



NATIONAL CANCER INSTITUTE

Support for Caregivers

When Someone You Love Is Being Treated for Cancer



For more information...

Other booklets for caregivers that can be downloaded from NCI's website are:

- When Someone You Love Has Completed Cancer Treatment
cancer.gov/publications/patient-education/someone-you-love-completed-cancer-treatment
- When Someone You Love Has Advanced Cancer
cancer.gov/publications/patient-education/when-someone-you-love-has-advanced-cancer
- When Your Parent Has Cancer: A Guide for Teens
cancer.gov/publications/patient-education/when-your-parent-has-cancer
- When Your Brother or Sister Has Cancer: A Guide for Teens
cancer.gov/publications/patient-education/sibling-has-cancer

These booklets and more are available from the National Cancer Institute (NCI). To learn more about specific types of cancer or to download any of these booklets, visit NCI's website (cancer.gov). You can also call NCI's Cancer Information Service toll-free at 1-800-4-CANCER (1-800-422-6237) to speak with an information specialist.

We would like to offer our sincerest gratitude to the extraordinary caregivers, health professionals, and scientists who contributed to the development and review of this publication.

The purpose of this book is to focus on *you* and *your* needs.

We've heard from many caregivers about things they wish they had known early on. We have collected their tips in this booklet. Some of the tips seem simple, but they may not always be easy to do.

Use this booklet in whatever way works best for you. You can read it from front to back. Or you can just refer to different sections as you need them.

No two people are alike. Some chapters of this booklet may apply to you, while others may not. Or you may find that some sections are more useful to you later.

Terms used: This booklet uses the terms “**loved one**” and “**patient**” throughout to describe the person you're caring for.

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Who Is a Caregiver?

This booklet is for you if you're helping your loved one get through cancer treatment. You are a "caregiver." You may not think of yourself as a caregiver. You may see what you're doing as something natural—taking care of someone you love.

There are different types of caregivers. Some are family members, while others are friends. People of different races and cultures give care to others in their own way. Every situation is different and there isn't one way that works best.

What does caregiving mean? It can be

- helping with day-to-day activities such as doctor visits or preparing food
- giving medicines or helping with physical therapy or other clinical tasks
- helping with tasks of daily living such as using the bathroom or bathing
- coordinating care and services from a distance by phone or email
- giving emotional and spiritual support

The natural response of most caregivers is to put their own feelings and needs aside. They try to focus on the person with cancer and the many tasks of caregiving. This may be fine for a short time. But it can be hard to keep up for a long time. And it's not good for your health. If you don't take care of yourself, you won't be able to take care of others. **It's important for everyone that you also give care to you.**

There are other booklets available that talk about how to give care to a loved one. But the purpose of this booklet is to focus on you and your needs.



"I think you can be the best caregiver you can be by taking care of yourself, by trying to get as much information as possible, and by letting yourself lean on the people who are willing to help you." —Leneice

Being a Cancer Caregiver

Changing roles

No matter your age, you may find yourself in a new role as a caregiver. You may have been an active part of someone's life before cancer, but perhaps now the way you support them is different. It may be in a way in which you haven't had much experience, or in a way that feels more intense than before.

Even though caregiving may feel new to you now, many caregivers say that they learn more as they go through their loved one's cancer experience. Here are common situations they describe:

- Their loved one only feels comfortable with a spouse or partner taking care of them.
- Caregivers with children struggle to take care of a parent too.
- Parents have a hard time accepting help from their adult child.
- Caregivers find it hard to balance taking care of a loved one with doing their job.
- Adult children with cancer may not want to rely on their parents for care.
- Caregivers with health problems themselves find it hard physically and emotionally to take care of someone else.

Whatever your roles are now, accepting the changes may be tough. It's very common to feel confused and stressed at this time. If you can, try to share your feelings with others or join a support group. Or you may choose to seek help from an expert if that's an option for you.

Many caregivers say that talking with a counselor helped them. They feel they were able to say things that they weren't able to say to their loved one. See [Talking to Other Family Members and Friends on page 38](#) for more tips.

"Once a week, after I take the kids to school, I take Mom to her doctor's appointment. Then I take her home and fix her lunch and sit with her awhile. She argues with me every time because she wants to do it herself. It's hard for her to have to rely on me."

—Lynn

Coping with your feelings as a cancer caregiver

Caring for someone with cancer can be very demanding. You've probably felt a range of feelings as you care for your loved one. They can be quite strong and may come and go as they go through treatment. Many caregivers describe it as being "like a rollercoaster." You may feel sad, afraid, angry, and worried. There is no right or wrong way to feel or react. **These feelings are all normal.**

You may relate to all of the feelings on the next page or just a few. You may feel them at different times, with some days being better than others. It may help to know that other caregivers have felt the same way that you do. **One of the first steps in coping with feelings is to recognize them.** Try to give yourself time to understand and work through your range of emotions.

Anger. Many caregivers say they often feel angry with themselves, their family members, or their loved one with cancer. Sometimes anger comes from feelings that are hard to show, such as fear, frustration, panic, or worry. Or it may come from resentment of all that you're going through.

Anger can be healthy if you handle it the right way. It can help motivate you to take action, find out more, or make positive changes in your life. But if these feelings persist and you stay angry at those around you, ask for advice from a counselor, social worker, or other mental health professional. Or even talking to a trusted friend about it may help.

Grief. You may be mourning the loss of what you hold most dear—your loved one's health or the life you had with each other before cancer. It's important to give yourself permission to grieve these losses. It takes time to work through and accept all the changes that are occurring.

Guilt. Feeling guilty is a common reaction for caregivers. You may worry that you aren't helping enough, or that your job or distance from your loved one is getting in the way. You may even feel guilty that you're healthy. Or you may feel guilty for not acting upbeat or cheerful. But know that it's okay. You have reasons to feel upset, and hiding these feelings may keep other people from understanding your needs.

Anxiety and depression. Anxiety means you have extra worry, you can't relax, you feel tense, or you have panic attacks. Many people worry about how to pay bills, manage work, and take care of the family. Now they have the added stress of how cancer affects the family, and of course, how their loved one is doing. Depression is a persistent sadness that lasts more than two weeks. If any of these symptoms start affecting your ability to function normally, talk with your doctor. Don't think that you need to tough it out without any help. There are ways your symptoms can be eased during this hard time.

Loneliness. You can feel alone in your role as a caregiver, even if you have lots of people around you. It's easy to feel like no one understands what you're going through. You may also feel lonely because you have less time to see people and do things that you used to. Whatever your situation, you aren't alone. Other caregivers share your feelings. See [page 15](#) for ways to connect with others.

Hopeful. You may feel hopeful throughout your loved one's cancer treatment. And what you hope for may change over time. You can hope for a cure most of all. But you may also hope for other things, such as comfort, peace, acceptance, and joy.

"It's emotionally exhausting, and I never know what to expect. One minute, things are looking up. Then a couple of hours later, something happens and I don't have the answers."

—David

"There are times when you don't know how to help. You can't take away the pain. You can't take away the frustration. All you can do is be there, and it's a very helpless feeling." —Cecile

Other ways to cope

Let go of mistakes. You can't be perfect. No one is. The best we can do is to learn from our mistakes and move on. Continue to do the best you can. And try not to expect too much from yourself.

Cry or express your feelings. You don't have to be upbeat all the time or pretend to be cheerful. Give yourself time to cope with all the changes you're going through. It's okay to cry and show that you are sad or upset.



Put your energy into the things that matter to you. Focus on the things you feel are worth your time and energy. Let the other things go for now. For example, don't fold the clothes when you're tired. Go ahead and take time to rest.

Understand where anger comes from. Your loved one may get angry with you. It's very common for people to direct their feelings at those who are closest. Their stress, fears, and worries may come out as anger. Try not to take it personally. Sometimes patients don't realize the effect their anger has on others. So if you feel comfortable, it may help to share your feelings with them when the timing is good. Try to remember that the anger isn't really about you.

Forgive yourself. This is one of the most important things you can do. Chances are that you are doing what you can at this moment. Each new moment and day gives you a new chance to try again.

Ways to learn more

Help for Cancer Caregivers

Provides resources and news on cancer caregiving.

Visit: helpforcancercaregivers.org

Family Caregiver Alliance

Their mission is to improve the quality of life for family caregivers and the people who receive their care.

Call: 1-800-445-8106

Visit: caregiver.org

National Alliance for Caregiving

Dedicated to improving the quality of life for friends and family caregivers and those in their care by advancing research, advocacy, and innovation.

