
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?

A caregiver is the person who most often helps the person with cancer but is not paid to do so. Caregivers may be partners, family members, or close friends. Most often, they're not trained to be a caregiver. Many times, they're the lifeline of the person with cancer. Professional care providers are paid to give care. They tend to have more limited roles and are not discussed in detail here.

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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. Caregivers take care of the patients in their home during or after treatments.

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 get through treatment plans and to take other steps to get well, like eating healthy meals or getting enough rest.

Caregivers are part of the cancer care 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 medicines
- Handling side effects
- Reporting problems
- Trying to keep other family members and friends up to date on what's happening
- Helping to decide if a treatment is working

As part of the team, you'll help arrange the patient's care. Caregivers often have to keep track of prescriptions, know which tests are to be done, and make sure all the patient's doctors know what's going on.

A good caregiver is an important 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 may come up.

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

- Help by pointing out that the patient will need to be in the hospital for only a short time and will have antibiotic treatment to control the infection
- While they are in the hospital, make sure that the patient has everything they need, including medicines that are not related to cancer , 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 make arrangements for 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 dealing with an infection. This kind of help is valuable. It's a reassuring sign for the patient that this short-term problem can be handled 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 with, or in some cases even do for someone with cancer:

- 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
- Handle medical problems at home
- Arrange cancer care

- Decide when to seek health care or see a doctor for new problems

All this work can be a load for caregivers to handle. Many caregivers are there for their loved one 24 hours a day for months or even years. You may focus a lot of your time on making sure the person with cancer is taken care of. You may not focus on your own care as much as you usually do. As a caregiver, your health and wellbeing are also important. Remember to take care of yourself so that you are able to care for your loved one.

Caregivers help handle insurance issues

You may need to get permission to talk with your loved one's health insurance company about coverage and reimbursement issues.

- Ask if there is a case manager for the insurance
- Talk with the health care team if you need to lower expenses
- Keep track of medical bills, explanation of benefits, and other receipts from health care expenses. Also, keep a record of who you talked with at the insurance company, including the date, the name of who you talked to and the outcome.

Caregivers help handle 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 they are still able to make choices. This way, you and the rest of the family can be clear about what the patient wants.

There are surrogate or fill-in 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 their behalf. (This is quite different from the [durable power of attorney for health care](#)¹) The durable power of attorney does not affect health decisions. If you are the health caregiver, you might want to think about asking the patient to let someone else make the financial decisions.

Caregivers help make sure the home environment is clean

Cancer treatments lower a person's immune system (protection system), making them more likely to get an infection from unclean things. Things can be done to help lower the chances of the person with cancer getting sick or an infection. Here are a few tips that can help to keep the home clean and prevent infection:

- Handwashing- with soap and warm water frequently.
- Wipe down areas that are touched the most (counter tops, remote controls, doorknobs, light switches, and phones).
- Wash all kitchen surfaces with warm, soapy water before and after preparing food.
- Sanitize surface areas in the kitchen after food prep with disinfectants.
- Wipe down kitchen appliances (refrigerator, stove, microwave) and sanitize.
- Clean all surfaces in the bathroom.
- Wear gloves when cleaning the toilet- cancer treatment can be stay in a person's body for a few days after treatment.
- Clean other bathroom areas (tub, shower, countertops)
- Wash and dry clothes, dedsheets, and towels on the warm setting to disinfect.
- Keep pet droppings and areas clean and disinfected.

Cleaning the kitchen and bathroom areas, weekly, would help protect the person with cancer from infection. Sometimes, these areas need to be cleaned more often than once a week. Talk to the cancer care team about cancer treatments to know about any special precautions you need to take for your loved one.

Caregivers keep the patient involved

Good communication with the person you are caring for is the most important part of your role. It may be hard for the patient to take part in daily planning and decision-making because they're dealing with the [physical, emotional,](#)² 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 to help, but don't force 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 might want to do it for them, but don't. Let them decide when they need help.

