# What You Need to Know as a Cancer Caregiver

## Who are caregivers, and what do they do?

Here we will talk about caregivers as the unpaid loved ones who give the person with cancer physical and emotional care. Caregivers may be partners, family members, or close friends. Most often, they are not trained for the caregiver job. Many times, they're the lifeline of the person with cancer.

Here are a few things caregivers might help the person with cancer do, or in some cases even do for them:

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

All of this work costs caregivers time and money. There may also be a cost to the caregiver's health and well-being, but often the caregiver just keeps doing what needs to be done and may suffer in silence.

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

Here we discuss some of the more common challenges caregivers may have to deal with while helping a loved one with cancer. It may help you to know this:

**Caregivers who take care of their own needs and get the information, help, and support they need are better prepared to take care of their loved ones.**

We will give you ideas on how to take care of yourself and find the support and help you need. We will also give you tips on how to be ready for some of the problems that might come up. Being a caregiver is a tough job, but it's an important and rewarding one, too. Today, more than 13 million Americans have or have had cancer. Each of them probably needed a caregiver at some point to help them through their cancer experience, especially the first year or 2 after diagnosis. This is when most of the treatment takes place and caregivers can be very important to its success.

There are some ways to make your work easier and more effective. We will discuss these topics here:

- Communication
- Understanding the health care system
- Making health decisions
- Long-distance caregiving
- The treatment timeline
- Organizing medical treatment and paperwork
- Taking care of yourself
- Asking for help
- Job, insurance, and money concerns
- Legal issues
- Where you can get more information about caregiving and coping

# Communication

Good communication lets you express yourself, help others understand your limits and needs, and understand the limits and needs of the person with cancer. You'll need to be able to talk to the patient, the medical team, friends, family, and even people you barely know who are concerned about the patient. This can be hard to do. And when you need information from the medical team, it may not be possible to get it without signed permission from the patient.

A few tips to help you communicate clearly:

- Respect your own feelings, needs, and desires, as well as those of the patient.

- Speak out about your feelings while being sensitive to those of others.
- Try to use “I” statements rather than “you” statements. For instance, say, “I need a break” instead of “You never help me!” Beware of statements like, “I feel you ignored me,” which says to the other person that he or she did something wrong. Instead, try “I didn’t hear you answer when I mentioned ______,” or “I need help with this problem.”
- Focus on the present rather than bringing up old patterns or hurts.

## How do I talk to the patient?

Start with the patient. Let them know you want to be there for them and want and need to be included in their care. Try something like:

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

It’s good to set a goal of openness and sharing right from the start. Remind each other that you’re “on the same team.” Share your fears and worries. Sometimes it may be hard and you’ll disagree and maybe even fight, but openness will help you deal with the conflict. It will also help you keep supporting each other and reduce distress and anxiety. Acceptance and sharing will help keep your relationship strong.

You can learn more about how to talk with the person with cancer in our document called *Listen With Your Heart*.

## How do I talk with the medical team?

### First, get the patient’s consent.

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

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

If you don’t have a form like this completed yet, you probably won’t be able to get certain kinds of information. But you can still share information with the doctor. You can tell the office staff that you are giving information rather than asking for it. Even without the patient’s consent, you can try asking for general information about problems the patient has; for example, “Is vomiting one of the side effects of the chemotherapy that Joe got this week?” Or you can ask for advice; for instance, “If Joe has been vomiting for 2 days, should we come in to see you?” Even though you may not get details of Joe’s care, you may be able to get some help in deciding what to do next.

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

If you want to learn more about informed consent, decision-making, or other forms that may affect treatment decisions, please see our documents called *Informed Consent* and *Advance Directives*.

## Which doctor do I talk to?

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

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

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

If you want to know more about how to talk with the health care team, please see our documents called *Health Professionals Associated With Cancer Care* and *Talking With Your Doctor*.

Most health experts who work in the field of cancer do so because they care about the needs of people with cancer. When you look back on this experience, some of your strongest memories may be of those health care providers who were with you through a really hard time.

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

Going to see the doctor with the patient is a good way to learn more about his or her medical condition. This can be very helpful when caring for the patient later on. It can also help the patient who forgets to mention problems to the doctor and/or comes home without the information you need. And finally, if you need a referral, maybe for a specialist, social worker, or medical supplier, you may be able to get the names of people who can help.

## How do I use time with the doctor well?

The average doctor’s appointment is about 10 to 15 minutes or even less, so it helps to be ready for each visit. You and the patient should figure out the most important things you need to talk about before you go. For instance:

- What symptoms do you need to tell the cancer team about?
- When did these symptoms start?

Making a list ahead of time to take with you will help you to use your time in the office well. And it means you won’t forget anything important.

Don’t leave the office until the doctor answers all your questions and you both understand what to do next. Nurses can also be great sources of information, and you might get to spend more time with them than the doctor. Take notes on what’s said to you. This will help you keep track of what you should remember. If you’re getting back test results, be sure you understand the results before you leave. If blood work or other tests were done, find out when and how you’ll get the results. Also, ask who will tell you what the results mean.

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

## What should I know about new medicines?

If the patient gets a prescription for a new medicine, be sure you know the name of the drug, what it’s for, and why they are getting it. Some other things you need to know are:

- How and when should the medicine be taken?
- What’s the dose?
- Should it be taken with food, water?
- Are there side effects? (Like sleepiness, nausea, or dry mouth?)
- How will you know if it’s working? How long before you can expect it to work?
- Will it interfere with any other medicines or supplements the patient is taking?

- Are there foods, vitamins, or medicines that should be avoided while taking this drug?
- What should you do if a dose is forgotten? Take another? Skip it?
- How much does it cost? Will health insurance cover it? Is there a generic substitute?

Be sure you add the new medicine to the list of all the medicines the patient is taking. (See the section called "Organizing medical treatment and paperwork.")

## How can family meetings help?

Today's families are very busy, and it can be hard to keep everyone up to date on what's happening with the patient. Family members may feel frustrated and left out. They may not understand the medical condition, especially if the patient is having problems. They also might not know that their help and ideas are needed, or how best to help.

