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## What a Cancer Caregiver Does

We think of caregivers as unpaid loved ones who give the person with cancer physical and emotional care. They may be spouses, partners, family members, or close friends. Most often, they are not trained for the caregiver job. Many times, they may be the lifeline of the person with cancer.

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## What Is a Cancer Caregiver?

We define caregiver as the person who most often helps the person with cancer and is not paid to do so. Professional care providers are paid to give care. They tend to have more limited roles, and are not discussed in detail here.

Caregivers may be partners, family members, or close friends. Most often, they're not trained for the caregiver job. Many times, they're the lifeline of the person with cancer.

Caregivers have many roles. These roles change as the patient's needs change during and after cancer treatment. Today a lot of cancer care is done in outpatient treatment centers and doctors' offices. This means that sicker people are being cared for at home.

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

## Caregivers are part of the team

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

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

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

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

## Caregivers are problem solvers

The person with cancer faces many new challenges. As the caregiver you can help the patient deal with these challenges and get through any problems that come up.

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

- Help address their concerns by pointing out that the patient will need to be in the hospital for only a short time until antibiotic treatment has the infection under

control.

- Make sure that the patient has everything they need while in the hospital, including doctor's prescriptions for non-cancer related medicines taken at home, such as thyroid or blood pressure medicine.
- Call all the doctors involved in the patient's care and tell them about the infection and that the patient is in the hospital.
- Check that arrangements have been made for the patient to stay on the antibiotics at home or as an outpatient after leaving the hospital. If daily visits to the outpatient clinic for IV (intravenous) antibiotics are needed, the caregiver can coordinate people to help the patient get there and back each day.

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

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

There are other day-to-day tasks a caregiver might do. 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](#)<sup>1</sup>.

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.

## Caregivers involve the patient

Good communication with the person you are caring for is the most important part of your role. It may be hard for the patient to take part in daily planning and decision-making because they're dealing with the [physical](#)<sup>2</sup>, [emotional](#)<sup>3</sup>, and social effects of cancer and treatment. Your job is to involve the patient as much as possible, so they know they're doing their part to get better. Here are some things you can try to do to keep the patient involved:

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

You might find that the person you're caring for is acting different – angry, quiet and withdrawn, or just sad. If you think they aren't talking to you because they want to spare your feelings, make sure they know that you are always open to listening, even about tough topics. If they keep acting very sad or withdrawn, you might want to talk to the cancer care team about what could be causing it and what can be done. Learn more in

[Anxiety, Fear, and Depression](#)<sup>4</sup> and [Distress in People With Cancer](#)<sup>5</sup>.

## Long-distance caregiving

Caregiving at 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 their phones. This can serve as a phone number directory and help with speed dialing.

- Use a website that lets people sign up for different jobs or tasks, such as [Lotsa Helping Hands](#)<sup>6</sup> and [CaringBridge](#)<sup>7</sup>. 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.

## Hyperlinks

1. [www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/distress-checklist-for-caregivers.html](http://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/distress-checklist-for-caregivers.html)
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6. <http://www.lotsahelpinghands.com/>
7. [www.caringbridge.org/](http://www.caringbridge.org/)

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## How to Communicate as a Caregiver

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](#)<sup>1</sup>. Acceptance and sharing will help keep your relationship strong.

You can learn more about how to talk with the person with cancer in [Listen With Your Heart](#)<sup>2</sup>.

## 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](#)<sup>3</sup> of the [chemotherapy](#)<sup>4</sup> 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, see [Informed Consent](#)<sup>5</sup> and [Advance Directives](#).<sup>6</sup>

### **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, see [Health Professionals Associated With Cancer Care](#)<sup>7</sup> and [Talking With Your Doctor](#)<sup>8</sup>.

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.

## 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.

## Hyperlinks

1. [www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/anxiety-fear-depression.html](http://www.cancer.org/treatment/treatments-and-side-effects/emotional-side-effects/anxiety-fear-depression.html)
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# Making Health Decisions as a Cancer Caregiver

The cancer care team will always discuss major health decisions with the patient if the patient can think clearly and share their thoughts. The patient's decisions will be followed as long as they don't 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.

## **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 even 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.

## **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 cancer care team can help you figure out what may be going on.

