“I was more overwhelmed with all of the details of treatment as a caregiver — much more so than as a patient.”

— Sarah Cooper, Breast Cancer Survivor and Caregiver

Your Role as a Caregiver
Your Role as a Caregiver

When you are someone’s spouse, parent, relative or friend, you may never imagine one day you’ll step into the role of that person’s caregiver. But when someone important to you is diagnosed with cancer, you’ll do whatever you can to help them. While doctors, clinicians, surgeons, dietitians and others team up to help your loved one, as the caregiver, you have one of the most indispensable roles of all. You’re often the one who helps with day-to-day life and activities, provides the shoulder to cry on and becomes the cheerleader. You may even take over routine tasks such as grocery shopping, running errands and paying bills. You may go with your loved one to appointments, tests and treatments. And, in some cases, you may help with other routine tasks of daily living, such as giving medication and taking care of other physical needs. These are all important roles to fulfill and can be both unfamiliar at first and rewarding in the long term.
Getting Organized

As you learn more about your loved one’s diagnosis and start to help plan treatment, be sure to keep all appointment and treatment records in one place. At CTCA, a nurse navigator gathers these records for you and ensures the care team is aware of your loved one’s comprehensive treatment plan. In addition, at CTCA, your loved one’s treatment records, medications and appointments are all stored online in myCTCA.com for you to access from anywhere, anytime. No matter where you choose to go for treatment, the care management staff should provide these services. Be sure to ask the care team to compile, track and share this information.

Consider using an organizational tool (such as this Guide, a three-ring binder or a cancer planner) to organize the records the care team provides along with notes about appointments, important insurance documents, questions you want to ask the doctor, medication schedules, educational materials you collect along the way and more. Keeping this information in one centralized location provides you with easy access to information throughout treatment and recovery. When your mind is focused on juggling so many different aspects of your loved one’s care, you’ll appreciate and benefit from having all of these pieces in one place. Plus, staying organized helps reduce the potential stress of losing or searching for important documents when you need them, since they’ll always be available right at your fingertips!

ASK FOR HELP

As you start putting together a care team and treatment plan, you may feel unprepared for the changes and decisions that lie ahead. Rest assured that cancer is a process—not just for the person who’s been diagnosed, but for you as well. There’s rarely a predictable progression with cancer. It’s best to take it one step at a time.

Though it can be difficult to ask for help, learning to accept support in your role as a caregiver can be valuable in managing both the practical and emotional burdens of daily life with cancer. Remember, the more help you have, the more help you can provide. Evaluate your needs, and then consider asking for or accepting help from family, friends, providers and your community with the following:

- Transportation (e.g., travel to and from treatment)
- Home maintenance (e.g., cleaning, cooking, laundry, etc.)
- Childcare
- Emotional support
From Sprint to Marathon

When your loved one is first diagnosed with cancer, you may experience a flurry of doctor appointments, tests, results and more doctor appointments. Perhaps you’re at a computer every chance you get, combing through pages of research and message boards—often late into the night. Then comes choosing a provider, assembling a care team and designing a treatment plan. It all seems to happen so fast—as if you entered a sprint to save your loved one’s life. But though it may seem difficult to believe in those moments, the entire cancer experience won’t always seem this fast or be filled with so many decisions and progress all at once.

The next phase of care—treatment—is often described as a marathon when compared to the fast-paced beginning of most people’s cancer experience. Treatment can be a long journey, ranging from months to years.

The Caregiver Experience

You may think that being a caregiver is a natural progression of your commitment to a loved one with cancer. However, being a caregiver is actually a job in and of itself, with its own set of rewards, anxieties and time-consuming activities.

Based on information we’ve gathered from other experienced cancer caregivers, here’s a look at some of the emotions you may experience along the way. Know that all of the emotions and feelings you encounter are valid—whether they fit into the model below or not. Be honest with yourself about what you’re feeling at each stage so you can take steps to cope with those emotions—not only to best support the patient, but also to best help yourself.

1. PATIENT IS DIAGNOSED WITH CANCER
   CAREGIVER EMOTIONS: shock, denial, disbelief, sadness, fear, numbness.

2. PATIENT AND CAREGIVER EVALUATE TREATMENT OPTIONS
   CAREGIVER EMOTIONS: wondering, chaos, panic, worry, naiveté, confusion, stress, depression, learning and hope, guidance and frustration.