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

- The latest report from the doctor: How things are going; what to expect next.
- Sharing feelings and concerns
- What the person with cancer wants and needs.
- How much time each family member has to help out or visit.
- Ways each person can help. What other help might be available.
- Financial concerns about caregiving
- How much the caregiving plans will cost
- How much work family members can afford to miss
- Other financial help available
- Help for the main caregiver (help with meals, shopping, cleaning, laundry, yard work, child care, etc.)
- How to get breaks from caregiving from time to time
- Emotional support for patient and caregiver by phone or email
- Who can help with medical care, like taking the patient for treatment or to doctor's appointments

- Who can help with sharing news and updates on the patient’s condition so that the main caregiver doesn’t have to spend time repeating the news each day

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

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

# Understanding the health care system

Going into a hospital, doctors’ office, or talking to a health insurance company can be scary and stressful. The people may seem to speak a different language, everyone may seem rushed, and you and the patient may feel overwhelmed. This is normal. It takes time to get to know your doctor and feel comfortable with him or her. It also takes time to get to know how the health care system works.

The patient is an important partner in their own health care, and so is the caregiver. You have a right to be treated with respect. Each health expert who sees the patient should listen to your concerns and spend enough time with you to answer your questions.

As you probably already know, not all health professionals are skilled in talking with patients and families. Many forget that the terms, procedures, and machines that they use every day are new and possibly frightening to others.

Don’t be afraid to ask questions. And then don’t give up until you get and understand the answer.

It helps to know about and keep lists of the different health professionals you may meet. You can learn more about this in our document called *Health Professionals Associated With Cancer Care*.

# Making health decisions

The health care team will always discuss major health decisions with a patient if the patient can think clearly and share their thoughts. And the patient’s decisions about their own health will be followed when their decisions do not create safety issues.

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

## What if we can’t agree on something important?

It’s good to know that you and the patient don’t always have to agree. Some of the decisions and problems that come with a cancer diagnosis can be very tough and very emotional. Remember to let the person with cancer make decisions about his or her care whenever possible. There are some things you can do to help them make the best choice:

- Explain your needs and wants clearly and let the patient to do the same. As an example, you may need to do this when deciding whether to give certain treatments, such as IV antibiotics, at home or in an infusion center. The patient may want to do this at home, but will need your help. You might need to say “This is too scary for me. I don’t think I can do this at home, but I can make sure you’re at the clinic every day.” Look for common ground: you both want the patient to get the best possible care, which includes antibiotics, but you feel strongly that you cannot safely give IV drugs at home.

- Offer choices or a time limit when decisions need to be made. A change in medicines is a good example. “Let’s try this sleeping pill for a few nights and see if it helps you get some rest. If not, we’ll talk to Dr. Smith about trying something else.”

- Focus your energy and influence on the issues that are important. Let the patient make as many choices as possible. For example, arguing over what clothes to wear probably isn’t the best use of anyone’s energy. But not taking medicines or not following activity restrictions may be issues that you can’t ignore. If reasoning with the patient doesn’t work, explain that you will talk to the medical team and get their help – then do it.

Again, open communication with the person you are caring for is the most important part of your role. Speak up for the patient and his or her needs. Help the patient get needed information. Get input from other team members, then offer your support and encouragement.

## When do I call the doctor?

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

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

You can find more details on dealing with symptoms and when to call the doctor in our booklet, *Caring for the Cancer Patient at Home: A Guide for Patients and Families*. You can read it online at www.cancer.org or call us for a copy.

## How do I know what the patient wants?

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

### What if the patient won’t do things for himself or herself?

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

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

- Try to figure out what self-care tasks the patient can safely do, such as bathing, dressing, and going to the bathroom. If you don’t know what the patient can do, get the medical team to evaluate the patient. Social workers and occupational health professionals may be able to help with this.
- Encourage the patient to do self-care as much as possible.
- Encourage the patient to talk about things they enjoy so the conversation isn’t always about cancer and illness.
- Let the patient make as many personal choices as they can. If they are overwhelmed with decisions, give them simpler choices by saying, “Would you prefer chicken or fish for dinner?” or “Would you rather wear your blue pants or the brown ones?”
- Get others involved if the patient is avoiding treatments or doing things that can cause harm. Family members can be a strong source of influence. Rally them for support.
- Once a decision is made, accept it and move on. And if you disagree with the decision that was made about the patient’s treatment, remember that it’s the patient’s decision to make. Congratulate them for being able to make a decision.

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

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

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

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

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

## Does the patient need to be moved or relocated?

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

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

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

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

- The amount or type of care needed. For instance, does the patient need 24-hour supervision? What can she or he safely do without help?

- What other living arrangements are available? Can the patient move in with another family member? An apartment closer to the primary caregiver? A smaller house? An independent retirement community?

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

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

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

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

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

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

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

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

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

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

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

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

You may want to start gently – keep in mind that the patient is probably already distressed. Sit down with the patient. Ask if there’s something that the patient would like to tell you. If the answer is no, ask if there’s something the patient **doesn’t** want to tell you. Give him or her a moment to consider it. Point out that you’ve noticed signs of a new problem or worsening symptoms. Remind him or her that this could be a serious problem, or just a new symptom that may be easy for the doctor to address. Mention how the problem is affecting the patient and you. If you’re having trouble handling it, say so; and share any concerns about needing help with it. If the problem is affecting others as well, say so.

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

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

## Long-distance caregiving

Caregiving from a distance can be even harder to do and can cost more, too. The cost of time, travel, phone calls, missed work, and out-of-pocket expenses are higher when the caregiver doesn’t live close to the person needing care. Sometimes paid “on-site” caregivers are needed, and this can be another large expense.

There’s often increased stress and greater feelings of guilt with long-distance caregiving. You may worry, “What if something happens and I can’t get there right away?” Or, “Who’s going to make sure they **______** (take their medicine, eat, don’t fall, etc.)?” And if you do have family living close to the person with cancer, you might feel guilty that the burden falls on them and you aren’t doing your share.

Along with this, there’s the guilt felt while you’re with the person with cancer: “Who’s going to **______** (pick up the kids from school, cook dinner, walk the dog, etc.) at home while I’m gone?”

You also may feel left out of decisions made by the person with cancer and those who do live nearby. But there are things you can do to help your loved one and take an active role in their care – even when you're far away.

- When you visit the patient check the house for safety issues like cluttered walkways, loose rugs, or bad lighting. Maybe grab bars in the bathroom or a shower seat would be helpful. Help make improvements or arrange for someone else to do so.
- Is the house clean? Is the yard cared for? Is there food in the house? Arranging help for chores like these can be a big help to the person with cancer.
- Get in touch with people who live near the person with cancer. This may be other family members, friends, neighbors, or the doctor. Call them. And make sure they know how to reach you.
- Plan for a crisis. Who can you count on to check on your loved one any time, day or night?
- Keep a list of all the medicines and treatments the patient is getting (include doses and schedules), and update it regularly.
- Make sure the person with cancer can reach you and others who help with care. This might mean buying a cell phone for your loved one or arranging for a long distance plan on their land line phone. You can also program important numbers into the phones. This can serve as a phone number directory and help with speed dialing.
- Set up a website that lets people sign up for different jobs or tasks. (See Lotsa Helping Hands and CaringBridge websites in the "To learn more" section.) Then you can keep an eye on what's needed and what's being done.

