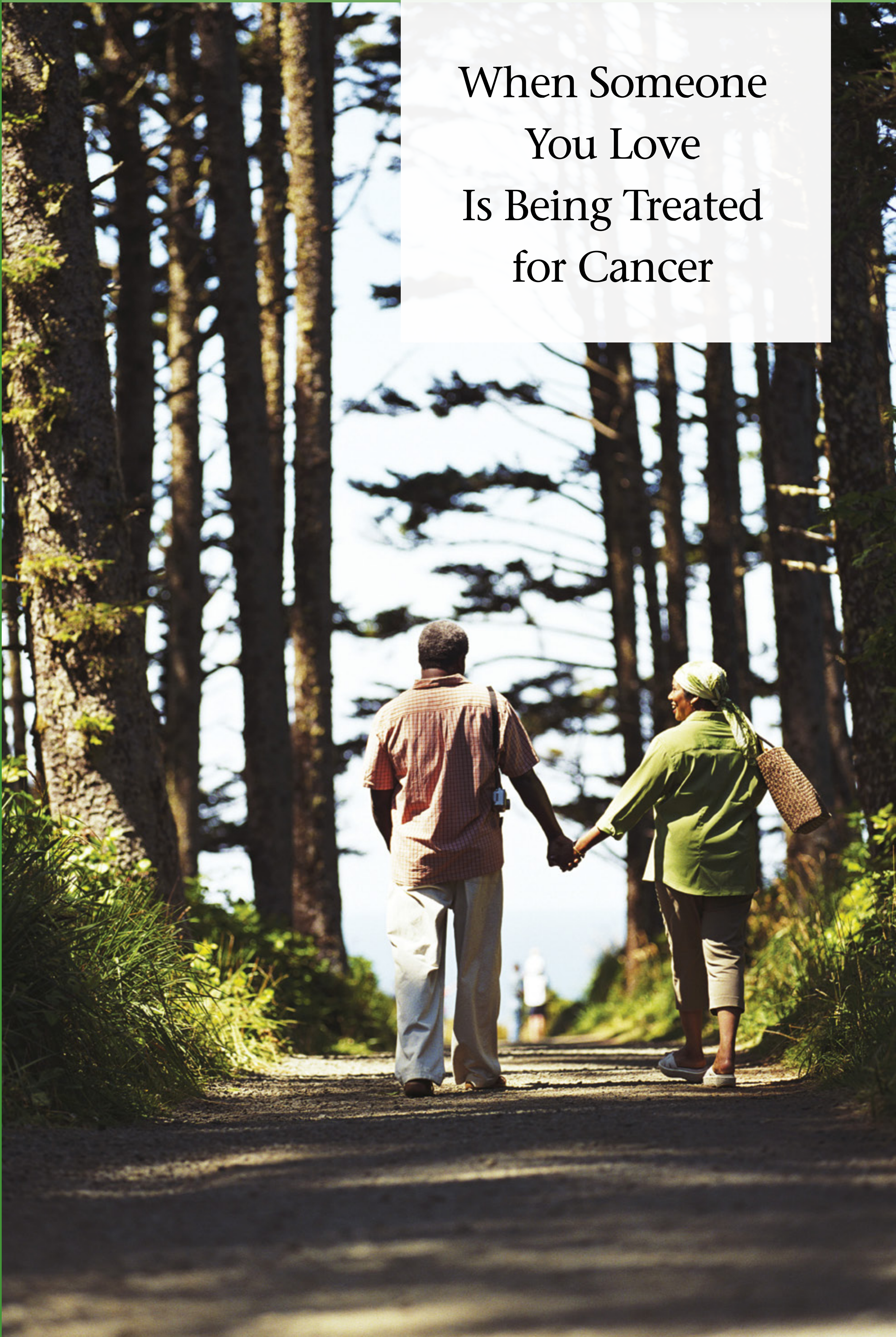
National Cancer Institute

Support for Caregivers

When Someone You Love Is Being Treated for Cancer



U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES
National Institutes
of Health

For more information…

The following free booklets may be helpful if your loved one is receiving cancer treatment:

- *Chemotherapy and You*
- *Coping With Advanced Cancer*
- *Eating Hints for Cancer Patients*
- *Taking Part in Cancer Treatment Research Studies*
- *Pain Control*
- *Radiation Therapy and You*
- *Taking Time*
- *Thinking About Complementary and Alternative Medicine*
- *When Cancer Returns*

These booklets are available from the National Cancer Institute (NCI). To learn more about specific types of cancer or to request any of these booklets, visit NCI's website (http://www.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.