Call: 1-202-918-1013

Visit: caregiving.org

“Growing up, we were taught two rules. One is, ‘Don’t sweat the small stuff.’ And second, ‘Everything is small stuff.’ And you have to decide what’s important to you. Focus on what you can do, not what you can’t.” —James

A Note for LGBTQ+ Caregivers

People with cancer who are lesbian, gay, bisexual, transgender, or queer (LGBTQ) may face more barriers during cancer care than those who are not. Some have experienced discrimination in health care settings or fear that they will. Worry that they will be treated differently or judged can cause stress and prevent people from getting the care they need.

If you are LGBTQ and a caregiver, you may have the same concerns. Or you may have already been discriminated against or treated differently or in a negative way. Some people say they aren't taken seriously as the caregiver. Others say they aren't given equal decision-making in their partner's care. Many have less social support and feel depressed.

Know you're not alone and there are places to find support. See the following websites for more information:

- National LGBT Cancer Network: cancer-network.org
- CancerCare: cancercare.org/tagged/lgbtq+
- Family Caregiver Alliance: caregiver.org/resource/special-concerns-lgbt-caregivers
- National LGBT Cancer Project: lgbtcancer.org



Ask Others for Help

Many caregivers say that, looking back, they took on too much themselves. Or they wish they had asked for help sooner. Take an honest look at what you can and can't do. What things do you need or want to do yourself? What tasks can you give to or share with others? Be willing to let go of things that aren't essential for you to do. You're taking care of someone. Let someone take care of you too.

Why getting help is important

Accepting help from others isn't always easy. When tough things happen, many people tend to pull away. They think, "We can handle this on our own." But things can get harder as cancer treatment goes on. You may need to change your schedule and take on new tasks. As a result, many caregivers have said, "There's just too much on my plate."

Remember that getting help for yourself can also help your loved one because

- you may stay healthier
- your loved one may feel less guilty about all the things that you're doing
- some of your helpers may offer time and skills that you don't have

"You have to learn that if people offer, let them do something. Ask for what you need, because they don't know. You have to be willing to let go of your pride and let them help you." —Chevonne

How can others help you?

When someone has a serious illness such as cancer, friends and family may reach out to help. Often people want to help, but many don't know what you need or how to offer it. It's okay for you to ask for what you need and the things that would be most helpful to you. For example, you may want someone to

- help with household chores, such as cooking, cleaning, or yard work
- go to the grocery store or pick up prescriptions
- keep your loved one company
- talk with you and listen to your feelings
- drive your loved one to appointments
- pick up a child from school or activities or help with childcare



- set up a website where people can find out what support you need or receive updates on your loved one
- look up information that you need or help you fill out forms
- be the contact person and help keep others updated on your loved one's situation

Finding respite help

Respite (RES-pit) helpers spend time with your loved one. They can be paid or may volunteer their time. Many caregivers say they wish they had gotten respite help sooner. It can leave you free to rest, see friends, run errands, or do whatever you'd like to do. Respite caregivers can also help with physical demands, such as lifting the patient into a bed or a chair. If this service appeals to you, you may want to

- talk with your loved one about having someone help out from time to time
- get referrals from friends, health care professionals, or your local agency on aging
- ask respite helpers what types of tasks they do

You can get respite help from family and friends, government agencies, or nonprofit groups. Whatever you do, remember that it isn't a failure on your part as a caregiver if you need some help and time to yourself.

Be prepared for some people not to help

It's important to know that there are others who may not be able to help you. This may hurt your feelings or even make you angry. You might wonder why someone wouldn't offer to help you. Some common reasons are that they

- may be coping with their own problems
- may not have time
- are afraid of cancer
- may have already had a bad experience with cancer and don't want to get involved and feel pain all over again
- believe it's best to keep a distance when people are struggling
- don't realize how hard things really are for you
- don't understand that you need help unless you ask them for it directly
- feel awkward because they don't know how to show they care

“We've gotten lots of support, and some of it comes from people we expected it from. But a lot has come from those we don't know very well. And others we do know well have stayed away. You just never know with people.” —Jessie

If someone isn't giving you the help you would like, you could try to talk to them and explain your needs. Or you can just let it go. But if the relationship is important, you may want to tell the person how you feel. This can help prevent resentment or stress from building up. These feelings could hurt your relationship in the long run.

Ways for cancer caregivers to ask for help

What may stop you from asking for help	What others have done
<p>“His cancer is a private thing. I’d have to tell people about it to get any support.”</p>	<p>You and your loved one can decide who to tell, what to tell them, and when and how. Some options are to</p> <ul style="list-style-type: none"> ■ tell only a few people close to you for now ■ limit the details about what you share, such as “he’s sick,” or “she isn’t feeling well today” ■ ask another family member, friend, or member of your faith or spiritual community to share the news ■ get help from services or agencies in your area instead of from people you know
<p>“Everyone has a lot going on. I don’t want to bother them or put them out.”</p>	<p>If you’re worried about being a burden to others, here are some things to think about:</p> <ul style="list-style-type: none"> ■ Many people probably want to help you. ■ If you let more people help, it can ease your workload. ■ Would you want to help someone else who was in a similar situation? Would you mind if they asked you to lend a hand?
<p>“I can’t explain it, but I just don’t feel up to asking for help right now.”</p>	<p>Many people don’t ask for support when they need it most. You may feel like backing away from your normal social life and from people in general. You may feel that it’s just too much work to ask for help. It’s okay if you feel that way. But try to be aware that over time, doing it all yourself can take its toll on you.</p> <p>Talk with someone you trust, such as a friend, member of your faith community, or counselor. This person can help you sort out your thoughts and feelings. They can also help you find ways to get support.</p>
<p>“It’s my duty to take care of my family, not someone else’s.”</p>	<p>Having a support system <i>is</i> a way of taking care of your family. Giving some tasks to others lets you focus on those that you feel you should do yourself.</p>

Long-Distance Caregiving

It can be really tough to be away from a loved one who has cancer. You may feel like you're a step behind in knowing what is happening with their care. Yet even if you live far away, it's possible for you to give support and be a problem solver and care coordinator.

Caregivers who live more than an hour away from their loved ones most often rely on the phone, video chats, or email as their communication link. But using these to assess someone's needs can be limiting. Aside from true medical emergencies, long-distance caregivers are faced with judging whether situations can be dealt with over the phone or require an in-person visit.

Finding contacts near your loved one

Develop a relationship with one or two key members of the health care team, such as a social worker or nurse. It may help you feel more at ease to have direct contact with someone involved in the medical care of your loved one. Also, many long-distance caregivers say that it helps to explore other ways to get support. Here are ways you can do this:

- Create a list of people who live near your loved one whom you could call day or night in a crisis or just to check in.
- Look into volunteer visitors, adult day care centers, or meal delivery services in the area.
- Make a list of websites in your loved one's area to give you quick access to resources.
- Ask if the hospital keeps visitor information packets or lists of area agencies and contacts.
- Remember to share a list of home, work, and cell phone numbers with the health care team and also give it to others in case of an emergency.

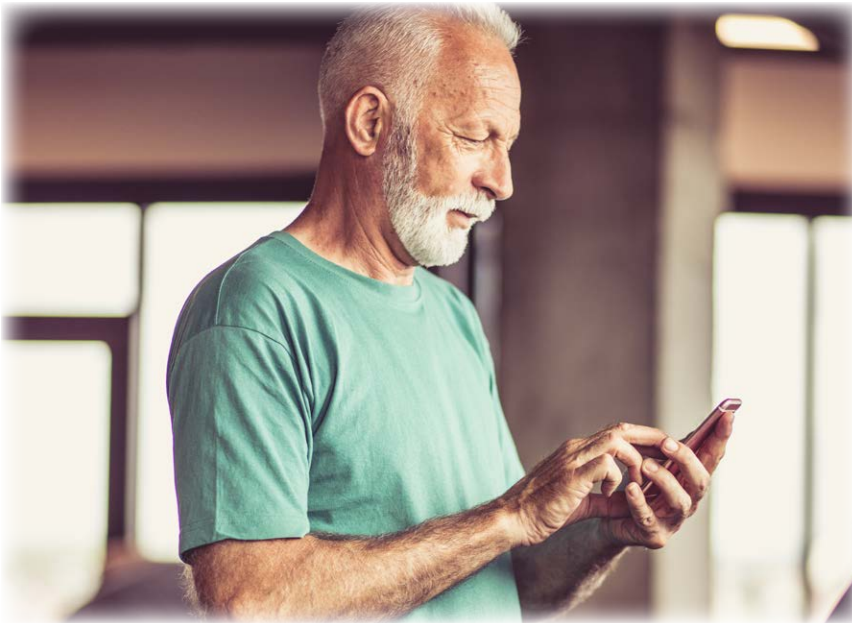
"Our family is spread throughout the country, so it's hard to have a hands-on experience. But the phone calls have increased, with them calling to say, 'I love you, and what can I do for you?' Even though there isn't much they can do to help me with Mom's care, just to have them call more has made it a little better."