Try to plan your visits. Once you get there you may be overwhelmed by everything that needs to be done, but having a plan keeps you focused and less stressed. Talk to the patient ahead of time about what's needed and set clear goals for your visit. And don't forget to visit! Remember to just spend time with them and do some activities together – things that you both enjoy.

If other family members are doing most of the hands-on work, you can step in for them to give them some time off. Maybe you can plan a visit so they can go on vacation or just take a much-needed break.

From a distance, it may be hard to feel that what you're doing is enough or important. But sometimes the distant caregiver is the one who ties things together and keeps everything organized. You may be the one called because you know what to do or where to go for help when something is needed or a problem comes up.

# The treatment timeline

## How do I learn about this new world I've entered?

One of the first steps after being told someone you love has cancer will be learning about their diagnosis. This will help you understand the disease process and get an idea of what lies ahead. Some of the first questions that you and the person with cancer should ask the doctor or the cancer care team are:

- What kind of cancer is it?
- Where is it? Has it spread beyond where it started?
- What are the treatment options? Which do you recommend?
- What's the goal of this treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What side effects should we expect?
- How will treatment affect everyday activities?
- What's the likely long-term outcome?

Call your American Cancer Society for easy-to-understand, reliable information. We have information on specific cancer types and many other related topics. See the "To learn more about caregiving and coping" section for a few suggestions.

## What can we expect?

When a person has cancer, no one can predict for sure how it will go. While there's no way for them to know for sure, your health care team should be able to give you an idea of how things are likely to go. This will become clearer over time and as they get to know the person with cancer better. Just a few possible cancer scenarios are:

- Diagnosis, active treatment, finish treatment, then survivorship with a normal life
- Diagnosis, active treatment, finish treatment, then survivorship with possible long-term treatment effects
- Diagnosis, active treatment, finish treatment, cancer comes back (recurrence), active treatment, survivorship with ongoing treatment and ongoing treatment effects
- Diagnosis, active treatment, recurrence, survivorship with possible long-term treatment effects, another recurrence, end of life
- Diagnosis, active treatment, end of life
- Diagnosis of late-stage cancer, comfort care, end of life

Again, with cancer, anything can change at any time, for better or for worse. While it would be great to know what to expect, there’s no way to predict how anyone will do.

## How do we deal with medical delays?

### Lab result delays

Sometimes it can take a while to get back lab results. This can be even harder to deal with when you and your loved one are waiting to get test results to see if it’s cancer or if cancer has come back. It’s scary to find out about a change in blood counts, or a tumor or mass (lump) and not know if it’s cancer.

In most cases, the only way to know for sure if something is cancer is for the doctor to do a biopsy (**by**-op-see). Part or all of the lump is taken out and looked at under a microscope to see if there are cancer cells in it. If there are problems with blood counts, a bone marrow biopsy sample may be taken. A doctor or nurse will use a needle to take out some of the liquid bone marrow that’s inside bones. It’s checked for cancer cells. The type of biopsy depends on the size and location of the lump or the area that has changed.

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

### Treatment delays

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

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

The patient might also want to get a second opinion on what’s the best treatment. This is often a good idea, especially if the patient can see a doctor experienced in treating their type of cancer. A second opinion can give the person with cancer more information and help them feel more confident about choosing a treatment plan. Some insurance companies even require a second opinion before they will agree to pay for certain treatments. And almost all will pay for a second opinion. Still, it’s a good idea to check the patient’s health insurance coverage first.

The patient also might want or need time to prepare to put their normal activities “on hold” while getting treatment. For instance, arrangements for work or child care may be needed, and taking care of these things ahead of time can help the patient better focus on dealing with treatment. (See our documents called *Family and Medical Leave Act* and *Helping Children When a Family Member Has Cancer: Dealing With Diagnosis* for more information on some of these topics.)

Different types of cancer grow at different rates. Certain types of leukemias and lymphomas tend to grow faster than solid tumors, and might need to be treated right away. But most cancers do not grow very quickly, so there's usually plenty of time to get information about the cancer, see specialists, and make decisions about which treatment option is best. Keep in mind that the information gathered during this time is key to planning the best treatment. If you or the patient is worried that treatment isn't starting right away, discuss your concerns with the cancer care team and be sure that any delays will not cause more problems.

## How do we deal with the uncertainty?

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

It can be hard to deal with this constant state of "not knowing" – for you and the person with cancer. Here are some ideas that have helped others deal with uncertainty and fear and feel more hopeful:

- Learn what you can do to keep the person with cancer as healthy as possible, and learn about the services available to you. This can give you a greater sense of control. And don't forget to keep yourself as healthy as possible, too.
- Know that you do not have control over some aspects of the cancer. It helps to accept this rather than fight it.
- Try to let go of your fears, but don't deny them. It's normal for these thoughts to enter your mind, but you don't have to keep them there. Some people picture them floating away, or being vaporized. Others turn them over to a higher power to handle. However you do it, letting them go can free you from wasting time and energy on needless worry.
- Express feelings of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions helps many people feel less worried. People have found that when they express strong feelings, like fear, they are better able to let go of these feelings. Thinking and talking about your feelings can be hard. And while it's important not to let cancer rule your life, it may be hard to do. If you find that you're thinking about nothing besides the cancer, it may be helpful to find a way to express your feelings.

- Use your energy to focus on wellness and what you can do now to stay as healthy as you can. Remember to take care of yourself, as well as the person with cancer.
- Find ways to help yourself relax.
- Make time for regular exercise, and be as active as you can.
- Control what you can. Some people say that putting their lives back in order makes them feel less fearful. Keeping your life as normal as possible and making changes in your lifestyle are just a few of the things you can control. Even setting a daily schedule can give you more power. And while no one can control every thought, some say they’ve resolved not to dwell on the fearful ones.

You play an important role in the health of the person you are caring for, but you cannot control how they are doing physically or mentally. Be careful not to look at your loved one’s progress and good days as proof of your caregiving skills. If you do this, you’ll be more likely to blame yourself when they have bad days and set-backs. Uncertainties and highs and lows are part of dealing with cancer – no one, not even the best caregiver, can control them.