When Someone You Love Is Being Treated for Cancer

"You definitely need to learn ways to take care of yourself. Because if you're not taking care of yourself, you can't take care of anyone else. Don't be afraid to ask questions and don't be afraid to ask for help." —
Francis

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.

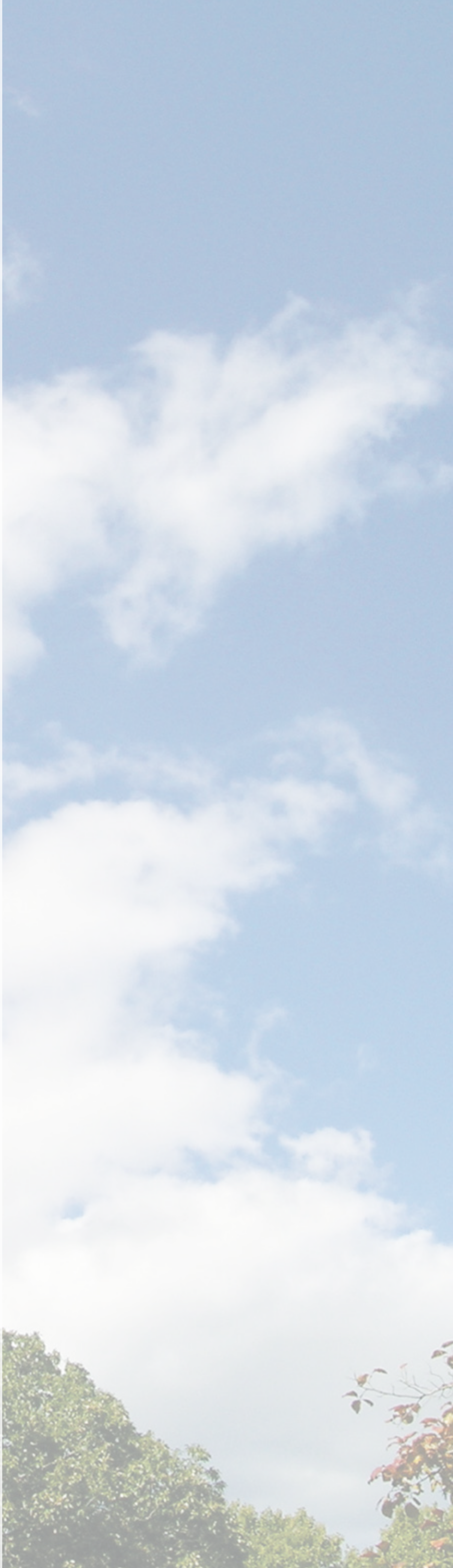
Use this booklet in whatever way works best for you. You can read it from front to back. Or you can just refer to different sections as you need them.

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 are caring for. In addition, for ease of reading, we alternate using the pronouns **"he"** and **"she"** when referring to the person with cancer.

Other booklets for caregivers that can be ordered or printed from the NCI website are:

- *Facing Forward: When Someone You Love Has Completed Cancer Treatment*
- *When Someone You Love Has Advanced Cancer*
- *Young People With Cancer: A Handbook for Parents*
- *When Your Parent Has Cancer: A Guide For Teens*
- *When Your Brother or Sister Has Cancer: A Guide for Teens*



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Who Is a Caregiver?

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**.

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. Every situation is different. So there are different ways to give care. There isn't one way that works best.

Caregiving can mean helping with day-to-day activities such as doctor visits or preparing food. But it can also be long-distance, coordinating care and services for your loved one by phone or email. Caregiving can also mean giving emotional and spiritual support. You may be helping your loved one cope and work through the many feelings that come up at this time. Talking, listening, and just being there are some of the most important things you can do.

Giving care and support during this challenging time isn't always easy. 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 give care to *you*.**

> "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

Adjusting to Being a Caregiver

Changing Roles

Whether you're younger or older, 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 that person 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. Common situations that they describe:

- Your spouse or partner may feel comfortable with only you taking care of him.
- Your parent may have a hard time accepting help from you (her adult child) since she's always been used to caring for you.
- Your adult child with cancer may not want to rely on his parents for care.
- You may have health problems yourself, making 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 other loved ones or join a support group. Or you may choose to seek help from a counselor or psychologist. 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 ones. See "Talking with Family and Friends" on page 21 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

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 you go through treatment with the patient. 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 that they exist and that having them is normal. 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 the patient. Sometimes anger comes from feelings that are hard to show, such as fear, panic, or worry. Or it may come from resentment of all that you're going through. If you can, try to avoid lashing out at others because of these emotions. 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 remain angry at those around you, seek help from a counselor or other mental health professional.

"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

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 work 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, how the cancer will affect 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 health care provider. 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.