—Patty



Other tips

- Ask a local family member or friend to update you daily by email. Or consider creating a website to share news about your loved one's condition and needs. There are a number of sites available. Examples include CaringBridge (caringbridge.org) and Lotsa Helping Hands (lotsahelpinghands.com).
- Sign up for online ways to connect with people. Free programs using video and instant messaging to communicate are very common. Examples include FaceTime, Zoom, and Skype.
- Airlines or bus lines may have special deals for patients or family members. The hospital social worker may also know of other resources, such as private pilots, advocacy organizations, or companies that help people with cancer and their families.
- If you're traveling to see your loved one, time your flights or drives so that you have time to rest when you return. Many long-distance caregivers say that they don't allow themselves enough time to rest after their visits.
- Review your long-distance and cell phone plans. See if you can make any changes that would reduce your bills.
- For more tips, see the National Institute on Aging's Long-Distance Caregiving page at nia.nih.gov/health/caregiving/long-distance-caregiving.



Caring for Your Mind, Body, and Spirit

Make time for yourself

You may feel that your needs aren't important right now. Or maybe by the time you've taken care of everything else you have to do, there's no time left for yourself. Or you may feel guilty that you can enjoy things that your loved one can't right now.

Most caregivers say they have those same feelings. But caring for your own needs, hopes, and desires is important to give you the strength to carry on. (See the Caregiver's Bill of Rights on [page 46](#).)

Taking time to recharge your mind, body, and spirit can help you be a better caregiver. When you can, try to

- find nice things you can do for yourself—even just a few minutes can help
- cut back on personal activities, rather than cutting them out entirely
- find things others can do or arrange for you, such as appointments or errands
- look for easy ways to connect with friends

Myths about taking care of yourself*

Myth	Fact
<i>"Taking care of myself means that I have to be away from my loved one."</i>	You can do things to take care of yourself with or without your loved one in the room with you. What's important is that you don't neglect yourself.
<i>"Taking care of myself takes a lot of time away from other things."</i>	Some self-care takes only a few minutes, such as reading a page from a book or doing some light stretches. Other self-care can be done in moments between longer tasks.
<i>"I'd have to learn how to focus on myself. I don't know if I can start."</i>	Whenever things make you feel happier, lighter, more relaxed, or more energized, these count as taking care of yourself. Think of things that you already know work for you.

* The Hospice of the Florida Suncoast. *Caring for Yourself While Caring For Others*. Adapted with permission.

Ways to take care of yourself

Caregivers say that even a few minutes a day without interruptions helps them cope and focus. Think about what you need. Would talking with others help ease your load? Or would you rather have quiet time by yourself? Maybe you need both! Take at least 15–30 minutes each day to do something for yourself, no matter how small it is.



“I just need some quiet time. If my husband’s taking a nap, I will read a book or sit on the porch because sometimes it’s so intense. We have days where we go straight from chemo to radiation. It can be very tiring.” —Margo

Join a support group

Support groups can meet in person, by phone, or over the internet. They may help you gain new insights into what is happening, get ideas about how to cope, and help you know that you’re not alone. In a support group, people may talk about their feelings, trade advice, and try to help others who are dealing with the same kinds of issues. Some people like to go and just listen. And others prefer not to join support groups at all. Some people aren’t comfortable with this kind of sharing.

If you can’t find a group in your area or don’t want to go to a meeting in-person, try an online support group. Some caregivers say websites with support groups have helped them a lot. Some examples.

- Cancer Support Community
Call: 1-888-793-9355
Visit: cancersupportcommunity.org
Email: help@cancersupportcommunity.org
- American Society of Clinical Oncology
Call: 571-483-1780 or 888-651-3038
Visit: cancer.net/coping-with-cancer/finding-social-support-and-information/online-communities-support
- CancerCare
Call: 1-800-813-HOPE (1-800-813-4673)
Visit: cancer.org
Email: info@cancer.org

Some other small things you could do for yourself might be

- exercise
- spend time with a friend
- watch TV or listen to music
- take a long shower or bath
- take a nap
- catch up on email or phone calls
- watch short videos online
- take a drive
- go shopping
- work on a puzzle or hobby



Talk to others for support

Studies show that connecting with other people is very important to most caregivers. It's especially helpful when you feel overwhelmed or want to say things that you can't say to your loved one with cancer. Talk to someone you can really open up to about your feelings or fears. You're allowed to feel angry, frustrated, or overwhelmed.

Besides a friend, you may want to talk to someone outside your inner circle. Some caregivers find it helpful to talk to a counselor, such as a social worker, psychologist, or leader in their faith or spiritual community. These types of experts may be able to help you talk about things that you don't want to talk about with your friends and family. They can also help you find ways to express your feelings and learn ways to cope that you hadn't thought of before.

*"What I need at least once or twice a week is to talk to one person or a group of people who are in the same shoes as I am."
—Vince*

To find a counselor, ask your doctor or nurse if your hospital has counseling services. If you have insurance, you could call and ask if they have a list of counselors under your plan. Also, some larger companies will have assistance programs for their employees. Some other resources:

- American Psychological Association at locator.apa.org
They have a Psychologist Locator to find a provider in your city and state.
- Psychology Today at psychologytoday.com. Their *Find a Therapist* tool will help you find a counselor in your area.
- Association of Oncology Social Work at aosw.org.
Use the *Find an OSW Near Me* form in the Patients & Caregivers section to find an oncology social worker where you live.
- CancerCare at cancercares.org/counseling or call 1-800-813-HOPE (4673). They have oncology social workers on staff to provide counseling and support.

“It’s okay for a neighbor to ask how I’m doing when they want the answer to be, ‘I’m fine.’ But when I’m really not fine, all I need is to talk to someone who can understand, or just hear me out. You don’t have to have an answer, just listen to me.” —Kathy

Connect with your loved one with cancer

Cancer may bring you and your loved one together more than ever before. Often people become closer as they face challenges together. If you can, take time to share special moments with one another. Try to gain strength from all you are going through together, and what you have dealt with so far. This may help you move toward the future with a positive outlook and feelings of hope.

Look for positive moments

Accepting the things you can’t change takes time. It can be hard finding positive moments when you’re busy caregiving. It can also be hard to adjust to your role as a caregiver. Caregivers say that looking for the good things in life and things to be grateful for helps them feel better.

When you can, think about what you find rewarding about caregiving, such as the offers of help you’ve received or extra support from a health care provider. Look for the positive moments in your days, such as nice weather, a hug, or something funny that you heard or read.



Let yourself laugh

It's okay to laugh, even when your loved one is in treatment. In fact, it's healthy. Laughter releases tension and makes you feel better. We all don't have the same sense of humor so think about what makes you laugh or smile. Whether it's reading funny articles, watching comedy shows or clips online, or talking with upbeat friends, focus on the things that amuse you the most. Keeping your sense of humor in trying times is a good coping skill.

Write in a journal

Research shows that writing or journaling can help relieve negative thoughts and feelings. And it may actually help improve your own health. You can write about any topic. You might write about your most stressful experiences. Or you may want to express your deepest thoughts and feelings. You can also write about things that make you feel good, such as a pretty day or a kind coworker or friend.

Another technique people use is to write down whatever comes to mind. It doesn't have to make sense or have correct grammar. It just helps to get all the "jumble" out of your mind by putting it all on paper.

Look for moments to feel thankful

You may feel thankful that you can be there for your loved one. You may be glad for a chance to do something positive and give to another person in a way you never knew you could. Some caregivers feel that they've been given the chance to build or strengthen a relationship. This doesn't mean that caregiving is easy, stress free, or without frustrations. But finding meaning in caregiving can make it easier to manage.

Keep up with your routine

Try not to neglect your personal life. Do your best to keep doing some of your regular activities. If you don't, studies show that it can increase the stress you feel. It's okay to cut back on activities, but don't cut them out entirely. You may have to do things at a different time of day or for less time than you normally would, but still try to do them when you can.

Learn more about cancer

Sometimes, understanding your loved one's cancer can make you feel more confident and in control. For example, you may want to know more details about their type and stage of cancer. It may help you to know what to expect during treatment, such as the tests and procedures that will be done, as well as the side effects that will result.

To learn more about cancer, go to NCI's website [cancer.gov](https://www.cancer.gov) or call 1-800-4-CANCER (1-800-422-6237) to speak with an information specialist.

Caring for your body

Taking care of someone with cancer can be exhausting and stressful. And yet you may find yourself so busy and concerned about your loved one that you don't pay attention to your own physical health. But it's very important that you take care of yourself. Taking care of your health will give you strength to help others.