## How do we deal with waiting for the diagnosis?

It can take anywhere from a few days to a few weeks to find out if it’s cancer and, if so, what kind of cancer. This is a difficult time for the patient as well as for loved ones who are aware of the possibility of cancer. Some notice that they think of worst-case scenarios and wonder if they’ll lose their loved one. Others may try to go through their days as normally as possible and not think about it. Most people have a mixture of dread and hope as they wait for the test results.

You may want to be there with your loved one when these results are shared. You can help remember questions, offer support, and begin to prepare yourself and others for what’s next.

## How do we adjust to the diagnosis?

With time, the patient and loved ones will start to adjust to the cancer diagnosis. This is a time of change and action – everyone is getting used to the unexpected and scary situation that they now find themselves in. Even with all the activity, some people go through their days feeling numb and disengaged. Others may be sad, edgy, or angry. Emotions may change from minute to minute as everyone copes in their own way. Things may not feel settled for a long time, but there are appointments to keep, things to discuss, and plans to make.

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

- What is the exact name and location of the cancer?

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

After you know the name and stage of the cancer, you can get more information about it by calling 1-800-227-2345 and talking with a cancer specialist who can help you. You can also get information online at www.cancer.org. You and others who care about the patient can learn more about recommended treatments there, too. As information is collected and shared, decisions are made, schedules are rearranged, and treatment is started.

## What do I need to know about treatment?

Cancer treatment varies a lot depending on the type and stage of the cancer. The most common treatments for cancer are surgery, chemotherapy, and/or radiation. Treatment may mean time in the hospital or making many trips to a clinic for radiation or chemotherapy. The person with cancer may need more than one type of treatment, and each type comes with its own challenges.

You’ll want to be sure that you understand the treatment options chosen by the patient and doctor, since you will probably be helping plan how to make it happen. If you’d like to read more about treatments, see our documents called *A Guide to Cancer Surgery, A Guide to Chemotherapy,* and *Understanding Radiation Therapy: A Guide for Patients and Families.*

The patient may be able to go to some treatments on their own. For other treatments, someone may need to drive the patient or go along. In some cases, the person will get medicines that make them sleepy, or cause symptoms that will require help from others.

If the person gets chemotherapy, there may be nausea, extreme tiredness, easy bleeding, and infections to worry about. Depending on the treatment, there may be many other side effects, too. There’s information on dealing with different types of treatments, symptoms and side effects in *Caring for the Cancer Patient at Home*, which you can read online at www.cancer.org, or you can call us for a copy.

Treatment can be long or fairly short, but even short treatments tend to disrupt a person’s life for several weeks. As the caregiver, your life and your family’s lives may be disrupted, too. You may find that you need to take time off from work. See the section called “Job, insurance, and money concerns” for more on this.

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

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

- What symptoms do we need to tell you about right away? Which ones can wait?
- How do we reach you after office hours? On weekends? Holidays?

- What can we do to manage side effects?
- How will we know if treatment is working?

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

## What happens when treatment ends?

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

There’s still uncertainty to deal with here. It’s hard to know if or when the cancer may come back even if the doctor says there’s “no evidence of cancer.” For more on this, see our document *Living With Uncertainty: The Fear of Cancer Recurrence*.

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

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

After treatment is over, be sure that the patient has copies of their medical information that includes:

- Their diagnosis, including pathology reports from all biopsies and surgeries
- Treatments used (including all medicines with name and dose)
- Summary of surgery (if done)
- Radiation treatment and dose records (if done)
- Discharge reports from any hospital stays
- Records of any major problems during treatment

The patient may need to go to different places to get these records. For instance, the hospital medical records department will usually have hospital discharge and surgical reports. If radiation or chemo was done on an outpatient basis, the doctor who coordinated the treatment can explain how to get the reports. You or the patient might need to ask the surgeon where to get copies of pathology reports.

Some people collect this information as they go through treatment instead of waiting until the end. Either way, once all of this information is collected, be sure to keep copies for the patient. These records are important in the event that questions come up later, the patient needs to see a different doctor in the future, or if the cancer comes back.

## What do we need to know about going back to work or normal activity?

As curative treatment (treatment aimed at producing a cure) winds down and the doctor checks the patient for any remaining signs of cancer, the patient may be given the "all clear" to go back to work. Or it may be that your loved one needs to slowly increase their work duties – this will depend on their physical condition and the type of job they have.

You may need to help get the letters from the doctor that will be needed to clear the patient for full work duties when the time comes. And even when your loved one starts working a more normal schedule, there may be days of extreme tiredness in which your help will still be needed. It may take some time to get past this phase, and you may still need your circle of helpers so that you, too, can start getting back to a more normal schedule. If tiredness (or any other problem) continues, a visit to the doctor might be needed to see if there's a new problem or if anything more needs to be done to help. This may be a time when the Americans with Disabilities Act can be helpful to some patients. If the patient can still do the essential part of their job, it can be used to negotiate for special equipment or a different work schedule. For more information, see our document called *Americans With Disabilities Act*.

It's possible that life-saving treatments may have affected the patient in ways that won't ever go away. For some people, long-term effects mean permanent life changes, so that they can't go back to the life they had before treatment. It's normal for the patient and sometimes loved ones to grieve whatever might have been lost due to treatment. Accepting these losses can take time for both the patient and caregiver.

As the caregiver, you may find yourself continuing to do the things you did when the patient was in treatment. But it's important that, over time, you let the patient go back to doing the things they can and should do on their own. This may take place over a period of months as the patient gets stronger. Check in every week or so to see what you're doing that the patient can start doing, either alone with a little help. If there are things that the patient can't quite do, talk with the doctor about a referral to a physical therapist or occupational therapist. These professionals may be able to maximize the patient's abilities by helping build muscle strength and/or offering assistive devices.

## What if the cancer comes back?

Sometimes there's no evidence of cancer when treatment is done, but the cancer still comes back. In this case, it helps to find out whether there is hope for a cure, what kind of treatment the doctor recommends, and what the goals of this treatment are.

It may be that the cancer cannot be cured, but treatment may prolong life. If this is the case, the patient may want to know the pros and cons of getting more treatment versus not getting treatment. For instance, if treatment can stop the cancer and is likely to prolong survival for several years, it may be worthwhile even if there will be serious side effects every few weeks. On the other hand, if treatment is expected to prolong life for 4 to 6 months and cause troublesome side effects, the patient might choose palliative (comfort) care only rather than active treatment.

Talk over the expected effects and outcomes of getting treatment versus not getting treatment to be sure you and the patient understand. Be sure you know what's being asked of you as a caregiver if further treatment is given. (For more information on cancer recurrence, you can read our document called *When Cancer Comes Back: Cancer Recurrence*.)