Hyperlinks

1. www.cancer.org/cancer/managing-cancer/making-treatment-decisions/advance-directives/types-of-advance-health-care-directives.html
2. www.cancer.org/cancer/managing-cancer/side-effects.html

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How to Communicate as a Caregiver

A caregiver needs to be able to talk to the patient, the medical team, friends, family, and even people they 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.

- [How do I talk to the patient?](#)
- [How do I talk with the medical team?](#)
- [Do I need to go to doctor visits with the patient?](#)
- [How do I make the most of my time with the doctor?](#)
- [How can family meetings help?](#)

How do I talk to the patient?

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

- I'll do whatever I can to help you through this. I might not know what to do sometimes, but I'll find out and do my best.
- I want to be here for you to help you get through this. You're not alone.
- 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 sharing and being open right from the start. Remind each other that you're on the same team. Share your fears and worries. Be honest. It will also help you keep supporting each other and reduce [distress and anxiety](#)¹. Acceptance and sharing will help keep your relationship strong.

A few tips to help you communicate more clearly:

- Respect your own feelings, needs, and desires, as well as those of the patient.
- Speak out about your feelings while being thoughtful about others' feelings .
- Try to use "I" statements rather than "you" statements. For example, say, "I need some help" instead of "You never help me!" Beware of statements such as, "You ignored me," which says to the other person that they did something wrong. Instead, try "I didn't hear you answer when I mentioned _____," or "I need help with this problem."

- Focus on the present rather than bringing up old patterns or hurts.

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 don't want to hurt 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 [Emotional, Mental Health, and Mood Changes](#)².

- Remember that people communicate in different ways. Try sharing by writing or by using motions, expressions, or touch. Sometimes, it may be really hard to say what you're feeling, but an act such as holding hands might show how you feel.
- Take hints 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.

How do I talk with the medical team?

First, get the patient's consent

If a release form hasn't been 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, not asking for it. It will be hard to get information without the patient's consent, so it is important to have the patient's consent even for general information such as the sideeffects from [chemotherapy](#)³. This information may be helpful in deciding what to do next.

Keep in mind that different forms are signed for different purposes. Here we are talking about a release form that only 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](#)⁴ and [Advance Directives](#).⁵

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'll need to ask which members of the cancer care team to contact for questions. After you find out which cancer care team members are your main contacts, it would be helpful to plug them into your phone contacts.

The person with cancer should feel comfortable talking with the cancer care team, and you should too. Take the time to ask questions and make your concerns known to them.

If you want to know more about who might be on the health care team and how to talk with them, see [Health Professionals Associated With Cancer Care⁶](#) and [The Doctor Patient Relationship⁷](#).

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.

Do I need to go to doctor visits with the patient?

Going to see the doctor with the patient is a good way to learn more about their medical condition. This can be very helpful when caring for the patient later on. It can also help the patient remember to mention problems to the doctor and/or to come home with the information you need. And finally, if a referral is needed, 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 make the most of my time with the doctor?

The average time you have with the doctor during an appointment is about 15 to 20 minutes or even less, so it helps to be ready for each visit. Before you go, it's a good idea to make a list of the most important things you need to talk about. For example:

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

Making a list ahead of time to take with you will help you to use your time with the doctor in the office to cover anything important.

While you and your loved one are with the doctor or a member of the cancer care team, make sure you both understand the plan for treatment. 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's important to remember. If you're getting test results back, be sure you understand them 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.

It's a good idea to ask if there is an online portal so that you can check results, and send and receive messages from the cancer care team.

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

What 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 have different on- the- go schedules, 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 ideas may be helpful or how to help.

Family meetings are one way to keep everyone informed. When planning a family meeting, it's important to include everyone who will be part of the caregiving team at home. This could include a family friend, neighbor, or paid caregiver. Remember to include the patient in the family meetings. If it's hard to get everyone together, a conference call, virtual/online app, Facetime, 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, childcare, 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

If there are family issues such as how members relate to each other, how they feel toward the person with cancer, and how they deal with illness, it could cause problems in the patient's care. It would be good to work with other family members on any issues that could get in the way of helping to care for the patient. A social worker or other professional can help with these issues.

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.