New stresses and daily demands often add to any health problems caregivers already have. And if you're sick or have an injury that requires you to be careful, it's even more important that you take care of yourself. Here are some changes caregivers often have:

- feeling tired or having no energy
- weaker immune system (poor ability to fight off illness)
- sleep problems
- slower healing of wounds
- higher blood pressure
- changes in appetite or weight
- headaches
- anxiety, depression, or other mood changes



“When I get home from class, my mom and I take turns running while one of us stays with my dad. My run is my time for me, and the only way I can keep it together.”
—Meredith

Taking care of your health

These ideas for taking care of your body may sound easy. But they're a challenge for most caregivers. You'll need to pay attention to how you're feeling, in both body and mind. Even though you may be putting someone else's needs first, it's important to help yourself as you help them.

- **Stay on schedule with your own medical needs.** Keep up-to date with your own check-ups, screenings, and other health issues as best as you can. Try not to put things off for later.
- **Try to remember to take your medicines as prescribed.** Ask your doctor to give you a larger prescription to save trips to the pharmacy. Find out if your grocery store or pharmacy delivers. If you have health insurance, you may be able to get medicines mailed to you.
- **Try to eat healthy meals. Eating well will help you keep up your strength.** If your loved one is in the hospital or has long doctor's appointments, try to bring easy-to-prepare food from home. For example, sandwiches, salads, or packaged foods and canned meats fit easily into a lunch container.
- **Get enough rest.** It's very common for caregivers to have trouble sleeping. If you can, listen to soft music or do breathing or relaxation exercises to help you fall asleep. Short naps (15–30 minutes) can energize you if you aren't getting enough sleep. If it's hard to find a quiet place, try wearing earplugs. Getting help from a counselor to reduce your anxiety may also help you sleep better. Be sure to talk with your doctor if lack of sleep becomes an ongoing problem.
- **Exercise.** Walking, swimming, running, or bike riding are only a few ways to get your body moving. Any kind of movement (including working in the garden, cleaning, mowing, or going up stairs) can help you keep your body healthy. Finding at least 15–30 minutes a day to exercise may make you feel better and help you manage your stress.
- **Make time for yourself to relax.** Whatever helps you unwind, you should take the time to do it when you can. Some caregivers find it helpful to do exercises designed to help you relax, such as stretching or yoga. You could try deep breathing exercises or meditation too. It's important to tend to your own needs and reduce your own stress levels.

Ways to learn more

MedlinePlus

An online health information resource for patients and their families and friends.

Visit: [medlineplus.gov](https://www.nlm.nih.gov/medlineplus/)



Do You Need Help with Depression or Anxiety?

As mentioned earlier, many of the things listed below are common. This is especially true when you are dealing with a lot of stress. But if you have any of these signs for more than two weeks, let your health care provider know. They may have ideas for treatment or can refer you to a mental health professional.

Changes in your feelings

- feelings of being worried, anxious, “blue,” or depressed that don’t go away
- feeling guilty or worthless
- feeling overwhelmed, out of control, or shaky
- feeling helpless or hopeless
- feeling grouchy or moody
- crying a lot
- thoughts of hurting or killing yourself*
- focusing on worries or problems
- not being able to get a thought out of your mind
- not being able to enjoy things anymore (such as food, being with friends, sex)
- avoiding situations or things that you know are really harmless
- having trouble concentrating or feeling scatterbrained
- feeling that you are “losing it”

Body changes

- weight loss or weight gain without meaning to
- trouble sleeping or needing more sleep
- racing heartbeat
- dry mouth
- sweating a lot
- upset stomach
- diarrhea (loose, watery stools)
- slowing down physically
- fatigue that won’t go away
- headaches or other aches and pains

*If you have these thoughts, dial 911 in an emergency or call the National Suicide Prevention Lifeline at 1-800-273-TALK (1-800-273-8255), 24 hours a day, 7 days a week. You can also use the Lifeline Chat at the Lifeline website ([suicidepreventionlifeline.org/](https://www.suicidepreventionlifeline.org/)). The Lifeline is free, confidential, and available to everyone.

Finding meaning during cancer

Many caregivers find that their loved one's cancer causes them to look at life in new ways. They may reflect on spirituality, their purpose in life, and what they value most. It's normal to look at the cancer experience in both a negative and positive way. You and your loved one may be struggling to understand why cancer has entered your lives. You may wonder why you have to endure such a trial in your life.

Spirituality means the way you look at the world and how you make sense of your place in it. It can include faith or religion, beliefs, values, and "reasons for being." The way cancer affects one's faith or religion is different for everyone. Some turn away from their religion, while others turn toward it. It's common to question one's faith after cancer. But for others, seeking answers and searching for personal meaning helps them cope.

Many caregivers have found that their faith, religion, or sense of spirituality is a source of strength as they face life during cancer treatment. Many say that

- through their faith, they have been able to find meaning in their lives and make sense of the cancer experience
- faith or spirituality can be a way for caregivers and their loved ones to connect with others in their community, as they share like experiences or outlooks, or provide support.

Some ideas that have helped others find comfort and meaning are

- reading uplifting stories and articles
- praying or meditating, which may also help you feel less stress
- talking about your concerns or fears with a leader of your faith or spiritual community
- taking time to be alone with yourself or writing thoughts and feelings down
- finding spiritual or faith-based resources for people dealing with chronic illnesses like cancer



Helping with Visits to the Doctor

You will be asked to do many things during your loved one's treatment. One of your main roles may be to help your loved one work with doctors and other members of the health care team. You may be asked to go to doctor visits, among other things. A few tips are listed below.

- Keep a file or notebook of your loved one's medical information. Include the dates of procedures and tests. Bring this file to doctor visits.
- Keep a list of names and doses of medicines and how often they are taken. Bring this list with you.
- Use only trusted sources if you do research for your loved one, such as government and national organizations.
- Make a list of questions and concerns. List the most important questions first.
- Call ahead of time to make sure of the following:
 - The doctor has copies of all needed test results, records, and other paperwork.
 - You have directions, transportation, and, if needed, hotel information.
- If you and your loved one have a lot to talk about with the doctor, ask if you can have a longer appointment or schedule time to talk with a member of the health care team afterward.
- Talk with your loved one before the visit to help prepare yourselves for the possibility that the information given could be different than what you both expect.

Talking about cancer with your loved one's doctor

Below are some tips for you and your loved one when talking to the doctor.

- Don't be afraid to ask questions. You have a right to any information you need. Ask as many questions as you need to.
- After asking a question, if you're unclear about the answer, ask the doctor to explain more to help you understand. Or ask the question in a different way. It's okay to ask them to use more simple words and terms.
- Talk with the doctor about any medical advice you have found or heard on your own. Some advice may be incorrect, misleading, or may conflict with what the doctor has told your loved one.
- Take notes or ask if you can record the visit.
- Ask if there is a patient portal where your loved one can get their electronic clinic notes and test results. Many portals also allow for emails to and from the health care team.

- Find out how to reach out if there are follow-up questions after the visit. Get the phone number of someone on staff who you can call for help. For example, a nurse may be able to answer many of your questions.
- Let the doctor know if there are concerns about costs. The health care team wants to know if there are worries about finances for cancer treatment so they can help you find ways to manage them.
- Know that your loved one has the right to change doctors if they feel their needs aren't being addressed.

Your loved one's doctor and other members of the health care team also need to know about your needs. As the caregiver, you are a very important part of the team. Let them know when you're feeling stressed and overwhelmed. They need to know how you're doing and if you need help and support.



Asking about cancer pain

Although different side effects happen with cancer treatment, pain is one that can be especially troubling. Many caregivers say the one thing they hesitate to ask about is pain. If your loved one is preoccupied by pain, you may notice personality changes. These might include being distant, not being able to sleep, or not being able to focus on daily activities. People who have their pain managed can focus on healing and enjoying life.

Your loved one does not have to be in pain or discomfort. The medical team should ask regularly about pain levels, but it's up to you and your loved one to be open about any pain. Some people assume that there will always be severe pain with cancer treatment. This is not true. Pain can be managed throughout your loved one's treatment. The key is to talk regularly with the health care team about pain and other symptoms.

Sometimes people with cancer don't want to talk to their health care team about their pain. They worry that the doctor will think that they're complaining or that pain means the cancer is getting worse. Or they think that pain is just something they have to accept. Sometimes people get used to the pain and forget what it's like to live without it.

It's important for your loved one to speak up. Or you can speak up on their behalf. Be honest with the doctor about pain and how it's affecting the daily routine. You and your loved one may need to talk to the health care team on a regular basis about the pain medicines given. These drugs can be adjusted or changed if they aren't working or are causing unpleasant side effects.

Do not give up hope, for pain can be managed. For more information about pain control, see the NCI booklet, Cancer Pain Control at cancer.gov/publications/patient-education/paincontrol.pdf.

Should we get a second opinion?

Some people worry that doctors will be offended if they ask another doctor for a second opinion. Usually the opposite is true. Most doctors welcome a second opinion. And many health insurance companies will pay for them.