Hope or hopelessness. You may feel hope or hopelessness to different degrees throughout your loved one's cancer treatment. And what you hope for may change over time. You may hope for a cure most of all. But you may also hope for other things, such as comfort, peace, acceptance, and joy. If you're not able to get rid of a feeling of hopelessness, talk to a trusted family member, friend, health provider, or spiritual or faith leader. As a caregiver, feelings of hope can get you through the next 5 minutes or the next 5 days.

"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

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 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 12 for ways to connect with others.

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 it may help to share your feelings with them when they're calm. 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.

Knowing Your Strengths and Limits

One way that caregivers cope is to focus their energy on things they can control. This can mean:

- Helping schedule doctor visits
- Helping with daily needs such as meals and errands
- Taking on your loved one's tasks
- Learning more about cancer and treatment options
- Doing whatever else you can do

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.

> "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

Setting Your Priorities

Make a list of your weekly tasks and activities. Figure out how much time you spend on each one and how important it is. Scratch things off your to-do list if they aren't important. That will give you more time for the things you really want and need to do. This may mean disappointing someone else. But you need to take care of what's important to you, regardless of what others may think. Most people will understand if you tell them what is going on.

> "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

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 the patient goes through treatment. 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.

How Can Others Help You?

Would you find it helpful if someone made dinner for you or ran some of your errands? If so, you may benefit from having people help with tasks you don't have time to do.

People want to help, but many don't know what you need or how to offer it. It's okay for you to take the first step. Ask for what you need and for the things that would be most helpful to you. For example, you may want someone to:

- Help with household chores, such as cooking, cleaning, shopping, yard work, and childcare or eldercare
- Talk with you and listen to your feelings
- Drive your loved one to appointments
- Pick up a child from school or activities
- 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
- Be the contact person and help keep others updated on your loved one's situation

Who Can Help?

Think about people who can help you with tasks. Think of all the people and groups you know, including family, friends, neighbors, and coworkers. Members of your faith community, civic groups, and associations may also be able to help. The hospital or cancer center may also be able to tell you about services they offer, or have a list of agencies to call.

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 come into your home to 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, but also 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.

> "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

Be Prepared for Some People to Say No

Sometimes people may not be able to help. This may hurt your feelings or make you angry. It may be especially hard coming from people that you expected help from. You might wonder why someone wouldn't offer to help you. Some common reasons are:

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

If someone isn't giving you the help you need, you may want 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.

Tips on How to Ask for Help

Roadblock	**What Others Have Done**
“His cancer is a private thing. I’d have to tell people about it to get any support.”	You and your loved one can decide who to tell, what to tell them, and when and how. Some options are to: ■ Tell only a few people close to you for now. ■ Limit specifics about what you share. You can say, “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.
“Everyone has a lot going on. I don’t want to bother them or put them out.”	If you’re worried about being a burden to others, here are some things to think about: ■ Many people probably want to help. ■ 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?
“I can’t explain it, but I just don’t feel up to reaching out right now.”	Many people don’t want support when they need it most. You may often back away from your regular social life and from people in general. You may feel that it’s just too much work to ask for help. 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.
“It’s my duty to take care of my family, not someone else’s.”	Having a support system is 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.

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 her 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 telephone 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

Many long-distance caregivers say that it helps to explore both paid and volunteer ways to provide support. Try to create a support network of people who live near your loved one whom you could call day or night in a crisis or just to check in. You could also look into volunteer visitors, adult day care centers, or meal delivery services in the area. Having a copy of the local phone book for your loved one's area or a list of websites can also give you quick access to resources. Share a list of home, work, and cell phone numbers with the health care team and others in case of an emergency.

> "Our family is spread throughout the U.S., 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, 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 Web site to share news about your loved one's condition and needs.
- Talk to electronic or computer experts to find out about other ways to connect with people. New advances using video and the Internet are being made every day.
- 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 or companies that help people with cancer and their families.
- If you are 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.
- Consider getting a phone card from a discount store to cut down on long-distance bills. Or, review your long-distance and cell phone plans. See if you can make any changes that would reduce your bills.

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 41.)

Taking time to recharge your mind, body, and spirit can help you be a better caregiver. You may want to think about:

- Finding nice things you can do for yourself—even just a few minutes can help
- Cutting back on personal activities, rather than cutting them out entirely
- Finding things others can do or arrange for you, such as appointments or errands
- Looking for easy ways to connect with friends
- Finding larger chunks of "off-duty" time

Myths About Taking Care of Yourself*

Myth	Fact
"Taking care of myself means that I have to be away from my loved one."	**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 do not neglect yourself.**
"Taking care of myself takes a lot of time away from other things."	**Some self-care takes only a few minutes, such as reading an upbeat passage from a book. Other self-care can be done in moments between longer tasks.**
"I'd have to learn how to focus on myself. I don't know if I can start."	**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 Nurture Yourself

Take Stock of Your Own Feelings

Giving yourself an outlet for your own thoughts and feelings is important. Think about what would help lift your spirits. Would talking with others help ease your load? Or would you rather have quiet time by yourself? Maybe you need both, depending on what's going on in your life. It's helpful for you and others to know what you need.