## What if treatment keeps going and doesn't stop?

Sometimes treatment doesn't end at the expected time. In some patients, cancer is treated as a chronic illness – a disease that people live with and manage on a day-to-day basis, much like diabetes or heart disease. To learn more about what this might be like, please see our document called *When Cancer Doesn't Go Away*.

The patient may decide to get treatment as long as it slows down or stops cancer growth, even if a cure is no longer possible. Side effects may still cause problems in certain activities. Care is more complex, and more and more often treatments are managed on an outpatient basis or even given at home. This means more responsibilities for the caregiver. And as time goes on, the people you have counted on to help you may need to cut back on the time they spend with your loved one. Some may still be able to offer time or help with limited activities.

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

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

Even if everyone goes back to their jobs, someone will still need to keep up with the treatment plan, the medical records, and the bills. This can be demanding for the patient and caregiver. You may both need support with the amount of work that's needed on top of working and dealing with cancer. And emotional support may be needed to help the patient, caregiver, and other family members cope with knowing that the cancer cannot be cured.

## When treatment stops helping – what then?

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

The patient will have to decide things like, "When do I stop trying to beat the cancer and enjoy the rest of my life?" or "Would I rather spend the next 2 months reading to and playing with my grandchildren or dealing with side effects?" Knowing what's most important to the patient helps the caregiver and family members understand these decisions. Sometimes, caregivers can help patients clarify their highest priorities so that they can focus on them before the chance is lost. Other times, it may take someone on the treatment team or a mental health professional to help the patient clarify what's most important to them, and what can be expected from further treatment. This is a difficult time for everyone, and help from the medical team may be needed to fully understand the situation and figure out what's best for the patient.

## What do I do if the patient decides to stop cancer treatment?

Once the decision to stop curative treatment (treatment aimed at producing a cure) has been made, make sure that other family members and loved ones understand and can support the patient's decision. It's now time for another family meeting, where questions can be answered and concerns addressed. Be sure that other day-to-day caregivers are invited, if they are still involved in the patient's care. You may need extra help from others at this point, since there's often more work for the caregiver to do as the end of life nears.

It's also time to talk with the doctor about focusing on palliative (comfort) care. Many things can be done to deal with symptoms of cancer, such as pain, trouble breathing, and fatigue. When these symptoms are helped, the patient often has more energy to spend time doing those things that mean the most to them. You'll want to be in close contact with the doctor to be sure that any new symptoms are quickly addressed. For more information on what to expect at this time, you might want to read our document called *Nearing the End of Life*.

If the patient is expected to live only a few months, hospice may be a good option. Hospice care is intended to relieve discomfort and make the patient better able to enjoy the time they have. In most cases, hospice is given at home and requires that the patient have a primary caregiver. Having hospice staff on call 24/7 can make it easier for you to know whom to call when the patient has a new problem or a symptom that's not relieved. Hospice also provides emotional and spiritual support for the family and caregiver. You may wish to talk with the hospice nurse or chaplain about coming to a family meeting to talk about the new goals of care and how the hospice staff will work with you. It's helpful if the patient is able to attend. For more on hospice and how it works, see our document called *Hospice Care*.

The physical care of the patient may become more complex and take up more time. Again, other family members will need to understand the situation and the patient's wishes.

If there are children in the family, it's important for them to understand what's going on. For ideas on talking with children and teens, see our document called *Helping Children With Cancer in the Family: Dealing With Terminal Illness*.

As you work with the patient and help make the most of the rest of his or her life, it's normal to feel sad and even start to grieve at the thought of losing your loved one. You will want to continue with your circle of support and any spiritual outlets you have. A support group or mental health professional may also help as you go through this time. You can find out more in our document called *Coping With the Loss of a Loved One*.

# Organizing medical treatment and paperwork

It helps to be organized. You'll be getting a lot of information – new information that can be hard to understand – and it helps to keep it all in one place. Take notes. A notebook or a file box might work well for you. Some people rely on their electronic organizers, which is good as long as it's secure and there are backup copies. Whatever you use, bring it to every office visit and every treatment.

Learn as much as you can about the illness and the treatment plan. This makes it easier to talk to the doctor and the patient. It also helps you better understand what to expect over time.

## How do I manage the medicines?

Keep a list of all medicines the patient is taking, including prescription and over-the-counter medicines, and any vitamins, herbs, or other supplements. This list should include the:

- Name(s) of the drug (both the brand and generic names if possible)
- Dose (number of milligrams [mg] per pill; this is usually on the bottle)
- Schedule (which days of the week and what times of the day it's taken)
- Reason for taking it
- Doctor who prescribed it (if the patient sees more than one doctor, one may not know what the other has prescribed)

Don't forget the medicines the patient takes every now and then or "as needed" – for instance, drugs for pain, fever, itching, or sleep.

Keep this list current and take it to each doctor's appointment. Have the doctor's office make a copy and be sure to update it each time a medicine gets added, taken away, or if a dose changes. Share the new schedule with each doctor on the next visit. Also have it handy if you call the doctor about a problem. You can call us for a chart to help you list medicines or find one online at www.cancer.org and enter “medicine list” (with the quotes) in the search bar.

Some caregivers make lists or spreadsheets and post copies on the refrigerator. That way the list is handy when someone comes in to help. A second copy in the patient’s wallet might be useful, too.

As the patient’s condition changes, ask about the need to continue medicines. For example, if he or she loses weight, some blood pressure medicines may not be needed. Or if treatment for cancer is stopped, there may be other drugs that can be stopped as well. Stopping medicines when they’re no longer needed can lower expenses and reduce the chance of drug interactions and side effects. And it’s one less medicine to keep up with.

## Should I keep medical expense records?

You may also need to help keep up with doctor bills, drugstore receipts, and insurance statements. Or the patient may ask another trusted family member to be the one to track bills and insurance payments. Getting someone else to do this can free up time for other things, which can help you as a caregiver. Still, you may need to take part in tracking the actual doctor visit dates, treatments, and prescription refills.

It’s a good idea to keep all medical bills, insurance EOBs (Explanation of Benefits), prescription drug receipts, and so on all in one place. For more on dealing with insurance, see our document called *Health Insurance and Financial Assistance for the Cancer Patient*.

# Taking care of yourself

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

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

Depression is common in caregivers. But caregiving does not always cause depression and not all caregivers have the difficult emotions that go with depression.

Everyone has emotional ups and downs, but if a person always feels down, has no energy, cries a lot, or is easily angered, it may be a warning sign of depression. Many people see the feelings of depression as a sign of weakness rather than a sign that something is out of balance, but ignoring or denying these feelings will not make them go away.