If your loved one gets a second opinion, the doctor may agree with the first doctor's treatment plan. Or the second doctor may suggest another approach. Either way, your loved one has more information and perhaps a greater sense of control. You can both feel more confident about the decisions you make, knowing that you've looked at your options.

Questions to Ask about Treatment

- What medical records, or copies, would you like us to bring?
- What can my loved one do beforehand to prepare for treatment?
- How long will the treatment take?
- Can my loved one go to and from treatment alone? Should someone else go with them?
- Can I or another family member be with my loved one during the treatment?
- What can I do to help them feel more comfortable during the treatment?
- What are the side effects of the treatment?
- After treatment, what do we need to watch for? When should we call you?
- How does filing insurance claims work? Who can help us if we have questions or problems?

Talking to Your Child about Your Loved One's Cancer

Helping children and teens cope

Be honest and open with your child. As a parent, your guidance has been central to your child's experience of the world. Being open and honest with your child gives them the space and opportunity to share their feelings with you and to ask questions. The same holds true when having conversations about cancer. Experts say that telling children the truth about cancer is better than leaving their imagination free to draw conclusions that are worse than reality.

Children as young as 18 months can understand the world around them. If you have a loved one with cancer, it's important to be honest with your child using words that are appropriate to your child's age and development. The sections below provide ideas for helping your child cope in healthy ways.

Start giving cancer information

For some families, talking about serious issues can be uncomfortable. But as hard as it may be, not talking about these issues can be worse for everyone. Here are some things you might want to say to children of any age about your loved one's cancer:

About cancer

- "Nothing you did, thought, or said caused the cancer."
- "You are not responsible for making them well. But there are ways you can help them feel better."
- "You can't catch cancer from another person."
- "Just because someone has cancer doesn't mean other people in the family will get it—even later. And that includes you."

About dealing with cancer

- "It's okay to be upset, angry, scared, or sad about all this. You may feel all kinds of feelings. You'll probably feel happy sometimes, too. It's fine to feel all these things."
- "No matter what happens, you will always be taken care of."
- "People may act differently around you because they're worried about you or worried about all of us."

"This is the only childhood they will ever have, a crucial time of development. Choose to see your illness not as an obstacle but as a powerful platform from which your messages are amplified, helping your children understand and believe you and feel your love in a powerful way... When the facts are couched in love and hopefulness, you can guide your children toward a life-enhancing perception of reality."
—Wendy Harpham, M.D.'*

* Harpham W. 2004. *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York, NY; Harper Paperbacks. Adapted with permission.

Tips for Talking about Cancer with Children of Different Ages

Youngest children (2–5 years old)

- Plan to talk for a very short time. Children this age can focus only for brief periods.
- Be clear and simple. It may help to draw a picture of what is happening.
- Tell them about any changes in their routine for the day or in the near future.
- Offer to answer any questions and to talk any time.



Young children (6–9 years old)

- Plan to talk for a short time. Children this age can focus only for brief periods. Plan more than one talk to cover what you need to say.
- Remember that young children may have strong feelings. They may express them by focusing on something else during your talk. This is okay. It allows them to deal with information and feelings at their own pace.
- Use examples. You could remind them of a time when they got sick and went to a doctor to get better.
- Help them to understand the things that will be happening soon. Children this age can't think weeks or months into the future.
- Let them know they will be taken care of and by whom.
- Answer all their questions. Invite them to talk more later.



Preteens (10–12 years old)

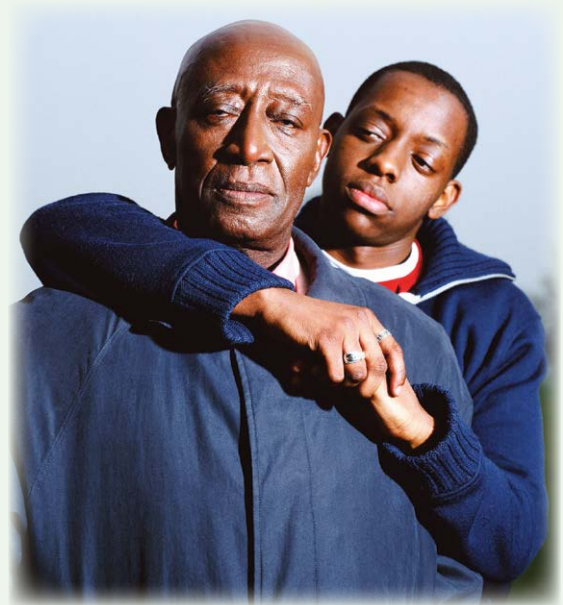
- Plan for a slightly longer talk. Let your child set the pace of the talk.
- Find out what your child already knows about cancer. Make sure that what they have heard applies to your loved one's situation. If not, give them the right information.
- Be aware that your child may ignore or avoid topics when they are afraid.

- Use simple, concrete information. For example, you could explain that there is a lump in your loved one's body that needs to be removed.
- Talk not only about now, but also about the future. For example, tell them how the cancer may affect your family at holidays or upcoming events.
- Tell your child you will do your best to answer their questions. Let them know you're there to talk whenever they want.



Teens (13–18 years old)

- You may be able to have a longer talk. Let your teens set the pace.
- Be prepared if your teens try to ignore or avoid topics. Teens may act this way because they're afraid or even embarrassed. They may not want to talk about your loved one's body. This may be especially true if your loved one's cancer is in the breast or sex organs.
- Teens often need time to themselves to deal with their feelings. They may want to be alone or with friends. Give them this time.
- Teens should be told the facts about the cancer. This can help you correct any wrong information that they may have. Give your teens booklets or websites to read later. They may want to do their own research. If so, make sure that what they learn is from a reliable source and applies to your loved one's situation.
- Often teens ask many "what if" questions. They may want to know more about the future. Again, answer their questions as best you can. And let them know you'll be glad to talk again later.
- Teens may also want to know how the cancer will affect them. Will it disrupt their social life? Will they have to do more chores? This is normal. Be honest with them.



Be open to all forms of communication

Very young children may have trouble talking about the impact of their loved one's illness on them. You might try asking them to draw a picture of the person with cancer. Or have them play dolls, with one doll being the patient. Other forms of art can help older children express themselves, such as painting, drawing, writing or performing poetry, or listening to or playing music.

Keep in mind that young children may ask the same question over and over. This is normal, and you should calmly answer the question each time. Your child may also ask tough questions or questions for which you don't have answers. Be honest with them. When you don't know the answer, say so. You can work together to get an answer. If that's not possible, you can show them how to live with unanswerable questions and uncertainty. Remember that thinking through these issues is part of your children's process of growing up.

Answering questions about your loved one's cancer*

Be prepared for your child's questions and concerns about cancer. They may worry, even if your loved one's prognosis is good.

- Teach them that cancer is an illness. If your loved one's prognosis is good, let them know that the type of cancer they have is one for which the doctors have good treatments to get them well again.
- Ask them what they think about your loved one's cancer and what they worry about. Then listen patiently to their answers. Correct misinformation.
- Tell them the truth, couched in love and hopefulness. Instead of trying to convince them of a good outcome (something that you can't guarantee), reassure them that your loved one is getting good care.
- Remind your child that you will keep them updated. Encourage them to focus on today.

* Harpham W. 2004. *When a Parent Has Cancer: A Guide to Caring for Your Children*. New York, NY; Harper Paperbacks. Adapted with permission.

Staying involved in your child's life while caregiving

It can be hard to remain active in your child's life as you take care of your loved one during their treatment. But it may be more important than ever to do so. Below are some ways that other caregivers have stayed connected with their children.

■ Focus on the most important activities.

If you can only do one thing with your child, what's the most important? Make a list of all the options. If possible, get their input. You may be surprised by what they choose.

■ Send someone else.

Is there another adult in your child's life who can go to an event that you can't? Maybe this adult can record or take pictures of the event.

■ Carpool.

If you have time, try to take turns carpooling with other parents. It will allow you to be present with your child, even if they're talking with others.

■ Be around before and after their events.

It can be hard to attend things such as sports games, recitals, or other events. If you can, try to be present beforehand while they're getting ready or be there to welcome them home.

■ Ask for a replay.

If you can't be there, sit down with your child to hear about what they did. Ask someone to record the event so you can watch it together later. Or have your child recreate some of the things that happened.

■ Create new ways of connecting.

Come up with new ways to connect with your child. Make a point of tucking them in at bedtime or saying goodnight, reading to them, eating together, or talking on the phone or by email or text. Have a set time when your child does homework while you do something else in the same room. Or, take a walk together. Even 10 minutes alone with your child without interruptions can make a world of difference.

■ Involve your child in "your" activities.

Could they join you for any daily tasks or activities? Even going to the grocery store could be time spent together.

■ Stay involved with their schooling.

Check with the teachers to find out how your child is doing in school. Or ask a guidance counselor or coach for input.