[For connecting and sharing during a cancer journey](#)

Anyone with cancer, their caregivers, families, and friends, can benefit from help and

support. The American Cancer Society offers the Cancer Survivors Network (CSN), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

Hyperlinks

1. www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes.html
2. www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes.html
3. www.cancer.org/cancer/managing-cancer/side-effects.html
4. www.cancer.org/cancer/managing-cancer/treatment-types/chemotherapy.html
5. www.cancer.org/cancer/managing-cancer/making-treatment-decisions/informed-consent.html
6. www.cancer.org/cancer/managing-cancer/making-treatment-decisions/advance-directives.html
7. www.cancer.org/cancer/managing-cancer/finding-care/health-professionals-associated-with-cancer-care.html
8. www.cancer.org/cancer/managing-cancer/finding-care/the-doctor-patient-relationship.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 they can think clearly and share their thoughts. A patient's decisions will be carried out as long as they are safe and don't cause problems.

- [How do I know what the patient wants?](#)
- [What if the patient won't do things for themselves?](#)
- [What if the person with cancer can't speak for themselves?](#)
- [What if there's abuse in the family?](#)
- [When do I call the doctor?](#)
- [What if the patient needs to be moved or relocated?](#)

How do I know what the patient wants?

Everyday choices are easier to make if you understand the patient's wishes, 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 too much and hard to make.

Sometimes even a small crisis can make the patient unable to express what they want or need. As much as possible, honor the patient's wishes, but be realistic about the limits on what you and other caregivers can do. 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 the patient won't do things for themselves?

This can be frustrating for a caregiver. You may feel that the patient is able to do some things for themselves, but they don't. Sometimes there are medical or emotional causes for this, such as severe tiredness (fatigue) or clinical depression. If you're not sure, get in touch with the patient's doctor and tell them exactly what is happening. 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, ask a member of the cancer care, physical therapy, or occupational therapy team to evaluate the patient. Social workers may also be able to help with this if assistive devices are needed.
- Encourage the patient to do as much for themselves as they can.
- 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.

Remember that you can also get professional help, such as a social worker. 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 the person with cancer can't speak for themselves?

There are legal documents that can allow a designated person to share the patient's treatment decisions and wishes. Health care decisions can be made ahead of time in writing and expressed through the following documents:

- An **advance directive** is a legal document that explains how you (the patient) want medical decisions about your care to be made if you cannot make them yourself. Give a copy of the document to the health care team.
- **Durable power of attorney for health care** is a legal document that names a person to be your **health care proxy**, a person who can make health care decisions for you if you are unable to make these yourself.
- A **DNR order** (do not resuscitate) says a patient does not want CPR if their heart stops beating.

What if there's abuse in the family?

Any crisis or stressful change can worsen abusive behaviors in families that already have tension. The crisis of a cancer diagnosis can take a toll on both the caregiver and the patient.

Patients are more commonly seen as victims of abuse, but sometimes the patient may be the abuser. Again, the stresses of cancer may make your relationship more difficult. If the patient's behavior becomes abusive after cancer treatment, the doctor can check to see if there are medical reasons for it. Just because the patient is sick, does not make abuse okay.

There may be misunderstanding, tension, hurt, and anger – but it's important to have ways to deal with these feelings so they don't happen all the time. Emotions need to be expressed and accepted. The cancer care team usually assumes that patients and their caregivers treat each other with respect. They don't assume there is emotional, verbal, physical, or sexual abuse. But it's important for them to know if abuse is happening or has happened in the past. 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 for a list of possible things to watch for. **Ask the doctor or nurse what problems you need to call about right away, no matter what time it is.** You can also ask what things 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 to do if there are problems. Should you call your pharmacist if there are problems with the medicines? Should you go to the ER? Have an emergency plan in place just in case problems come up after the doctor's office is closed.

For more details on when to call the doctor, see [Managing Cancer-related Side Effects¹](#).

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, instead of alone.

Cancer and its treatment can cause confusion, forgetfulness, and unsteadiness walking,

and may worsen the symptoms of other conditions such as dementia. Patients can harm themselves by forgetting to take 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.