Early attention to symptoms of depression can make a big difference in how the caregiver feels about their role and how well they can do the things they need to do. There are ways to help reduce stress and remind you to enjoy life. They might help prevent a more serious depression that can develop over time:

- Support from family and friends in caring for the patient
- Exercise
- A healthy diet
- Spiritual support, such as religious activity, prayer, journaling, or meditation
- Recreational time, when you can enjoy friends socially
- Help from a trained mental health professional

But caregivers often focus on the person with cancer and don't take care of themselves. You may be a caregiver, but you still have your own needs that cannot and should not be put aside. Please see our document called *What it Takes To Be a Caregiver*. If you have concerns about how well you're doing, please also see the *Distress Checklist for Caregivers,* and the *Coping Checklist for Caregivers.*

## Know what you can't do

Some caregivers feel like they have to do it all alone. They may believe that, as the partner, sibling, son, or daughter that they are responsible for the sick loved one. It's painful for them to admit that they can't do it all and still keep their own health and sanity. They'll bend over backwards to meet their loved one's every need. Some feel guilty if they can't do it all and say they feel "selfish" if they ask for help. These are people who, if they spot their loved one falling, will dash over to try and catch them. They don't think about their own injuries or wellness. When they end up seriously injured or sick, they become unable to help anyone.

Set realistic limits on what you can do. For instance, if you have a back injury, and/or if your loved one is too big for you to lift, you may be able to help them roll over in bed, but don't try to lift them alone or catch them when they fall. There are ways you can safely help a person sit up or walk but you have to learn how to do it without hurting yourself. This is where expert help is needed – home care nurses or physical therapists can show you how to do it safely. They can also help you get special equipment if it's needed. Your own health and safety must come first if you want to keep helping your loved one.

When you need help, reach out to others, including professionals. Talk with your loved one's doctor or nurse about what you are doing and where you need help. Involve them in your life and your loved one's care.

### Where do I find support for me?

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

Some groups are formal and focus on learning about cancer or dealing with feelings. Others are informal and social. Some groups are made up of only people with cancer or only caregivers, while others include spouses, family members, or friends. Other groups focus on certain types of cancer or stages of disease. The length of time groups meet can range from a set number of weeks to an ongoing program. Some programs have closed membership and others are open to new, drop-in members.

Online support groups may be another option. The Cancer Survivors Network, an online support community of your American Cancer Society, is just one example. You can visit this community at http://csn.cancer.org. There are many other good communities on the Internet that you can join, too.

Support in any form allows you to talk about your feelings and develop coping skills. Studies have found that people who take part in a support group have an improved quality of life, including better sleep and appetite. You can contact your American Cancer Society to find out about available sources of support in your area.

Religion can be a source of strength for some people. Some find new faith during a cancer experience. Others find that cancer strengthens their existing faith or their faith provides newfound strength. If you are a religious person, a minister, rabbi, other leader of your faith, or a trained pastoral counselor can help you identify your spiritual needs and find spiritual support. Some members of the clergy are specially trained to help people with cancer and their families.

People who are not religious may find spiritual support in other ways. Meditation, journaling, and being outside in nature are examples of different ways a person may feel they are part of something greater than themselves. For others, serving at a local homeless shelter or other types of volunteer work may renew their energy.

## Asking for help

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

Caregivers have been shown to have less distress and feel less burdened when they have social support. In fact, in one study, neither age or cancer stage affected the caregivers as much as having a network of people around them as a support system. Human connections can help you stay strong. Let people know what you need and ask for help. You cannot and should not try to be responsible for all the caregiving by yourself.

## Can I count on family and friends for help?

You need to know who you can talk to and count on for help. Families facing cancer can become stronger. If family members do not offer help, or if you need more help than they can give you, you may be able to set up a circle of friends to help you. Church members, neighbors, and others may be willing to help. Include them in “family meetings.” Share information with them on the patient’s condition, needs, and care.

One way to make it easier to get help is to set up a website that lets people sign up for different jobs or tasks to help get things done for the patient and for yourself. People can look on the website to see what’s been signed up for and what’s still needed of the task list you post. (See Lotsa Helping Hands and CaringBridge websites in the “To learn more” section.) You may still have to recruit “offline” volunteers to help with things no one signs up for.

They may not be able to be a part of your loved one’s care every day, but perhaps a friend can come once a week for 3 or 4 hours so that you can take time for yourself. Someone else may be able to be there for an hour or 2 twice a week so you can go to a support group, shopping, or church. See the section below called “Can I take a break or time for myself?” for more ideas.

## How do I take care of my children during this time?

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

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

For more information, see our documents called *Helping Children With Cancer in the Family: Dealing with Diagnosis* and *Helping Children With Cancer in the Family: Dealing With Treatment*.

## How do I get professional help?

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

- Feel depressed, physically sick, or hopeless
- Feel like hurting yourself or hurting or yelling at the people you care for

- Depend too heavily on alcohol or recreational drugs
- Fight with your spouse, children, stepchildren, or other family members and friends
- No longer take care of yourself

If you decide you do need help, usually the first people to ask are members of the cancer care team. They might know more about who works with people caring for those with cancer in your area. For more on recognizing when you or your loved ones may need help with emotional issues, see our document called *Anxiety, Fear, and Depression*.

## Can I take a break or time for myself?

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

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

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

Another type of respite uses a specialized, local facility where the patient may stay for a few days or even a few weeks. This gives the caregiver a chance to take a vacation from caregiving and catch their breath, whether or not they leave town.

Depending on the state, Medicaid or Medicare may help cover the costs. Also check with the patient's health insurance to see what kind of respite help might be offered. See the "To learn more about caregiving and coping" section for groups that can help you find respite care where you live.

## Are there tools to help the patient be more independent?

*Assistive devices* are tools that can help a person be more independent and make your job a little easier. You may also hear these called *adaptive equipment* or *independent living aids*. These tools can be something as simple as a cane, or as complex as a high-tech lift used to move the patient. Some other examples are walkers, wheelchairs, shower chairs, bath mats, grab bars, portable commodes, or urinals. Monitored medical response systems, webcams, and intercom systems are other options that can help some patients feel safer and give the caregiver peace of mind. But even little things like a pill organizer or large wall calendar can make things easier for everyone.

Think about the tasks the person with cancer wants or needs to do and how these devices may make it easier or safer. If you're not sure, talk to your health care team or maybe an occupational therapist about tools that might help at home. These professionals can give you ideas for ways to help the patient. They can also help you find out where to buy or rent the assistive devices you need. And some may be covered by health insurance, too.

