National Hospice and Palliative Care Organization (NHPCO)**

Telephone: 1-703-837-1500

Website: [nhpco.org](http://nhpco.org)

NHPCO offers CaringInfo ([caringinfo.org](http://caringinfo.org)), which provides free resources to help people make decisions about end-of-life care and services before a crisis. Download your state-specific Advance Directive.

### **National Institute of Mental Health (NIMH)**

Telephone: 1-866-615-6464

Website: [nimh.nih.gov](http://nimh.nih.gov)

NIMH provides information on symptoms, diagnosis, and treatment of mental disorders.

### **National Respite Network and Resource Center**

Website: [archrespite.org/respitelocator](http://archrespite.org/respitelocator)

This website provides a respite locator to find local programs and services that help caregivers take a short-term break from caregiving.

### **National Suicide Prevention Hotline**

Telephone: 1-800-273-8255

Website: [suicidepreventionlifeline.org](http://suicidepreventionlifeline.org)

The Lifeline provides 24/7, free and confidential support for people in distress, prevention and crisis resources for you or your loved ones, and best practices for professionals.

### **Sage: Advocacy & Services for LGBT Elders**

Telephone: 1-212-741-2247

Website: [sageusa.org](http://sageusa.org)

This organization offers counseling, information, and support groups for gay, lesbian, bisexual, and transgender elder caregivers.

### **Substance Abuse and Mental Health Services Administration (SAMHSA)**

Telephone: 1-877-726-4727

Website: [samhsa.gov](http://samhsa.gov)

SAMHSA provides substance use/abuse treatment referrals and information. Find alcohol, drug, or mental health treatment facilities and programs around the country with the Behavioral Health Treatment Services Locator.

### **US Equal Employment Opportunities Commission (EEOC)**

Telephone: 1-800-669-4000

Website: [eoc.gov](http://eoc.gov)

The EEOC provides information about employment discrimination laws and describes how to submit a formal complaint to an employer where discrimination might exist.

### **Veteran Affairs Caregiver Support Program**

Telephone: 1-855-260-3274

Website: [caregiver.va.gov](http://caregiver.va.gov)

This program offers services and support for veterans and their caregivers, including a Caregiver Toolbox.

### **Well Spouse Association (WSA)**

Telephone: 1-800-838-0879

Website: [wellspouse.org](http://wellspouse.org)

The WSA is a national, nonprofit membership organization (dues are charged) that provides emotional support to spouses and partners of chronically ill and/or disabled people.

*\*Inclusion on this list does not imply endorsement by the American Cancer Society.*

Please email us at [caregiving@cancer.org](mailto:caregiving@cancer.org) if you have questions related to the *Caregiver Resource Guide*.



# CAREGIVER RESOURCE GUIDE



When you become a caregiver for someone with cancer, you have questions. Lots of them. This guide helps answer those questions, while providing information on what it means to be a caregiver, perspective on what your loved one is going through, and tips on taking care of yourself and coping with your new role. Inside, you'll also find resources to connect you with other caregivers and additional help.

For the latest cancer information, day-to-day help, and emotional support, visit the American Cancer Society website at **cancer.org** or call us at **1-800-227-2345**.



cancer.org | 1.800.227.2345



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