Sometimes the less serious problems can be managed at home if someone can stay with the patient at all times. These problems call for a special discussion by the family for them to possibly take turns staying with the patient. Otherwise, the family 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 they safely do without help?
- What other living arrangements are available? Can the patient move in with another family member? An apartment closer to the primary caregiver? A smaller house? An independent retirement community?

This discussion can be tricky if 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, something else must be done. An occupational therapist's, or OT, assessment can also tell you if the patient can be kept safely in the home if certain changes are made. Ask your doctor about a referral to an 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 anywhere else but home. It can be 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 not being as independent as before. Maybe they don't want to feel they are a burden to 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 feel you need 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 work something out. **Be sure that you, the patient, and all caregivers have looked at all options.**

You'll also need to talk about each person's concerns. For example, things like keeping the patient safe, convenience of the decision, finances, and the care needed are important to discuss. It helps to check out the physical setting and set up a timeline of patient needs. For example, are there 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 finding other options and setting up plans that will work. 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. [Home care services](#)² may need to be looked into for support.

Hyperlinks

1. www.cancer.org/cancer/managing-cancer/side-effects.html
2. www.cancer.org/cancer/managing-cancer/finding-care/home-care-agencies.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 to plan for.

- [How do we deal with medical delays?](#)
- [What do I need to know about treatment?](#)
- [What tools can help the patient be more independent during and after treatment?](#)
- [What should I know about new medicines?](#)
- [What if they refuse cancer treatment?](#)
- [What happens when treatment ends?](#)
- [When can the person go back to their normal activities?](#)
- [What if treatment doesn't stop?](#)

Some of the first questions that you and the person with cancer can think about asking

the doctor and/or the cancer care team are:

- What kind of cancer is it?
- Where is it? Has it spread to other areas from 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. There's no way for them to know for sure, but **the cancer care team can 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?

Test result delays

Sometimes it can take a while to get results back for lab tests, imaging (x-ray, scan) tests, procedures, or biopsy . 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.

While waiting for these results, concerns and emotions may come up. 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 time that could be spent treating the cancer.

Cancer treatment should start very soon after diagnosis, but for most cancers, it's okay 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 maybe a good idea, especially if the patient can see a doctor who has more experience 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](#)¹.

The patient also might want or need time to prepare to put their normal activities “on hold” while getting treatment. For example, 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 the [Family and Medical Leave Act](#)² and [Helping Children When a Family Member Has Cancer](#)³.

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 will need to get more information about the processes of treating the cancer. You also will need to know about side effects of treatments and when to contact the cancer care team to let them know.

Some ideas that have helped others deal with uncertainty and worry 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.
- Recognize when you worry. 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. Others turn them over to a higher power to handle.
- Express feelings of worry or uncertainty with a friend or counselor you trust. 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. Your loved one may have good and not so good days. Uncertainties, 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 normal as possible and not think about it. Most people have a mixture of worry 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 different situations that they now find themselves in. Even with all the activity, some people go through their days feeling numb and withdrawn. Others may be sad, on edge, 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 are the treatment plans? 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 [find your cancer type](#)⁴ to get more information about or call 1-800-227-2345 to talk with a cancer information

specialist.

What do I need to know about treatment?

Cancer treatment varies a lot depending on the type and [stage⁵](#) 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 with them. They 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. There's more information here if you'd like to read more about [treatments and their expected side effects⁶](#).

Treatment can be long or short, but even short treatments tend to throw off a person's life for several weeks. As the caregiver, your life and your family's lives may be a bit off, too. You may find that you need to take time off from work. See [Taking Care of Yourself When You're a Cancer Caregiver](#) 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 might want to discuss with the cancer team ahead of time are:

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

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

What tools can help the patient be more 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 get in the way of 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 they refuse 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 high-risk. 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. Sometimes, their reasons make sense to you and give you a different point of view. Your loved one may or may not ask what you think about their decision. It is helpful to remember to support their choice and help them through this time the best that you 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 their 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 can help anyone with cancer – even those who are sure that they don't want treatment for the cancer itself. Sometimes called [palliative care](#)⁷, 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](#)⁸. 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. Keep in mind that a patient who is able to make their own decisions may choose to refuse this care. This can be hard on the family and loved ones, if the person seems to be suffering with pain and other symptoms. If this happens, you can keep offering hospice and palliative care as an option. 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. The caregiver plays a key role during this time and there can be many responsibilities.