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

- Try to figure out what self-care tasks the patient can safely do, such as bathing, dressing, and going to the bathroom. If you don't know what the patient can do, get the cancer care 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're overwhelmed with decisions, give them simpler choices by saying, "Would you prefer chicken or fish for dinner?" or "Would you rather wear your blue pants or the brown ones?"
- Get others involved if the patient is avoiding treatments or doing things that can

cause harm. Family members can be a strong source of influence. Rally them for support.

- Once a decision is made, accept it and move on. And if you disagree with the decision that was made about the patient's treatment, remember that it's the patient's decision to make. Congratulate them for being able to make a decision.

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

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

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

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

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

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

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

Also be sure you know whom to call after hours, on weekends, and on holidays. If you don't have 24-hour access to someone on the cancer care team, find out what you should do if there are problems. Should you call your pharmacist if there are problems

with the medicines? Should you go to the ER? It often seems like problems come up when the doctor's office is closed, so be sure you have an emergency plan in place.

Get more details on dealing with symptoms and when to call the doctor in [Managing Cancer-related Side Effects](#)<sup>1</sup>.

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

Open and honest discussion with the patient and other family members is the first step in deciding whether the patient needs to live somewhere else for a time.

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

For less severe problems, such as mild forgetfulness, unsteady walking, and occasional minor confusion, there may be other options. Again, tell the cancer care team about these problems to find out if there 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 or occupational therapists' (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're a caregiver. It just may look different, since you're no longer providing all of the hands-on care. But you'll still be talking with the staff at the facility, visiting the patient, and staying in touch with those who are providing care.

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've lived in the same place for a long time, they probably have strong ties to the community, family, friends, and health care providers, as well as social lives and daily routines.

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

You'll also need to talk about each person's concerns. For instance, things like 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 cancer care team so that you can get their input and support.

## Hyperlinks

1. [www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html](http://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects.html)

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# Understanding the Cancer Experience When You're a Caregiver

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 and/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?

When a person has cancer, no one can predict the outcome. While there's no way for them to know for sure, **the cancer 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.

## 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're 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.

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 cancer 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. Learn more in *Seeking a Second Opinion*.

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. Learn more about these topics in [1Family and Medical Leave Act<sup>2</sup>](#) and [Helping Children When a Family Member Has Cancer: Dealing With Diagnosis<sup>3</sup>](#).

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.

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

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

You play an important role in the health of the person you are caring for, but you cannot control how they are doing physically or mentally. Be careful not to look at your loved one's progress and good days as proof of your caregiving skills. If you do this, you'll be more likely to blame yourself when they have bad days and 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.

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 going to [Find a Cancer Type](#)<sup>4</sup> or by calling 1-800-227-2345 and talking with a cancer information specialist.

## 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 patient may be able to go to some treatments on their own. For other treatments, someone may need to drive or go along. 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 and their expected side effects](#)<sup>5</sup> contact your American Cancer Society.

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 [If You Are About to Become a Cancer Caregiver](#)<sup>6</sup> 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.

### **Are there tools to help the patient be independent during and after treatment?**

*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 the cancer 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.

### **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?

## What if my loved one refuses cancer treatment?

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

As someone who cares about and supports the person with cancer, you may wonder why they would make this choice. Maybe the person has health problems that make cancer treatment harder or more risky. Maybe they feel that with their age and life history, it's just "their time." Sometimes, the person's religious beliefs come into play. There are many reasons why people choose to not get cancer treatment. It's OK to ask your loved one about their reasons for refusing cancer treatment. Even though the answer may be hard to hear, the choice to refuse treatment is the patient's – no one else's. Often, the reasons make sense and give you a better idea of what's going on. It's also OK to tell the patient what you think. You may say something like, "I hadn't thought about it that way, and I'm glad you shared your point of view with me." Or, "I wish you would talk to a doctor about treatment options, but I'll support your choice and help you through this time the best that I can."

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

[Supportive care](#)<sup>7</sup> can help anyone with cancer – even those who are sure that they don't want treatment for the cancer itself. Sometimes called palliative care, supportive care



helps keep people with cancer from having severe pain, nausea, or other symptoms. It's care that aims to treat symptoms, not cancer. It helps the person feel as good as possible for as long as possible.

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

## **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."

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. 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.



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

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

It’s possible that 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 treatment doesn’t stop?

Sometimes treatment doesn’t end at the expected time. In some patients, [cancer is treated as a chronic illness](#)<sup>8</sup> – a disease that people live with and manage on a day-to-day basis, much like diabetes or heart disease.