# Job, insurance, and money concerns

## How can I be a caregiver and keep my regular job?

Researchers have just begun looking at the financial costs of being a caregiver. Many caregivers already have paying jobs, but we know that caregiving can be a full-time job itself. This can lead to work-related issues like missed days, low productivity, and work interruptions. Some caregivers even need to take unpaid leave, turn down promotions, or lose work benefits. The stress of caring for someone on top of worrying about keeping your job can be overwhelming. Dealing with these issues is important to both the employer and the employee.

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

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

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

There is a Federal law called the Family and Medical Leave Act that guarantees up to 12 weeks off per year to take care of a seriously ill family member (spouse, parent, or child). It only applies to larger companies, and not every employee qualifies for it. Even though some companies pay you for part of the time, there may be only unpaid leave. But you do get to keep your health insurance benefits. You can find out more from our document called *Family and Medical Leave Act (FMLA)*. Even if you use the FMLA, you still may not be able to arrange enough time off. And if the person you are caring for is not your parent, child, or spouse, the law does not apply to you.

If you don’t qualify for legal job protection, you may still explain your situation and ask your employer if you can adjust your schedule to allow you to give care without leaving your job. Some employers are flexible in these situations. You’ll need to think ahead and be ready to spell out clearly what you can keep doing and how long you think you will need extra time off.

## Can the patient keep working?

The patient with cancer often wants to keep working through treatment. In some cases, it’s possible. In others, it doesn’t work well. But the employee with cancer who wants to keep his or her job may be able to take some time off during treatment, using either company benefits or the Family and Medical Leave Act (FMLA – see the previous section). FMLA can be used by the person with a serious illness as well as by the sick person’s caregiver.

Taking leave under FMLA is usually much better for the person with cancer than quitting, because they get to keep their health insurance. If the person with cancer later learns that they must leave their employment permanently, they may be able to use COBRA (Consolidated Omnibus Budget Reconciliation Act) to extend health insurance coverage even further. But COBRA can be very expensive and might not be needed if the new health care marketplace offers affordable health plans to replace the lost insurance. Before making a decision about COBRA, check the health insurance marketplace in your state. If the patient can find a health plan on the marketplace very soon after leaving the job, they can enroll in the new plan right away. You can call 1-800-318-2596 or visit the healthcare.gov website to get to your state marketplace, or call your American Cancer Society at 1-800-227-2345 to find out more.

See our documents called *Family and Medical Leave Act* and *What Is COBRA?* for more information.

The patient with cancer may also benefit from the Americans with Disabilities Act (ADA). This Federal law requires employers to make “reasonable accommodations” for an employee with a long-term or permanent disability. Still, the person must be able to do the main job functions in order to qualify for this protection. And it doesn’t apply to every employer. For more information, see our document called *Americans With Disabilities Act: Information for People Facing Cancer*.

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

## As a caregiver, how can I keep my health insurance if I quit my job?

When caregivers quit their jobs, they usually lose their health insurance coverage as well as their source of income. But if you're able to pay for your own insurance, COBRA will allow you to be covered for some months after you leave your job. (See our document called *What Is COBRA?* for more on this.) Like the patient, you should compare health insurance costs on the marketplace before you choose COBRA. (See the section above for details.)

If you look carefully and find that you can't afford to quit your job and lose your insurance, there are some options that you can look into that may allow you to keep working (see the section above).

## What do I need to do with the patient's health insurance?

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

You or someone else will probably need to help set up a system for tracking costs, comparing insurance statements, and keeping careful records. Patients will need to stay in touch with their insurance plan in case there are reimbursement problems. The patient may need to give permission to the insurance company to talk about problems and disputes with the person chosen to help with insurance. See our document called *Health Insurance and Financial Issues for the Cancer Patient* for more on how to deal with this.

## How do I deal with all the money issues?

For the person who has lost their income because they had to quit their job to be a full time caregiver, financial problems can become overwhelming very quickly. See our documents called *Health Insurance and Financial Issues for the Cancer Patient* and *Financial Guidance for Cancer Survivors and Their Families: In Treatment* for more information on dealing with money issues.

If you are still working, the patient may need extra help – someone to check in on them while you are working. Some caregivers may be able to check in by phone as long as their loved one can do some of their own basic care. Or you can start pulling your family together to find people who can be there or call while you're at work. If there's a need for skilled nursing care, the patient may be able to get home health visits through their health insurance. (See our document called *Home Care Agencies*.)

A few people are able to get paid for time spent caregiving. Some states have Medicaid programs known as Cash and Counseling that can directly pay some caregivers. You can find out whether your state has a program by contacting your local Medicaid office, social services, or health department. Or you can visit cashandcounseling.org online.

# Legal issues

We have already referred to some legal issues:

- Consent for the doctor or health care team to share information with you or others (see the section, “Communication”)
- Job protections related to your and the patient’s work (see the section: “Job, insurance, and money concerns”)

## Are there other legal issues I should know about?

It may be hard to talk about, but legal issues can be a huge source of stress for caregivers, patients, and families. Common worries include who will manage the person’s money and who will make important health care decisions if the patient is unable to do so. It’s important to bring these up with the patient while he or she is still able to make choices, so that you and the rest of the family can be clear about what the patient wants.

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

There are surrogate decision-making tools that may help you and the patient. One example is the **durable power of attorney**, which allows the patient to choose the person who can make financial decisions on behalf of the patient. (This is quite different from the *durable power of attorney for health care*, which is discussed below.) The durable power of attorney does not affect health decisions. If you are the health caregiver, you might want to consider asking the patient to let someone else make the financial decisions.

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

A **durable power of attorney for health care** has nothing to do with money or finances, only health care decisions. It allows the patient to choose someone to make health care decisions if he or she becomes unable to do so. Many times, this is a close family member, partner, or spouse who is aware of the health condition and the patient’s wishes. The caregiver is a logical choice in many cases, given their knowledge of the patient and their condition. But it becomes more difficult when the patient and the caregiver have different goals and values. For instance, if the patient is nearing the end of life and wishes to stop treatment, and the caregiver is still looking for a cure, it may not work the way the patient wants. For more information on living wills and durable powers of attorney for health care, see our document called *Advance Directives*.

### Attorneys can help with difficult issues

In some cases, such as consent for the health care team to share information, legal issues can be handled without a lawyer (attorney at law). But there are times when one may be needed. In cases where there is disagreement about advance directives or durable powers of attorney among family members and loved ones, a lawyer can help. The lawyer can talk with the patient and draw up documents that say exactly who makes decisions for the patient if he or she becomes unable to do so. Or the patient may want to say what to do or what not to do in certain health-related situations.