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

- What kind of follow-up visits are needed? How frequent 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 they have been off work or working fewer hours)?
- How will we know if the treatments worked? Are there tests for cancer after treatment?

After treatment is over, be sure that the patient has [copies of their medical information](#)⁹. 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 or the patient needs to see a different doctor in the future.

When can the person go back to their normal activities?

In most cases, the person with cancer 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, or may still be getting.

It's possible that life-saving treatments may have an impact on the patient that may be temporary or permanent. For some people, there may be short-term effects and for others, there may be long-term effects. The long-term impact may limit the patient from going back to the activities they did 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 the patient can start doing, either alone or with a little help. If there are things that the patient can't quite do, talk with the doctor about a referral to a physical therapist or occupational therapist. These professionals may be able to maximize 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](#)¹⁰ – 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 they get treatment, so there are ongoing side effects and frequent appointments to deal with. The difference is that in this case, you don't really know how long it will last. Living with this uncertainty can be challenging..

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 treatments and better management of side effects mean that the caregiver can work a more normal schedule during long-term or maintenance 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 a lot of work 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 treatments are longer than expected.

When treatment stops helping – what then?

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

The patient will have to decide things like "Should I choose other options to deal with the cancer and its side effects or enjoying time with my grandchildren without treatments?" Knowing what's most important to the patient helps the caregiver and family members understand these decisions. Sometimes caregivers help patients set priorities to focus on. Other times, it may take someone on the cancer care team or a mental health professional to help the patient define what's most important to them, and what can be expected from further treatment. This maybe 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?

If the decision to stop treatment has been made, it's important to make sure that other family members and loved ones understand and can support the patient's decision. This would be a good time for a family meeting, where questions can be answered, and concerns addressed. Be sure that other fill-in caregivers are invited, if they're still involved in the patient's care. It's helpful for all caregivers work together to support the patient.

It's also time to talk with the doctor about focusing on palliative (comfort) care. Palliative care helps to deal with the patient's symptoms and often times helps them have 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 addressed quickly. For more information on what to expect at this time, you might want to read [Nearing the End of Life](#)¹¹.

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 able to enjoy the time they have better. 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](#)¹².

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 Manage Uncertainty, Loss, and Grief](#)¹³.

As you work with the patient and help make the most of the rest of their 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](#)¹⁴.

[For connecting and sharing during a cancer journey](#)

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the Cancer Survivors Network (CSN), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

Hyperlinks

1. www.cancer.org/cancer/managing-cancer/finding-care/seeking-a-second-opinion.html
2. www.cancer.org/cancer/financial-insurance-matters/health-insurance-laws/family-and-medical-leave-act.html
3. www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer.html
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Caregiving in Special Situations

There are many ways to be a caregiver. Not every situation is the same, and it's possible things can change as the cancer and treatment change. Here are some circumstances that might need different or more creative solutions.

- [Long-distance caregiving](#)
- [Caregiving for a parent when you're a young adult](#)
- [Caregiving for someone 65 or older](#)
- [Caregiving for someone with a brain tumor](#)

Long-distance caregiving

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 might be 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 you feel about your own responsibilities 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 live closer. 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.

- Be ready for unexpected travel on short notice if the person with cancer needs your help.
- Have someone ready to help with your children, pets, and plants if you have to leave suddenly.
- When you visit the patient check 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 those 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?
- Have your loved one use a recording device at the doctor appointments or have you on speaker phone to help you to know what is going on with treatments.
- 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 for speed dialing.
- Use a website that lets people sign up for different jobs or tasks, such as [Lotsa Helping Hands](#)¹ and [CaringBridge](#)². Then you can keep an eye on what's needed and what's being done.

Try to plan your visits. Talk to the patient ahead of time about what's needed and set clear goals for your visit. Remember to 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.