> *"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." —Adele*

Find Comfort

Your mind needs a break from the demands of caregiving. Think about what gives you comfort or helps you relax. Caregivers say that even a few minutes a day without interruptions helps them to cope and focus.

Take 15–30 minutes each day to do something for yourself, no matter how small it is. ("See Small Things I Can Do for Me" on page 12.) For example, caregivers often find that they feel less tired and stressed after light exercise. Try to make time for taking a walk, going for a run, or doing gentle stretches.

You may find that it's hard to relax even when you have time for it. Some caregivers find it helpful to do exercises designed to help you relax, such as stretching or yoga. Other relaxing activities include taking deep breaths or just sitting still.

Small Things I Can Do for Me

Each day, take some time to do something for yourself, no matter how small it is. This might include:

- Napping
- Exercising or yoga
- Keeping up with a hobby
- Taking a drive
- Seeing a movie
- Working in the yard
- Going shopping
- Catching up on phone calls, letters or email

You may find that it's hard to relax even when you have time for it. Some caregivers find it helpful to do exercises such as deep breathing or meditating.

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.

> "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

If you can't find a group in your area, try a support group on the Internet. Some caregivers say websites with support groups have helped them a lot.

Talk to a Counselor

You may be feeling overwhelmed and feel like talking to someone outside your inner circle of support. Some caregivers find it helpful to talk to a counselor, social worker, psychologist or other mental health professional. Others also find it helpful to turn to a leader in their faith or spiritual community. All may be able to help you talk about things that you don't feel you can talk about with your loved one or others around you. You also might find ways of expressing your feelings and learn ways of coping that you hadn't thought of before.

Connect with Your Loved One

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.

Connect with Others

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. Try to find someone you can really open up to about your feelings or fears. You may find it helpful to talk with someone outside the situation. Also, it may help to have an informal network of people to contact, either by phone or in person. But if you're concerned about a caregiving issue, you may want to talk with your loved one's doctor. Knowledge can help reduce fears.

"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

Look for the Positive

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 helps them feel better. Once a day, think about something that you find rewarding about caregiving, such as gratitude you've received, or extra support from a health care provider. You might also take a moment to feel good about anything else from the day that is positive—a nice sunset, 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. You can read humor columns, watch comedy shows, or talk with upbeat friends. Or just remember funny things that have happened to you in the past. 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 and onto the paper.

Be 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. But finding meaning in caregiving can make it easier to manage.

Do Your Usual Activities

If you can, try to keep doing some of your regular activities. Studies show that not doing those activities increases the stress you feel. Keep it simple and stick with things you do well. Be willing to change your routines. You may have to do things at a different time of day or for less time than you do normally.

Learn More About Cancer

Sometimes, understanding your loved one's medical situation can make you feel more confident and in control. For example, you may want to know more about his 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. (See the Resources section on page 42.)

Caring for Your Body

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 your health. Taking care of yourself will give you strength to help others.

New stresses and daily demands often add to any health problems caregivers already have. And if you are 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:

- Fatigue (feeling tired)
- 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 Yourself

These ideas for taking care of yourself 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:

- **Keep up with your own checkups, screenings, and other medical needs.**
- **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.
- **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, 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.** Listening to soft music or doing breathing exercises may help you fall asleep. Short naps can energize you if you aren't getting enough sleep. 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 exercise (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.** You may choose to stretch, read, watch television, or talk on the phone. Whatever helps you unwind, you should take the time to do it. It's important to tend to your own needs and reduce your own stress levels.

Do You Need Help with Depression or Anxiety?

As mentioned earlier, many of the things listed below are normal. 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. He or she may have ideas for treatment.

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

Finding Meaning During Cancer

Many caregivers find that cancer causes them to look at life in new ways. They may reflect on spirituality, the purpose of life, and what they value most. It's normal to view the cancer experience both negatively and positively at the same time. 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.

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 religion can also be a way for caregivers and their loved ones to connect with others in their community. These may be people who share similar experiences or outlooks, or who can provide support. Studies have also shown that for some, faith can be an important part of both coping with and recovering from cancer.