# To learn more about caregiving and coping

## From your American Cancer Society

Here is more information you might find helpful. You also can order free copies of our documents from our toll-free number, 1-800-227-2345, or read them on our website, www.cancer.org.

### About caregiving

What It Takes to Be a Caregiver

Listen With Your Heart (also in Spanish)

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also in Spanish)

Home Care Agencies (also in Spanish)

Distress Checklist for Caregivers

Coping Checklist for Caregivers

### Coping with cancer and treatment

After Diagnosis: A Guide for Patients and Families (also in Spanish)

Coping With Cancer in Everyday Life (also in Spanish)

Choosing a Doctor and a Hospital (also in Spanish)

Health Professionals Associated With Cancer Care

Talking With Your Doctor (also in Spanish)

A Guide to Chemotherapy (also in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also in Spanish)

A Guide to Cancer Surgery (also in Spanish)

Medicine List

Nutrition for the Person With Cancer: A Guide for Patients and Families (also in Spanish)

Anxiety, Fear, and Depression

Sexuality for the Man With Cancer (also in Spanish)

Sexuality for the Woman With Cancer (also in Spanish)

## Children and family members

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also in Spanish)

Helping Children When a Family Member Has Cancer: Dealing With Treatment (also in Spanish)

## Job, insurance, money, and legal issues

Americans With Disabilities Act: Information for People Facing Cancer (also in Spanish)

What is COBRA? (also in Spanish)

Family and Medical Leave Act (FMLA) (also in Spanish)

Health Insurance and Financial Assistance for the Cancer Patient (also in Spanish)

How to Find a Financial Professional Sensitive to Cancer Issues: Financial Guidance for Cancer Survivors and Their Families

In Treatment: Financial Guidance for Cancer Patients and Their Families (also in Spanish)

Advance Directives

## Advanced illness

Advanced Illness: Financial Guidance for Cancer Survivors and Their Families

Advanced Cancer (also in Spanish)

Nearing the End of Life (also in Spanish)

Helping Children With Cancer in the Family: Dealing With Terminal Illness

## Books

Your American Cancer Society also has books that you might find helpful. Call us at 1-800-227-2345 or visit our bookstore online at www.cancer.org/cancer/bookstore/to find out about costs or to place an order.

## National organizations and websites*

Along with the American Cancer Society, other sources of information and support include:

### Just for caregivers: information, support, and respite

**Family Caregiver Alliance (FCA)/National Center on Caregiving**
Toll-free number: 1-800-445-8106
Website: www.caregiver.org

> Provides information and resources for long-term caregiving, including practical skills, how to hold family meetings, decision-making, assistive equipment, online support, and more; some info in Spanish and Mandarin

**National Alliance for Caregiving (NAC)**
Website: http://www.caregiving.org

> A national coalition of organizations focused on caregiving issues; provides www.familycaregiving101.org, a resource for answers, new ideas, and helpful advice for caregivers.

**Well Spouse Association (WSA)**
Toll-free number: 1-800-838-0879
Website: www.wellspouse.org

> A national, non-profit membership organization (dues are charged) which provides emotional support to spouses and partners of chronically ill and/or disabled people. Helps with setting up calendars to organize help from others. Also offers Regional Respite Weekends for spousal caregivers

**Caregiver Action Network**
Telephone: 202-772-5050
Website: www.caregiveraction.org

> Supports and educates family caregivers, helps them connect with other caregivers; and helps them become their own advocates. Membership is free to caregivers.

**National Respite Locator Service**
Website: www.respitelocator.org

> Helps caregivers and professionals find respite services in their state and local areas so that they can take short-term breaks from caregiving

**Medicare: Caregiving**
Website: www.medicare.gov/campaigns/caregiver/caregiver.html

Fact sheets and information for caregivers. Choose “What caregiver support is available in my area?” for information on the Medicaid Cash and Counseling program that can pay some caregivers for their time.

## Tools to organize family, friends, and share information

**Lotsa Helping Hands**
Website: www.lotsahelpinghands.com

Volunteer coordination service for friends, family, colleagues, and neighbors to help loved ones in need. You can set up a free online program that allows volunteers to sign up to help with meals, rides, and other tasks on an easy-to-use, private group calendar.

**CaringBridge**
Website: www.caringbridge.org/

Provides free personal websites that make it easy to stay connected to family and friends during illness and treatment; allows patients and caregivers to keep loved ones informed, as well as get and receive pictures and messages privately online.

## Legal and mental health help

**American Association for Marriage and Family Therapy**
Telephone: 703-838-9808
Website: www.aamft.org

Sponsors www.therapistlocator.net which provides referrals to local marriage and family therapists. The site also contains educational materials on helping couples live with illness, as well as other issues related to families and health.

**Cancer Legal Resource Center**
Toll-free number: 1-866-843-2572 (1-866-THE-CLRC)
TTY: 213-736-8310
Website: www.cancerlegalresourcecenter.org/

A non-profit program of the Disability Rights Legal Center offering free and confidential information and resources on cancer-related legal issues such as insurance, disability, discrimination, child custody, residency, and more to cancer survivors, their families, friends, employers, health care professionals, and others coping with cancer.

## Information and support for people with cancer and their families

**Cancer Hope Network**
Toll-free number: 1-877-467-3638 (1-877-HOPENET)
Website: http://www.cancerhopenetwork.org

Volunteers provide free and confidential one-on-one telephone support for people with cancer and family members.

**CancerCare**
Toll-free number: 1-800-813-4673 (1-800-813-HOPE)
Website: www.cancercare.org

Free professional support, such as phone counseling, online support groups, and educational materials, for people with cancer, their loved ones, and caregivers. Also offers CancerCare for Kids at www.cancercareforkids.org or CancerCare's main number, above. This program is for kids with a parent, sibling, or other family member who has cancer. It offers practical support, education, and counseling for parents and children. Spanish also available.

**Cancer Support Community (was Gilda's Club)**
Toll-free number: 1-888-793-9355
Website: www.cancersupportcommunity.org

Provides support for those living with cancer and their loved ones. Offers information, stress management, and online support groups led by professionals, including some in Spanish; has a special sub-site (http://grouploop.org/) for teens and their parents.

**National Cancer Institute**
Toll-free number: 1-800-422-6237 (1-800-4-CANCER)
TTY: 1-800-332-8615
Website: www.cancer.gov

An excellent source of up-to-date information about cancer for patients, families, and caregivers.

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345** or visit www.cancer.org.

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