Helping your child cope with their feelings*

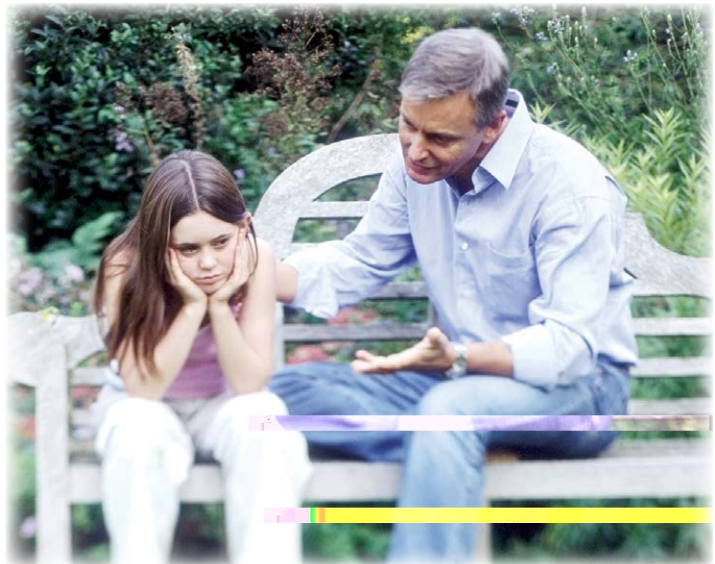
Children react to a loved one's cancer in many different ways. They may

- be confused, scared, angry, lonely, or overwhelmed
- be scared or unsure how to act when they see the effects of treatment on your loved one
- act clingy or miss the attention they used to get
- feel responsible or guilty
- get angry
- get into trouble at school or neglect their homework
- have problems eating, sleeping, keeping up with schoolwork, or relating to friends

While these reactions can be normal, it's important to know that your child may need extra support to deal with their emotions. Below are some tips for handling their feelings.

If your child seems confused or scared:

- Remind them that you love them.
- Set aside special time that your child can spend with you or your loved one with cancer.
- Try to stick to reassuring routines, such as bedtime rituals or checking in with them after school.
- Be together, even if you are each doing different things in the same room.
- Prepare your child for changes and side effects of cancer treatment (such as hair loss, vomiting, or tiredness) so they won't be surprised.
- Remind your child that your loved one may seem worse for a while before they get better. Explain that this is all part of cancer treatment and doesn't have to mean they won't improve.



* Bromberg JJ, McCabe CS, Patenaude AF. 2002. *We Can Cope: When a Parent Has Cancer*. Newton, MA: Inflexion.
"Adapted with Permission."

If your child seems lonely or misses the attention they used to get:

- Help your child talk about their feelings and ask you questions. Let them know you're listening and validate their feelings.
- Find new ways to give your child attention. You may want to leave notes where they will find them or schedule special phone conversations if you're spending a lot of time at the hospital or away from home.
- Think of a special treat your child might enjoy.
- Encourage them to talk with other kids or adults to ease their loneliness.



If your child has stopped doing their regular activities:

- It isn't okay for your kids to respond to the changes at home by stopping normal activities or letting grades and friendships slide. Find out why your child has stopped any usual activities. They may be
 - feeling tired
 - feeling unhappy
 - having trouble getting along with friends
 - unable to concentrate or succeed
- Ask your child how you can help them get back to their normal routines. You could also ask them if they'd like to talk to their school counselor or a therapist outside the school for support. This is something you might like to do as well if you feel like you need extra guidance during this time.

If your child feels guilty and think they somehow caused the cancer:

- State clearly, and remind them, "You did not cause the cancer. You can't cause cancer by anything you do, think, or say."
- Explain in simple ways how cancer develops.
- Read a children's book together that talks about having a loved one with cancer. Your hospital social worker or patient educator should have some examples. You can also ask a local librarian for help.
- Ask a doctor or nurse to explain the facts.

If your child feels angry or resentful that their own lives are affected:

(for example, having to be quiet, doing more chores, missing out on fun activities with friends)

- Validate their feelings. Talk with them about what's causing the anger. Even though you may know that the anger comes from fear or fatigue, it's important to listen to what they say and acknowledge their feelings.
- Help your child understand that their anger may be a stand-in for something else. Maybe they're really angry at the cancer or at the family. Maybe they're scared or worried. Or maybe they're sad.
- Do your best to try not to get angry back at them. Again, the anger is probably about something else.

If your child starts to rebel or gets into trouble:

- Tell your child that you understand how they feel. You know that this situation is hard.
- Find out if they're acting out of fear, anger, loneliness, or boredom. Whatever the feeling, remind them that it's okay to feel that way. But it is not okay to act out in this way. If necessary, ask a teacher, pediatrician, or counselor for advice and support.

Understanding teenagers' feelings

With your teens, problems may be harder or less obvious than with younger children. Having a parent or other family member with cancer or taking care of someone with cancer brings extra burdens to kids at this age. Some common issues they struggle with include

- increased anxiety and depression
- extra stress and worry
- trouble keeping up with schoolwork
- problems being on time to class or attending at all
- lack of time for social activities
- trouble balancing school with a job, especially if they're busy caregiving too

Teenagers are moving towards independence from their families. They're also trying to balance schoolwork, time with friends, and activities. Cancer in the family makes this harder to do, leading some kids to act out or withdraw. Keep in mind:

- Some teens may give off the message, "leave me alone." But they still need and want your attention and support.
- This age is always stressful. Some moods you see may have nothing to do with your loved one's illness.

- Try to keep the lines of communication open. Involve them in decisions as much as possible.
- You can ask your hospital social worker about internet resources for this age group. Many organizations have online chats and forums for support.
- Make sure they're keeping up with friends, sports, social activities, and hobbies. It's important to keep their life as normal as possible.
- It's good to talk to their teachers or encourage them to do so. It's very important that teachers and school officials know what your child is going through and the added stressors they're dealing with.
- Direct them to NCI's page Support for Teens When a Family Member Has Cancer at [cancer.gov/about-cancer/coping/caregiver-support/teens](https://www.cancer.gov/about-cancer/coping/caregiver-support/teens). You can also show them the NCI booklets When a Parent Has Cancer and When Your Brother or Sister Has Cancer at [cancer.gov/publications/patient-education](https://www.cancer.gov/publications/patient-education).

Understanding college students' feelings

All of the above about teens can be true for college students too. Young people in this group are also in a transition period. They're trying to balance classes and studying while deciding their next steps in life. Whether it's close to home or long-distance, having a loved one with cancer can cause the same issues mentioned above for teens. If you can, try these ways to help:

- Remind them that they can talk to their advisor or college counselor. They can go over the course load and schedule together, looking for ways to find balance.
- Advise them to talk to their professors if necessary. They might be able to adjust assignments or change dates of exams. It may also help teachers understand why they have been absent or late to class a lot.
- Ask them to do what they can to stay healthy. They need to keep up their strength and take care of their body. Remind them to try to eat healthy foods, exercise, and get good sleep.
- Encourage them to make time for themselves. They shouldn't neglect their social life. It's important for them to spend time with friends, enjoy clubs or other activities, or take part in sports.
- Urge them to take advantage of their school's wellness center or student health center. They should have counselors on staff in case your child needs to talk to someone about what they're going through.



Talking to Your Partner with Cancer

Some relationships get stronger during cancer treatment. Others may feel more stressed. Nearly all caregivers and their partners feel more stress than usual as a couple. They often feel stress about

- knowing how to best support each other
- dealing with new feelings that come up
- figuring out how to communicate
- making decisions
- changing roles
- juggling lots of roles (such as childcare, housekeeping, work, and caregiving)
- changing their social life
- changing their daily routine
- not feeling connected sexually

“I try to give my wife time to think things through. Not to be so quick to try and fix everything.” —Gail

People express their emotions differently. Some like to talk things out or focus on others. And some prefer to express emotions by doing things, such as washing the dishes or fixing things around the house. They may be more likely to focus inward. These differences can cause tension because each person may expect the other to act the way they would in their place. To reduce stress, it may help to remind yourself that everyone reacts differently.

Bringing up hard topics with your loved one with cancer

Bringing up tough subjects is emotionally draining. You may think, for example, that your loved one needs to try a different treatment or doctor. Or they may be worrying about losing independence, being seen as weak, or about being a burden to you, but don't want to talk about it. Here are some tips on how to bring up hard topics:

- Practice what you'll say in advance.
- Know that your loved one may not want to hear what you have to say.
- Find a quiet time and ask if it's okay to talk.



- Be clear on what your aims are. (Let your loved one know why you are having this talk and what you hope will come from it.)
- Speak from your heart.
- Allow time for your loved one to talk. Listen and try not to interrupt.
- Don't feel the need to settle things all at once.
- You don't have to always say, "It'll be okay."