Here are ways you may find comfort and meaning through your faith or spirituality:

- Reading materials that are uplifting and can help you connect to a higher power
- Praying or meditating to help you feel less fearful or anxious
- Talking about your concerns or fears with a leader of your faith or spiritual community
- Going to religious or spiritual gatherings to meet new people
- Talking to others who have had similar experiences
- Finding spiritual or faith-based resources for people dealing with chronic illnesses like cancer

Talking with the Health Care Team

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 his health care team. You may be asked to go to doctor visits, among other things. A few tips are listed below.

Helping to Get Ready for Visits to the Doctor

- Keep a file or notebook of the patient'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 the patient have a lot to talk about with the doctor, ask whether:
    - You can have a longer appointment (check on fees for this).
    - You can talk to the doctor by phone if there are further questions. Or perhaps others on staff can help you. For example, a nurse may be able to answer many of your questions.
- 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 with the Doctor

If your loved one takes you with him to talk with the doctor, here are some tips:

- After asking a question, if you're unclear about the answer, ask the doctor to explain more to help you understand.
- Talk with the doctor about any medical advice you have found on your own. Some advice may be incorrect or misleading, or may conflict with what the doctor has told your loved one.
- If a concern isn't being addressed, ask the question in a different way. This may help the doctor understand your concern better.
- Take notes or ask if you can tape-record the visit.
- Know that your loved one has the right to change doctors if he feels his needs aren't being addressed.

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 him?
- Can I or another family member be with my loved one during the treatment?
- What can I do to help her 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?

Asking About Pain

People who have their pain managed are able to focus on healing and on enjoying life. 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.

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 his behalf. Be honest with the doctor about pain and how it is 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.

Don't be afraid to ask for stronger pain relievers or larger doses if your loved one needs them. Addiction is rarely an issue in people with cancer. Instead, drugs help patients stay as comfortable as possible. People with a history of addiction will want to talk with their doctor about any concerns. To learn more, see the NCI booklet, *Pain Control*. (See inside cover.)

Should We Get a Second Opinion?

Some people worry that doctors will be offended if they ask 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.

Helping Children and Teens Cope

Children as young as 18 months begin to understand the world around them. It's important to be honest with them and explain that your loved one has 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.

Your own daily stresses and fears can affect how you act with your kids. You may be torn between wanting to give time to your kids, and knowing your loved one with cancer also needs your time. That's why it's good to let children know how you're feeling, as well as to find out how they're feeling. And never assume you know what your children are thinking. You can't predict how they will react to changes, losses, and information.

This section provides ideas for helping children cope in healthy ways.

Start Giving Information

For some families, talking about serious issues is 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 her well. But there are ways you can help her feel better while the doctors take good care of her."
- "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, MD*

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

Be Open to All Forms of Communication

Very young children may have trouble talking about the impact of their parent'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.

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. Teens may ask difficult questions or questions for which you don't have answers. Be honest with them. When the answer is not known, you can teach your teens to live with unanswerable questions and uncertainty. Remember that thinking through these issues is part of your children's process of growing up.

Talking About Death*

Be prepared for your children's questions and concerns about death. 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 he or she has is one for which the doctors have good treatments to get him or her 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, you are hoping for a recovery, and that your children can live well with the uncertainty.
- Teach your children that even if the unexpected happened due to cancer or anything else, they would be taken care of and be okay. Although they would feel sad for a while and they would miss your loved one, they would also feel that love forever and learn how to be happy again.
- Remind them that your loved one is *not* dying now. Reassure them that you will tell them if this ever changes and dying becomes a possibility. Conclude by telling them you expect and hope your loved one to get better, and encourage them to focus on today.

Stay Involved in Activities

It can be hard to remain active in your children's lives during your loved one's treatment. But it may be more important than ever to do so. On the next page are some ways that other caregivers have stayed connected with their children.

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

Ways to Stay Involved in Your Children's Lives

- **Focus on the most important activities.**
  If you can only do one thing with each of your children, what's the most important? Make a list of all the options. If possible, get the children's 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 videotape or take pictures of the event.

- **Carpool.**
  Take turns driving with other parents.

- **Be around before and after.**
  Try to be around to help prepare your children for an activity and to welcome them home.

- **Ask for a replay.**
  If you can't be there, sit down with your children to hear about what they did. Or have your children re-create some of the things that happened.

- **Create new ways of connecting.**
  Come up with new ways to connect with your children. Make a point of tucking them in at bedtime, reading to them, eating together, or talking on the phone or by email. Have a set time when your children do homework while you do something else in the same room. Or, take a walk together. Even 5 minutes alone with each child without interruptions can make a world of difference.

- **Involve your children in "your" activities.**
  Could your children join you for any of your activities? Even going to the grocery store could be time spent together. Your children may feel special if they can attend adult events with you.

- **Stay involved with their schooling.**
  Check with their teachers to find out how your children are doing in school. Or, ask a guidance counselor or coach for input.