Caregiving for a parent when you're a young adult

If your parent has cancer, you may feel torn between independence as a young adult and helping your parent. Caregiving can be a rewarding way to reconnect with parents. It may also limit your freedom and ability to explore new opportunities.

As a caregiver for your parent, you may be concerned about how to support them when you have limited time and resources. Meanwhile, your friends lives may revolve around careers, relationships, and outside interests. You might feel very alone in managing your new responsibilities and emotions.

Talking with your parent and siblings is important during an illness. You may feel uncomfortable talking about difficult topics and want to avoid these discussions. But talking about your shared concerns with family members may give you more support. It also helps each family member understand what is expected and needed. Here are some things that could help ease the burden you may feel.

- Avoid discussions when you are rushed, if possible. Schedule time for regular meetings.
- Respect your parent's privacy. Ask if it's all right to tell others about their illness.
- Ask your parent about his or her treatment wishes. Respect those wishes and your parent's right to control his or her own health care decisions.
- Talk about how to manage finances during your parent's illness.
- Set realistic expectations about your caregiving role. Agree to review these expectations on a regular basis.
- Write a letter or record your thoughts if you find it hard to bring up these topics. This may help set the stage for easier in-person talks.

Caregiving for someone 65 or older

People age 65 and older may have other health conditions to manage in addition to

cancer. These other health conditions are called comorbidities or co-existing conditions. Arthritis, diabetes, and high blood pressure are examples of co-existing conditions. Some things to think about and help your loved one manage include:

- Reactions to medicines - unwanted reactions between cancer medicines and other medicines.
- A slower recovery from cancer treatment because of other health problems.
- Cancer treatments making other conditions worse.

Make sure you know which pharmacies (and their phone numbers) are filling each medication.

Make the living space at home safer by adding grab bars, extra lighting, and removing clutter to prevent falls.

Caregiving for someone with a brain tumor

In addition to physical changes, a brain tumor or brain metastases may affect a person's ability to communicate or make decisions. It's important for you and the patient to understand there might come a time when they will not be able to make decisions about their health care. It's important to think about naming someone else to make those decisions before it becomes necessary. Things for the person with cancer to consider include:

[An advance directive:](#)³ An advance directive is a legal document that explains how you (the patient) want medical decisions about your care to be made if you cannot make them yourself. Give a copy of the document to the health care team. Also, keep a copy at home.

[Durable power of attorney for health care:](#)⁴ A durable power of attorney for health care is a legal document that names a person to be your health care proxy, a person who can make health care decisions for you if you are unable to make these yourself.

Hyperlinks

1. www.lotsahelpinghands.com/
2. www.caringbridge.org/

3. www.cancer.org/cancer/managing-cancer/making-treatment-decisions/advance-directives.html
4. www.cancer.org/cancer/managing-cancer/making-treatment-decisions/advance-directives/types-of-advance-health-care-directives.html

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Taking Care of Yourself When You're a Cancer Caregiver

In most cases, the main (primary) caregiver is a spouse, partner, parent, sibling, or an adult child. Close friends, co-workers, or neighbors may fill this role when family is not around. The caregiver has a key role in the patient's care. Good, reliable caregiver support is very important to the physical and emotional well-being of people with cancer.

- [What does it feel like to be a caregiver?](#)
- [What if you don't want to be the caregiver?](#)

- [Caregivers need to take care of themselves, too](#)
- [Get professional help if you think you need it](#)
- [Respite care for caregivers](#)
- [Finding support for yourself](#)
- [Caring for your children during this time](#)
- [Being a caregiver while you're working](#)
- [If you make mistakes](#)

What does it feel like to be a caregiver?

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

Today, most cancer treatment is given in outpatient treatment centers – not in hospitals. This means someone is needed to be part of the day-to-day care of the person with cancer. Caregiver roles change as patient's needs change during and after cancer treatment.

You'll become an important part of the cancer care team along with the normal day-to-day tasks such as meal prep, cleaning, and transportation.

Here are some things to think about if you are about to become a caregiver for a person with cancer.