Sometimes the best way to communicate with someone is to just listen. This is a way of showing that you're there for them. It may be one of the most valuable things you can do. And it's important to be supportive to whatever your loved one wants to say. It's their life and their cancer.

People need to process their thoughts and fears in their own time and in their own way. You could also ask whether they're willing to think about the issue and talk another time. Your loved one may even prefer to talk with someone else about the topic.

Some people won't start a conversation themselves, but may respond if you begin first. Here are some ways caregivers do this:

- "I know this is hard to talk about, but know that I'm ready to listen or to talk any time."
- "I feel that it would be helpful to talk about how your treatment is going so far and how we're both coping with it. Would you be willing to talk with me about that sometime this week?"

Sometimes it helps to ask other caregivers how they talk to their loved one with cancer, or others close to them. For example, you may want to ask:

- "How do you keep someone's feelings in mind when you're coping with so many feelings of your own?"
- "How do you talk about these hard topics and still stay supportive?"

If you continue to have trouble talking about the cancer and other painful issues, you could ask for professional advice. A mental health expert may be able to help you explore issues that you don't feel you can yourselves. But if your loved one doesn't want to go with you, you can always make an appointment to go by yourself. You may pick up some ideas for how to bring up these topics and talk about other feelings that you're coping with right now.

Ways to improve communication

Some couples find it easier to talk about serious issues than other couples. Only you and your partner know how you communicate with each other. The sections below may help you think about ways to address sensitive issues that work for both of you.

Be open about the stress you have

Some things that cause stress for you and your partner can't be solved right now. Sometimes talking about these things can be helpful. You may want to say up front, "I know we can't solve this today. But I'd like to just talk about how it's going and how we're feeling."

Topics to explore may include how each of you

- deals with change and the unknown
- feels about being a caregiver or being cared for
- handles changing roles in your relationship or home
- wants to connect with one another
- sees what issues may be straining the relationship
- feels, or would like to feel, cared for and appreciated
- feels thankful for the other person

"I've noticed that my boyfriend tries to stay really positive with everyone else, even his good friends. He'll say he's feeling and doing great. This is frustrating for me because when I'm with him, I see that he isn't." —Emily

Make decisions together

You and your partner may need to be a team now more than ever. It may help to think things through together such as the examples below.

- Which decisions should you make together?
- Which decisions should each of you make alone?
- What were some other tough times that you got through together? How is this situation similar or different?
- Which family tasks could you share?
- What kinds of tasks are easier for you? Which ones are harder?
- What does each of you need?
- How can others help?

Find ways to say thanks

Perhaps your partner used to do a lot to keep your family going. And now, because they're sick, you're trying to get used to less help. This can be frustrating and may even make you feel resentful from time to time. It may be hard to notice the small things your partner is still doing to help out. There's often too much going on. But when you can, try to look for these things, and thank your partner for doing them. Showing a little gratitude can make both of you feel better.

Make dates with each other

Many couples find that it helps to plan special occasions. Some days may end up being better than others for these dates, depending on how your partner feels. So you may need to be okay with last-minute changes.

Your dates don't have to be fancy. It's about spending time together. That can mean watching a video, going out to eat, or looking through photos. It can be whatever you both like to do. You can also plan these dates to include other people, if you miss being around others.

Find ways to be intimate

You may find that you and your partner's sex life is different than it used to be. Many things could be affecting it such as

- your partner is tired, in pain, or uncomfortable
- you're tired
- your relationship feels distant or strained
- you or your partner may not be comfortable with the way your partner looks due to treatment
- you may be afraid of hurting your partner
- your partner's treatment might be affecting their interest in sex or ability to perform

You can still have an intimate relationship in spite of these issues. Intimacy isn't just physical. It also involves feelings. Here are some ways to improve your intimate relationship:

- **Talk about it.** Choose a time when you and your partner can talk. Focus on just talking. Talk about how you can both renew your connection.
- **Try not to judge.** If your partner isn't performing, try not to read meaning into it. Let your partner talk—or not talk—about what they need.
- **Make space.** Protect your time together. Turn off the phone and TV. If needed, find someone to take care of the kids for a few hours.
- **Take it slow.** Reconnect. Plan an hour or so to be together without being physical. For example, you may want to listen to music or take a walk. This time is about reconnecting.
- **Try new touch.** Cancer treatment or surgery can change your partner's body. Areas where touch used to feel good may now be numb or painful. Some of these changes will go away. Some will stay. For now, you can figure out together what kinds of touch feel good, such as holding, hugging, and cuddling.
- **Talk to a therapist or counselor.** There are many who deal with intimacy and sexuality issues with cancer patients.

“I feel like it's been such a blessing to be able to show my husband way beyond words how much I love him. And to see him fighting cancer because of his love for life. It's a privilege to be so closely involved in something of such value and importance.”

—Rose Mary

Communication Troubles

Studies show that open and caring communication works best. Yet caregivers often run into

- tension from different ways of communicating
- lack of sensitivity or understanding about appropriate ways to talk and share feelings
- people who don't know what to say, won't communicate at all, or won't be honest



Talking to Other Family Members and Friends

Any problems your family may have had before the cancer diagnosis are likely to be more intense now. This is true whether you're caring for a young child, an adult child, a parent, or a spouse. Your caregiver role can often trigger feelings and role changes that affect your family in ways you never expected. And relatives you don't know very well or who live far away may be present more often, too, which may complicate things. Some people have said that

- seeing their adult child ill can trigger feelings of needing to protect or help them

"Watching my daughter go through cancer is really painful for me. I can't stand not being able to help her. But they won't let me help out. She and her husband like to handle things by themselves." —Margo

- seeing their parent as someone who needs their help can be hard to accept

"My mother got cancer. Just like she nursed me back to health as a child, I wanted to do the same for her. Yet she's used to doing everything herself. She keeps saying, 'I'm still your mother.'" —Faith

"I have my own life, with young kids to take care of, and a job. It's hard trying to figure out how to help my dad." —Jason

- seeing an in-law or a friend's parent worry or try to help out can feel like "too much"

"I need to run my own home. I know his mother just wants to help, but she's too much in my business right now." —Keisha

Hold a family meeting

Sometimes other close family and friends may not agree on what should be done. It's very common for families to argue over treatment options. Or they argue because some caregivers help more than others.

While everyone may be trying to do what they think is best for your loved one, family members may disagree about what this means. Everyone brings their own set of beliefs and values to the table, which makes decisions hard. It is often during these times that families ask their health care team to hold a family meeting.

Talk with your loved one to see if they want a family meeting. Ask if they would like to be involved. At the meeting, all members share as much information as they can. You can ask a social worker or counselor to be there, if needed. If you need to, you can bring a list of issues to discuss. Meetings can be used to

- have the health care team explain the goals for treatment
- let the family state their wishes for care
- give everyone an open forum in which to express their feelings
- clarify caregiving tasks

During these meetings, family members may want to talk about how they feel. Or they may want to talk about what kind of help they can give to the patient. Each person may have certain skills to offer. At the end of the meeting, ask the health care team to summarize and help plan the next steps.

Keep people updated

Often, you will be the main person updating family, friends, and coworkers about how your loved one with cancer is doing. Ask your loved one what they want to share, with whom, and when. If this is a task that someone else can do, select a "point person." This person can make phone calls or send email or letters to update others.

If you have created a website to keep others informed about your loved one, the point person or someone else can help update that as well. Also, it's important to let others who care know whether your loved one likes getting cards, calls, or visits.

"You do want to stay positive and upbeat. But at the same time, I feel like you want to share your reality with other people in your family so that they can know how to support you and how not to be shocked if things get worse."—Maya

What to do when support isn't helpful

If people offer help that you don't need or want, thank them for their concern. Let them know you'll contact them if you need anything. You can tell them that it always helps to send cards and letters. Or they can pray or send good thoughts.

Sometimes people offer unwanted advice on parenting, medical care, or any number of issues. It can be unpleasant to hear such comments. For example, some caregivers have shared,

- “We have a problem with a member of my husband’s family. She doesn’t live here and keeps questioning all our decisions. It’s gotten so bad that we’ve had our doctor explain to her that she’s not here all day, and, therefore, doesn’t understand the situation. She has been a real pain.”
- “I feel like people really want her to do the treatment they are suggesting, rather than what we feel is best. It’s making this harder than it needs to be.”

People often offer unwanted advice because they aren't sure what else they can do. They may feel helpless to do anything, yet want to show their concern. While it may come from a good place, it can still seem judgmental to you.

It's your decision on how to deal with these opinions. You don't have to respond at all if you don't want to. If someone has concerns about your kids that seem valid, talk to a counselor or teacher about what steps to take. Or if the concerns are about your loved one, you can talk to the medical team. Otherwise, it might help to just thank them. And reassure them that you are taking the necessary steps to get your loved one and family through this tough time.