Understand Your Children's Actions and 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 treatment's effects on your loved one
- Act clingy or miss the attention they used to get
- Feel responsible or guilty
- Get angry if they're asked to do more chores around the house
- Get into trouble at school or neglect their homework
- Have trouble eating, sleeping, keeping up with schoolwork, or relating to friends
- Be angry that someone else is taking care of them now

These behaviors are normal. Still, your child may need extra support to deal with their troubles. (See the tips on the next page.)

Understanding Teens' Feelings

With teens, problems may be less obvious or more complicated than with younger children. Here are some things to keep in mind:

- Teens are supposed to be moving toward independence from their families. This is natural for them. Cancer makes this harder to do, leading some teens to act out or withdraw.
- Teens may give off the message, "leave me alone." But they still need and want your attention and support.
- Being a teen is always stressful. Some moods you see may have nothing to do with your loved one's illness.
- Teens want to feel "normal." Make sure that they have time for regular activities.
- Keep the lines of communication open. Involve teens in decisions as much as possible. Make sure that they have someone to talk to about what is going on in their life.

It may be hard for you to stay on top of your teen's activities and feelings right now. If so, ask another responsible adult to stay connected with your teen. Also, ask your social worker about Internet resources for this age group. Many organizations have online chats and forums for support.

How Children May React, and What to Do*

If your children seem confused or scared:

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

If your children seem lonely or miss the attention they used to get:

- Help your children talk about their feelings and ask you questions. Let them know you're listening and validate their feelings.
- Find new ways to give your children 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 children might enjoy.
- Encourage them to talk with other kids or adults to ease their loneliness.

If your children have 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 children have stopped any usual activities. They may be:
  - Feeling tired
  - Feeling unhappy
  - Having trouble getting along with friends
  - Unable to concentrate or succeed

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* J. I. Bromberg, C. S. McCabe, A. F. Patenaude. 2002. *We Can Cope: When a Parent Has Cancer*. Newton, MA: Inflexxion.

- Talk about the importance of adjusting to these changes at home. Ask your children how you can help them get back to their normal routines.

If your children feel 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.
- Ask a doctor or nurse to explain the facts.

If your children feel 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 children 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 children start to rebel or get into trouble:

- Tell your children that you understand how they feel. You know that this situation is hard.
- Find out if they are acting out of fear, anger, loneliness, or boredom. Whatever the feeling, remind them that it is 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.

Tips for Talking 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.

Pre-Teens (10–12 years old)

- Plan for a slightly longer talk. Let your children set the pace of the talk.
- Find out what your children already know 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 children 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 children 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.

Communicating with Your Partner with Cancer

> "I try to give my husband time to think things through. Not to be so quick to try and fix everything."
> —Pauline

Some relationships get stronger during cancer treatment. Others are weakened. 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 child care, housekeeping, work, and caregiving)
- Changing their social life
- Changing their daily routine
- Not feeling connected sexually

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

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 she may be worrying about losing independence, being seen as weak, or about being a burden to you, but doesn'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 in one talk.
- 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 are 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 her life and her cancer. People need to process their thoughts and fears in their own time and in their own way. You could also ask whether she is 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 another person's feelings in mind when you're coping with so many feelings of your own?
- How do you talk about tough topics and still stay supportive?

If you continue to have trouble talking about the cancer and 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 are 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. The sections below may help you think about ways to address sensitive issues that work for both of you.

Be Open About Stress

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."

> "I've noticed that my husband tries to stay really positive with everyone else, even his parents. He'll say he's feeling and doing great. This is frustrating for me because at home, I see that he isn't."
> —Emily

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 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 his life. It's a privilege to be so closely involved in something of such value and importance." —Rose Mary

Become a Team

You and your partner may need to be a team now more than ever. It may help to think things through together:

- 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 he's sick, you're trying to get used to less help. 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

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 old 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:

- 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 his or her interest in sex or ability to perform.

> "After 42 years of marriage, there's that bond that doesn't need words." —George

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 he or she needs.
- **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.

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

Communicating with 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 your adult child ill can trigger feelings of needing to protect or help him or her.

> *"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."*

- Seeing your parent as someone who needs your 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.'"*
>
> *"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."*

- 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."*

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 she wants a family meeting. Ask if she 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:

"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

- 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.

Choose the Right Time

Sometimes when one person feels like talking about important things, the other person doesn't. Try choosing a time when you and the person you want to talk to won't be doing other things. Find a quiet place, turn off the TV, and don't answer the phone.

Keep People Updated

Often, you will be the main person updating family, friends, and coworkers about how the patient is doing. Ask your loved one what he wants 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. Or if you've created a website to keep others informed about your loved one, they can update that as well. It's important to let others who care know whether your loved one likes getting cards, calls, or visits.