This can be a very demanding situation for a caregiver. You’re helping 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 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 cancer care 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 cancer care team may be needed to fully understand the situation and figure out what's best for the patient.

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

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're still involved in the patient's care. You may need extra help from others at this point, since there's often more work for the caregiver to do as the end of life nears.

It's also time to talk with the doctor about focusing on [palliative \(comfort\) care](#)<sup>9</sup>. 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 [Nearing the End of Life](#)<sup>10</sup>.

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. For more on hospice and how it works, see [Hospice Care](#)<sup>11</sup>.

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 [Helping Children With Cancer in the Family: Dealing With Terminal Illness](#)<sup>12</sup>.

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'll want to continue with your circle of support and any spiritual outlets you have. A support group or mental health professional may also help as you go through this time. You can find out more in [Coping With the Loss of a Loved One](#)<sup>13</sup>.

## Hyperlinks

1. [www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/health-insurance-laws/family-and-medical-leave-act.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance/health-insurance-laws/family-and-medical-leave-act.html)
2. [www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-diagnosis.html](http://www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-diagnosis.html)
3. [www.cancer.org/cancer/all-cancer-types.html](http://www.cancer.org/cancer/all-cancer-types.html)
4. [www.cancer.org/treatment/treatments-and-side-effects.html](http://www.cancer.org/treatment/treatments-and-side-effects.html)
5. [www.cancer.org/treatment/caregivers/if-youre-about-to-become-a-cancer-caregiver.html](http://www.cancer.org/treatment/caregivers/if-youre-about-to-become-a-cancer-caregiver.html)
6. [www.cancer.org/treatment/treatments-and-side-effects/palliative-care.html](http://www.cancer.org/treatment/treatments-and-side-effects/palliative-care.html)
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9. [www.cancer.org/treatment/end-of-life-care/nearing-the-end-of-life.html](http://www.cancer.org/treatment/end-of-life-care/nearing-the-end-of-life.html)
10. [www.cancer.org/treatment/end-of-life-care/hospice-care.html](http://www.cancer.org/treatment/end-of-life-care/hospice-care.html)
11. [www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-parents-terminal-illness.html](http://www.cancer.org/treatment/children-and-cancer/when-a-family-member-has-cancer/dealing-with-parents-terminal-illness.html)
12. [www.cancer.org/treatment/end-of-life-care/grief-and-loss.html](http://www.cancer.org/treatment/end-of-life-care/grief-and-loss.html)

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# Patient Job, Insurance, and Money Concerns for Caregivers

## Can the patient keep working during treatment?

The patient with cancer often wants to keep working through treatment. Work is an important part of many people's lives, and often a way to maintain some stability and control. In some cases, it's possible to work during treatment. In others, it's not. There are many things to take into consideration when deciding whether to work through treatment. Talk to the cancer care team for advice. You can also see [Working During Cancer Treatment](#)<sup>1</sup> to learn more about how to do this and the legal protections the patient has available. It also covers what can be done to keep health insurance coverage if the patient is unable to work or can only work part time.

## What do we need to know about the patient going back to work after treatment?

As cancer treatment comes to an end and the patient begins to recover, at some point the patient may be given the "all clear" to go back to work. 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.

Tips on how to manage this transition and the legal protections available are covered in [Returning to Work After Cancer Treatment](#)<sup>2</sup>.

## **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](#)<sup>3</sup>, 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.

## **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. Contact us or visit our website for more information on dealing with money issues.

If you're still working, the patient may need extra help – someone to check in on them while you're at work. Some caregivers may be able to check in by phone as long as their loved one can do some of their own basic care. 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.

A few people are able to get paid for time spent caregiving. Some states have Cash and Counseling Programs 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.

## **Legal issues**

It may be hard to talk about, but legal issues can be a huge source of stress for caregivers, patients, and families. Common worries include who will manage 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. This way, 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. 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. Contact us for more information on living wills and durable powers of attorney for health care, see <sup>4</sup>[Advance Directives](#)<sup>5</sup>.

## **Hyperlinks**

1. [www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/working-during-and-after-treatment/working-during-cancer-treatment.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/working-during-and-after-treatment/working-during-cancer-treatment.html)
2. [www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/working-during-and-after-treatment/returning-to-work-after-cancer-treatment.html](http://www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-financial-and-legal-matters/working-during-and-after-treatment/returning-to-work-after-cancer-treatment.html)
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