“My mother came by and commented on how much television the kids were watching. She made some remark about how she knew I was stressed, but could I find something better for them to do? I told her I’ve got a lot on my mind, and I needed her understanding.” —Carrie

Life Planning

It's common to feel sad, angry, or worried that your lifestyle may change because of your loved one's cancer. You may have to make major decisions that will affect your job or your finances. Finding ways to cope with these issues can bring some peace of mind.

Facing fertility issues

Some people are concerned about the effects of cancer treatment on their ability to have children. If this is true for you and your loved one, talk to the doctor before your loved one starts treatment. Ask about options for protecting fertility. Or the doctor can recommend a counselor or fertility specialist. This person can discuss available options and help you and your loved one make informed choices. (For more information, call Livestrong Fertility at 1-877-236-8820 or go to livestrong.org.)

Handling money worries

The financial challenges that people with cancer and their families face are very real. During an illness, you may find it's hard to have enough time or energy to review your options. Yet it's important to keep your finances in order as best as you can. Some tips are below.

- **Be aware of your costs from the very beginning.** Costs can vary depending on where you live, what insurance you have, and what each hospital charges. You will also want to think about the costs of drugs, travel, childcare, or anything else that may be a result of your loved one's cancer. As much as possible, know what costs to expect from the start.
- **Learn about payment and other options from the hospital financial office.** For hospital bills, you or they may want to talk with a hospital financial counselor. You may be able to work out a monthly payment plan or even get a reduced rate. You also should stay in touch with the insurance company to make sure certain treatment costs are covered.
- **Talk to your loved one's doctors.** Tell the health care team if you think the costs of care could be a burden for you and your loved one. Talking with them about these issues may make you feel uncomfortable, but they are there to help you. Some patients say it makes them feel better to share their concerns with their doctor. Then decisions about what treatments to use and what medicines to use can be made with those concerns in mind.

"I'm not working for the money. I'm working for the benefits. If we don't have benefits, we could lose everything." —Philip

■ **Understand your loved one's health insurance.**

It's normal to feel confused about what health insurance covers and the details of the plan. But it's important to understand the policy and to create an organized way to pay and follow up on health care bills. Call the insurance company and talk with a benefits coordinator. Ask about co-pays, deductibles, and any other costs. Ask how and when to make payments.



Ways to learn more

- **Managing Costs and Medical Information.** These NCI web pages have more details about understanding costs and insurance, and ways to keep track of medical information.

Visit: cancer.gov/about-cancer/managing-care/track-care-costs

- **Coping with Cancer When You're Uninsured.** A fact sheet by CancerCare that lists ways to get health insurance or find the resources you need.

Visit: cancer.org/publications/300-coping_with_cancer_when_you_re_uninsured

- **Cancer Financial Assistance Coalition.** A coalition of organizations helping cancer patients manage their financial challenges.

Visit: cancerfac.org

- **National Organizations That Offer Support Services.** A database from NCI where you can choose from a list of services to search, including financial help.

Visit: supportorgs.cancer.gov

Call toll-free: 1-800-4-CANCER (1-800-422-6237) and ask for help.

Handling problems with your job

One of the greatest sources of strain for some caregivers is trying to balance work demands with providing care and support to a loved one. Caregiving can have effects on your work life in many ways, such as

- causing mood swings that leave coworkers confused or reluctant to work with you
- making you distracted or less productive
- causing you to be late or call in sick because of the stress
- creating pressure from being the sole provider for your family if your spouse or partner is not able to work
- creating pressure to keep working, even though retirement may have been approaching

It's a good idea to learn more about your company's rules and policies related to a family member's illness. See if there are any support programs for employees. Many companies have employee assistance programs with work-life counselors for you to talk to. Some companies have eldercare policies or other employee benefit programs that can help support you. Your employer may let you use your paid sick leave to take care of your loved one. Or they may let you take leave without pay.

If you work for a small company or a single employer, and there are no policies in place, you could try to arrange something informally. Examples include flex-time, shift-exchanging, adjusting your schedule, or telecommuting as needed.

Ways to learn more

Triage Cancer

Provides free education on the legal and practical issues that may impact people with cancer and their caregivers, including employment and workplace issues after a cancer diagnosis.

Call: 424-258-4628

Visit: tragecancer.org

Cancer Legal Resource Center

Addresses the legal issues faced by people with cancer and provides information and resources about cancer-related legal issues to those in the cancer community.

Call: 1-866-843-2572

Visit: thedrlc.org/cancer

The Family and Medical Leave Act

This law states that covered employers must give eligible employees up to 12 work weeks of unpaid leave during a 12-month period to care for an immediate family member with a serious health condition.

Visit: dol.gov/agencies/whd/fmla

American Society of Clinical Oncology (ASCO)

ASCO's patient information website, cancer.net, is for people living with cancer and their caregivers. Visit their Financial Resources page for national and local organizations that help people with cancer who are facing financial challenges.

Visit: cancer.net/navigating-cancer-care/financial-considerations/financial-resources

Looking at living arrangements

Sometimes treatment raises questions about living arrangements. When making these decisions, you should ask questions such as,

- What kind of help does your loved one need, and for how long?
- Could you rearrange your house or apartment? Or move to a smaller or different one?
- Is it risky for your loved one to be home alone?

You'll also need to consider how your loved one feels. They may fear

- losing their independence
- being seen as weak or a burden to you and others
- moving to a health care or other type of assisted living facility

These are tough issues. Sometimes it's easier to consider a change in living arrangements when the advice comes from a health care professional. Social workers, doctors, nurses, home care providers, and agencies that work with older adults may be able to help you talk to your loved one.

Preparing advance directives

If you have not done so already, it's important to start talking with your loved one about advance directives. Advance directives are legal papers that tell the doctors what to do if your loved one can't tell them themselves. The papers let the patient decide ahead of time how they want to be treated, stating their wishes and goals for care.

These decisions can seem overwhelming. But patients should keep in mind that avoiding these decisions when they are well will only place a heavier burden on them and their loved ones later on. Even if your loved one has a good prognosis, they should fill out advance directives. These may include a living will and a durable power of attorney.

“My partner and I sat down together as he filled out his living will. We made sure we were in agreement with one another. It relieves me of a lot of stress and worry I was having.” —John

Legal Papers At-A-Glance

Advance directives:

- A living will lets people know what kind of medical care patients want if they are unable to speak for themselves.
- A durable power of attorney for health care names a person to make medical decisions for a patient if they can't make them. This person, chosen by the patient, is called a health care proxy.

Other legal papers that are not part of the advance directives:

- A will tells how a person wants to divide money and property among their heirs. (Heirs are usually the surviving family members. Other people may also be named as heirs in a will.)
- Power of attorney appoints a person to make financial decisions for the patient when they can't make them.

Note: A lawyer does not always need to be present when you fill out these papers. However, a notary public may be needed. Each state has its own laws about advance directives. Check with a lawyer or social worker about the laws in your state.

Reflection

As a caregiver, you try to strike a balance each day. You have to care for your loved one while keeping up with the demands of family and work. Your focus tends to be on the patient's needs. But it's also up to you to try to stay in tune with yourself. Remember the things you need to maintain a healthy mind, body, and spirit. And, if you can, try to find a quiet time for reflection each day. Meditating, praying, or just resting may help you keep a sense of peace at this time.

Whether good or bad, life-changing situations often give people the chance to grow, learn, and appreciate what's important to them. Many people who care for someone with cancer describe the experience as a personal journey. They say it has changed them forever. This is much like the way people with cancer describe their experience. It's not necessarily a journey that caregivers would have chosen for themselves. But they can use their skills, strength, and talents to support their loved one while finding out more about themselves along the way.

*“If you find it in your heart
to care for somebody else,
you will have succeeded.”
—Maya Angelou*

Caregiver's Bill of Rights

I have the right to **take care of myself**. This is not an act of selfishness. It will give me the ability to take better care of my loved one.

I have the right to **seek help from others** even though my loved one may object. I know the limits of my own endurance and strength.

I have the right to **maintain parts of my own life** that do not include the person I care for just as if they were healthy. I know that I do everything that I reasonably can do for this person. I have the right to do some things just for myself.

I have the right to get angry, be depressed, and **express difficult feelings** once in a while.

I have the right to **reject any attempt** by my loved one to make me do things out of guilt or anger. (It doesn't matter if they know they are doing it or not.)

I have the right to **get considerations, affection, forgiveness, and acceptance** for what I do for my loved one, as I offer these in return.

I have the right to **take pride in what I'm doing**. And I have the right to applaud the courage it has taken to meet the needs of my loved one.

I have the right to **protect my individuality**. I also have the right to a life that will sustain me when my loved one no longer needs my full-time help.

—Jo Horne



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