How to Communicate When Support Isn't Useful

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 him 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, 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 starting treatment. You may want to ask about options for protecting your 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 Fertile Hope at 1-888-994-HOPE, or go to http://www.fertilehope.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 family financially healthy.

For hospital bills, you or your loved one 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.

For information about resources that are available, see the Resources section on page 42. You can also get the NCI fact sheet, "Resources for Financial Assistance for Patients and Their Families," at http://www.cancer.gov, by searching for the terms "financial assistance." Or call toll-free 1-800-4-CANCER (1-800-422-6237) to ask for a free copy.

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

Handling Work Issues

"A lot of times I come home from being at the hospital with no sleep and then have to go to work the next morning. It's very tiring." —Betsy

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 these:

- 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 your employer doesn't have any policies in place, you could try to arrange something informally. Examples include flex-time, shift-exchanging, adjusting your schedule, or telecommuting as needed.

The Family and Medical Leave Act may apply to your situation. 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 the U.S. Department of Labor website at http://www.dol.gov/esa/whd/fmla for more information. For sources of support, see the Resources section on page 42.

Looking at Living Arrangements

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

- What kind of help does your loved one need, and for how long?
- Could you remodel the house 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. She may fear:

- Losing her 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 himself. The papers let the patient decide ahead of time how he wants to be treated, stating his wishes 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, he should fill out advance directives. These may include a living will and a durable power of attorney.

> "My husband 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 guilt I could have had." —Alma

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 he or she 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 his or her 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 he or she can't make them.

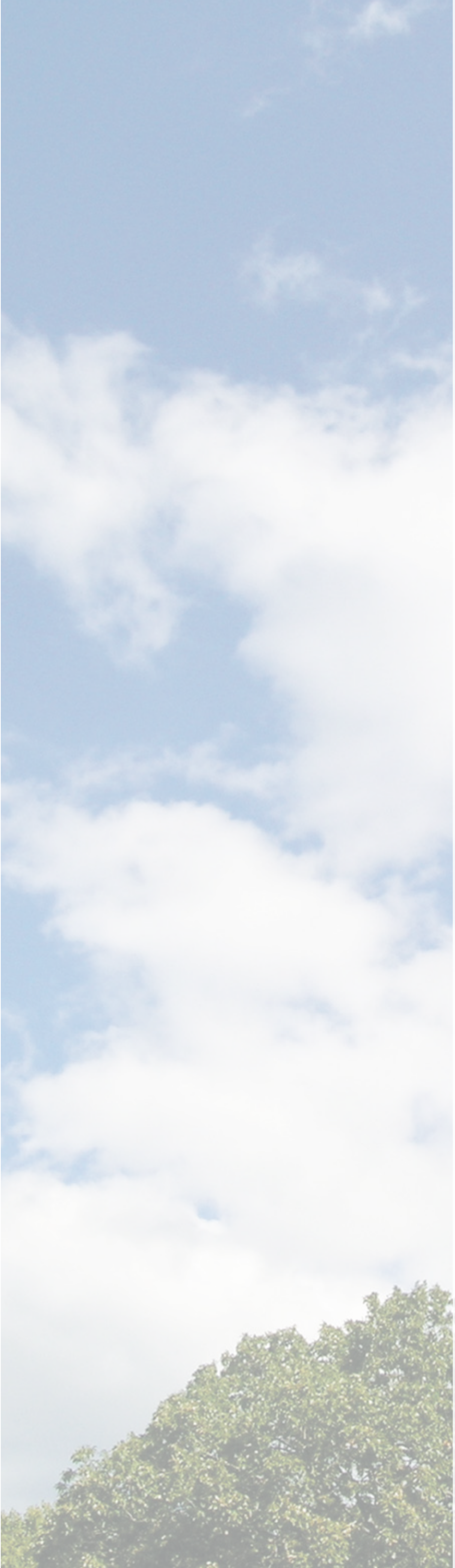
Note: A lawyer does not always need to be present when you fill out these papers. However, a **notary public** may be needed. Each state has its own laws about advance directives. Check with a lawyer or social worker about the laws in your state. (For more, see the Resources on page 42.)

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 he was 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 she knows 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.

(Author unknown)

Cancer Information and Support

For more resources:

See *National Organizations That Offer Cancer-Related Services* at http://www.cancer.gov. In the search box, type in the words "national organizations."

Or call 1-800-4-CANCER (1-800-422-6237) to seek more help.

Federal Resources

National Cancer Institute

Provides current information on cancer prevention, screening, diagnosis, treatment, genetics, and supportive care.