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

- The caregiving role can open up doors to new friends and relationships, too. Through a support group, you can get to know people who have faced the same kinds of problems.
- Caregiving can also draw families together and help people feel closer to the person who needs care.
- Caregiving can also be hard at times. Caregivers may feel down over their loved one's illness and may also feel overwhelmed as they try to manage many difficult problems.
- Caregivers can develop physical symptoms, like being tired and having trouble

sleeping. It is important for you to be aware of your body's need and take care of yourself. Reach out to other family members to step in and support you and your loved one when you feel the need to do so.

- Caring for someone going through cancer treatment can be demanding, but being good at it can give you a sense of meaning and pride. These good feelings can help provide the strength and endurance to continue in the role for as long as needed.

What if you don't want to be the caregiver?

It's quite normal to feel overwhelmed or burdened at times while caregiving. You may feel unprepared or even unable to manage the responsibilities and feelings that go with it. Whether you desire to take on this role or not, talk with the cancer care team, family members, and friends about the details of what your role would be.

If you have mixed feelings at the onset of this role, it can lead to problems later on. **Decide on your limits and make them known as soon as you can** – before the demands of caregiving become a problem.

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

Caregivers need to take care of themselves, too

You might become a caregiver without a lot of advance warning. Taking on the role of making decisions about medical care and supporting the person with cancer can seem a bit much at times. Carve out time to do things to help your body and mind stay as healthy as possible. These things include anything to help you relax, such as physical exercise, meditation, listening to music, or reading. Try to have backup caregivers in place to help for times you feel that you need a break.

There may be times you feel tired from all the energy spent in providing care to the person with cancer. This tiredness can lead to depression if it is not dealt with. Everyone has emotional ups and downs, but if someone feels down, has no energy, cries a lot, or is easily angered, it could be a warning sign of depression.

It is important to let someone know if you are feeling down more frequently or feel like you are in a depression. Early attention to [symptoms of depression](#)¹ 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:

- Get family and friends to pitch in caring for the patient
- Get some exercise
- Try to eat a healthy diet
- Look for things that give you spiritual support
- Build in recreational time, when you can enjoy friends socially

Plan things that you enjoy

The 3 types of activities to do for yourself are:

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

Make an effort to notice and talk about things you do as they happen during the day. Watch the news or take time to read the morning paper. Set aside time during the day, like during a meal, when you do not talk about illness.

Get professional help if you think you need it

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

- Feel depressed, physically sick, or hopeless
- Feel like hurting yourself or hurting or yelling at the people you care for
- Depend on alcohol or recreational drugs
- Fight with your spouse, children, stepchildren, or other family members and friends

- Are no longer taking care of yourself

Respite care for caregivers

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 for a short break from caregiver responsibilities most days – even if it's only to take a short walk or shop for food. If you can't leave the patient alone and don't have friends or family to relieve you, you might want to look into getting help from backup caregivers for respite care or a break.

Respite care is the term used to describe short-term, relief for those who are caring for family members who might need more help than usual to care for themselves. Respite is a short break from the demands of being a caregiver. It's been shown to help keep family caregivers healthy and improve their sense of well-being.

In most cases, the respite caregiver comes to the home and gets to know the patient, the family routine, and things like where medicines are stored. Having someone to come and sit with the your love one is also a respite option. This respite option is called a sitter-companion. 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 your state, [Medicaid](#)² or [Medicare](#)³ may help cover respite costs. Also check with the patient's health insurance to see what kind of respite help might be offered.

Know what you can't do

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

Some caregivers feel they have to do it all alone. They may believe that, as the partner, sibling, son, or daughter they're responsible for the sick loved one. It's hard for them to admit that they can't do it all and still keep their own health and peace of mind. They'll

do everything possible to meet their loved one's every need. Some feel guilty if they can't do it all and say they just don't feel right if they ask for help.

Set limits on what you can do. For example, if you are not used to lifting your loved one and try to do it alone, you could injure them and yourself. There are ways you can safely help a person sit up or walk but you have to learn to do it without hurting yourself. This is where expert help is needed – home care nurses or physical therapists can show you how to do it safely. They can also help you get special equipment, if you need it.