Visit..................http://www.cancer.gov

Cancer Information Service

Answers questions about cancer, clinical trials, and cancer-related services and helps users find information on the NCI website. Provides NCI printed materials.

Toll-free.................. 1-800-4-CANCER (1-800-422-6237)
Visit........................... http://www.cancer.gov/aboutnci/cis
Chat online .... Click on "LiveHelp" from the home page.

Administration on Aging

Provides information, assistance, individual counseling, organization of support groups, caregiver training, respite care, and supplemental services.

Phone.............1-202-619-0724
Visit..................http://www.aoa.gov

Centers for Medicare and Medicaid Services

Provides information for consumers about patient rights, prescription drugs, and health insurance issues, including Medicare and Medicaid.

Toll-free.........1-800-MEDICARE (1-800-633-4227)
Visit..................http://www.medicare.gov (for Medicare information) or
http://www.cms.hhs.gov (other information)

Equal Employment Opportunity Commission

Provides fact sheets about job discrimination, protections under the Americans With Disabilities Act, and employer responsibilities. Coordinates investigations of employment discrimination.

Toll-free.........1-800-669-4000
TTY...................1-800-669-6820
Visit..................http://www.eeoc.gov

- **National Association of Area Agencies on Aging**
  Eldercare Locator

  The Eldercare Locator is a nationwide directory assistance service designed to help older persons and caregivers find local resources for support. Areas of support include transportation, meals, home care, housing alternatives, legal issues, and social activities.

  Toll-free.........1-800-677-1116
  Visit..................http://www.eldercare.gov

- **U.S. Department of Labor**
  Office of Disability Employment Policy

  Provides fact sheets on a variety of disability issues, including discrimination, workplace accommodation, and legal rights.

  Toll-free.........1-866-ODEP-DOL (1-866-633-7365)
  TTY...................1-877-889-5627
  Visit..................http://www.dol.gov/odep

Non-Profit Organizations

- **American Cancer Society (ACS)**

  Mission is to end cancer as a major health problem through prevention, saving lives, and relieving suffering. ACS works toward these goals through research, education, advocacy, and service. The organization's National Cancer Information Center answers questions 24 hours a day, 7 days a week.

  Toll-free.........1-800-ACS-2345 (1-800-227-2345)
  TTY...................1-866-228-4327
  Visit..................http://www.cancer.org

- **American Pain Foundation**

  Serves people with pain through information, advocacy, and support; pain and resource information, practical help and publications are available through toll-free telephone service and website.

  Toll-free.........1-888-615-PAIN (1-888-615-7246)
  Visit..................http://www.painfoundation.org

- **CancerCare**

  Offers free support, information, financial assistance, and practical help to people with cancer and their loved ones.

  Toll-free.........1-800-813-HOPE (1-800-813-4673)
  Visit..................http://www.cancercare.org

- **Cancer Support Community**

  The CSC is dedicated to providing support, education, and hope to people affected by cancer.

  Toll-free 1-888-793-9355
  website...........http://www.cancersupportcommunity.org

Fertile Hope

Fertile Hope provides reproductive information, support, and hope to cancer patients who are at risk for treatment-related infertility.

Toll-free.........1-888-794-HOPE (4673)
Visit..................http://www.fertilehope.org

Lance Armstrong Foundation

The Lance Armstrong Foundation seeks to inspire and empower people living with, through, and beyond cancer to live strong. It provides education, advocacy, and public health and research programs.

Phone.............1-512-236-8820 (general number)
Toll-free.........1-866-235-7205 (LIVESTRONG SurvivorCare program)
Visit..................http://www.livestrong.org

NeedyMeds

Lists medicine assistance programs available from drug companies.
NOTE: Usually patients cannot apply directly to these programs. Ask your doctor, nurse, or social worker to contact them.

Visit..................http://www.needymeds.com

National Coalition for Cancer Survivorship (NCCS)

Gives out information on cancer support, employment, financial and legal issues, advocacy, and related issues.

Toll-free.........1-877-NCCS-YES (1-877-622-7937)
Visit..................http://www.canceradvocacy.org

National Family Caregivers Association (NFCA)

NFCA provides information, education, support, public awareness, and advocacy for caregivers.

Toll-free.........1-800-896-3650
Visit..................http://www.nfcacares.org

Patient Advocate Foundation

Offers education, legal counseling, and referrals concerning managed care, insurance, financial issues, job discrimination, and debt crisis matters.

Toll-free.........1-800-532-5274
Visit..................http://www.patientadvocate.org

The Well Spouse Foundation

The foundation provides support to wives, husbands, and partners of chronically ill and/or disabled persons.

Toll-free.........1-800-838-0879
Visit..................http://www.wellspouse.org

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