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

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

Finding support for yourself

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

Talk with a nurse or social worker or contact your local American Cancer Society to learn about services in your area. If you can't visit a group in person, the American Cancer Society has the [Cancer Survivors Network⁴](#) (CSN), an online community of people whose lives have been touched by cancer. Other organizations have internet-based groups and even online counseling, too. Through online or in person support groups, people can share their stories, offer practical advice, and support each other through shared experiences.

Faith can be a source of strength for some people. Some members of the clergy are specially trained to help people with cancer and their families. Some people may find spiritual connection in other ways; for example, meditation, journaling, and being outside in nature.

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 worry and feel less of a load when they have social support. Connecting with others can help you stay strong. Let people know what you need and ask for help. It would hard to try being responsible for all the caregiving by yourself.

You need to know who you can talk to and count on for help. Families facing cancer can become stronger. If family members don't offer help, or if you need more help than they can give you, you may be able to set up a circle of friends to help you. 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.

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

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

There are many online resources that can help you manage your job as caregiver. Some sites offer support for people caring for a loved one who has cancer. Other sites have features like group calendars to organize helpers and areas to create personal websites that concerned people can access for updates. Some of these also allow others to sign up for specific tasks when help is needed. Taking full advantage of the resources available to you is another way you can take care of yourself.

Caring for your children during this time

If you have young children, you'll need to figure out how to take care of them and their needs while you're caring for the person with cancer. Juggling children's schedules and

trying to keep their lives as normal as possible often requires more help from friends and family members. As you're setting up care for the person with cancer, you might also need to check with other parents and trusted friends and neighbors for help with your children.

Children can pick up on seeing their family members stressed and they know when there's less time for them. They may start to have trouble in school or act out at home. Even though your time is limited, you'll need to take time to check in with them to learn about [their fears and concerns](#)⁵.

Being a caregiver while you're working

Caregiving itself can be a full-time job, but many caregivers already have paying jobs. This can lead to work-related issues like missed days, low productivity, and work interruptions. Some caregivers may have 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 example, when the patient is diagnosed, getting cancer treatment, getting treatment for recurrence, or nearing the end of life. A caregiver who is working may end up having to take time off from their paying job to provide care.

For caregivers 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 the 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.

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

The [Family and Medical Leave Act \(FMLA\)](#)⁶ guarantees up to 12 weeks off per year to take care of a seriously ill family member (spouse, parent, or child). It only applies to larger companies, and not every employee qualifies for it. If you can't or don't want to stop working, you might be able to take unpaid time off under the FMLA.

Keeping your health insurance if you have to quit your job

When caregivers quit their jobs, they usually lose their employer's health insurance coverage as well as their source of income. It's very important for you still to have some type of health care coverage. If you're able to pay for your own insurance, [COBRA](#)⁷ will allow you to be covered for some months after you leave your job. Another option might be insurance from the [Health Insurance Marketplace](#)⁸.

If you make mistakes

No matter what you do, you will very likely come to a point where you feel that you did not do something as well as you'd liked to do. As a caregiver, you do the best you can. You try to include the patient, other concerned family members, and close friends in important discussions. You always try to make decisions that are in the patient's best interest – decisions that you and the patient can live with. But sometimes you'll feel that you could have handled a situation better or done something a better way.

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

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

[For connecting and sharing during a cancer journey](#)

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the Cancer Survivors Network (CSN), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

[Hyperlinks](#)

1. www.cancer.org/cancer/managing-cancer/side-effects/emotional-mood-changes/depression.html
2. www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance/government-funded-programs/medicaid.html
3. www.cancer.org/cancer/financial-insurance-matters/understanding-health-insurance/government-funded-programs/medicare.html
4. csn.cancer.org/
5. www.cancer.org/cancer/caregivers/helping-children-when-a-family-member-has-cancer.html
6. www.cancer.org/cancer/financial-insurance-matters/health-insurance-laws/family-and-medical-leave-act.html
7. www.cancer.org/cancer/financial-insurance-matters/health-insurance-laws/what-is-cobra.html
8. www.healthcare.gov/

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