3. PATIENT AND CAREGIVER ASSEMBLE CARE TEAM AND MAKE DECISIONS ABOUT TREATMENT PLAN
   CAREGIVER EMOTIONS: on a mission, acceptance, advocate, learning, control.

4. PATIENT BEGINS TREATMENT; YET REALITY SETS IN AS TREATMENT BEGINS TO IMPACT DAILY LIVING
   CAREGIVER EMOTIONS: anger, guilt, stress, anger at God, anger at patient, anger at relatives, loneliness, exhaustion, depletion, need for new hope.
An Important Conversation

As you and your loved one embark on the next steps of this journey together, there's an important conversation you need to have: a discussion about life goals. You may be thinking, “What do life goals have to do with cancer treatment?” In a word: Everything. It's very difficult to define what an ideal treatment plan looks like when you've never had to make a decision like this before. Clearly defined life goals can help guide your decisions when choosing treatments because you gain clarity about which options fit those life goals. In doing this, you'll find that decisions become more seamless and can give your loved one a greater chance of achieving the desired outcome.

For example, ask your loved one, “What do you want to accomplish in life?” Answers can range from wanting to attend a daughter’s wedding in a year to wanting to live another 50 years to being able to continue working throughout treatment. There are no wrong answers. You can also ask if your loved one is willing to negotiate when it comes to personal priorities. The goal of this question is to understand the balance of your loved one's hopes and dreams as well as those things they may be willing to change in the short term, such as a stricter diet that supports their well-being during treatment or a lightened work schedule that gives them more energy for treatment. Knowing these factors helps put you both in the best possible frame of mind when meeting with the care team. It helps you make sense of the options, ensures you investigate the pros and cons of each treatment and ultimately allows you to design the optimal treatment plan for battling the disease while supporting your loved one’s short- and long-term life goals.

During your conversation, keep a notepad nearby and jot down any points you want to remember when discussing treatment options with doctors. As treatment progresses, you can revisit this conversation with your loved one as many times as you like. Not only does it empower you both when learning about and deciding on different treatment options, it aligns your expectations and draws you even closer to one another as you embark on this life-changing journey together.

Just as no two cancer experiences are the same for patients, no two caregiver experiences are the same. Every person, every family and every experience with cancer is different. Therefore, it can be difficult to know, as you begin, exactly what role you need to play. One thing you can expect is that your role can, and probably will, change as the needs of the person you are caring for evolve. For example, when treatment ends, you may find yourself once again a spouse, child or parent—and no longer a caregiver. Or you may find that providing care consumes an increasingly large part of your life and may continue even after treatment ends.

12 million
Number of Americans today who’ve had cancer.
Each needs someone to help them through their journey with cancer.
Caregiver Roles

As the caregiver, you often take on countless roles and wear many different hats—some you may have never experienced before. Below are some of the roles your loved one may need fulfilled while being treated for cancer:

- **Catalyst**: Who gets them to take action?
- **Shoulder to Cry On**: Who can they share their pain with?
- **Normalizer**: Who lets them feel normal?
- **Understander**: Who do they relate to that’s been through it before?
- ** Advocate**: Who keeps them positive?
- **Life Advisor**: Who do they trust to help make decisions?
- **Problem Solver**: Who helps keep their world in order day to day?
- **Perspective Provider**: Who do they go to for the big picture?
- **Navigator**: Who guides them through the process?
- **Educator**: Who helps them gain knowledge?
- **Clinical Advisor**: Who talks to them about the science?

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Your Extended Care Team

Caregiving can encompass a lot of roles. If you’re feeling overwhelmed by the heap of new responsibilities you feel you need to take on—not to mention the weight of coping with a cancer diagnosis and treatment—take a step back for a moment. Know that no one—including your loved one—expects you to take on each and every one of these roles.

Because the role of the caregiver is a multi-faceted one, we encourage patients and their families to assemble an extended care team—a group of people who can play some role in supporting you and your loved one during this journey. Since you are the most important person in your loved one's care right now, look at the chart and put a checkmark next to one or two circles that represent roles you’re already playing and one(s) that you want to continue to fulfill. Now, take a more in-depth look at what each role means. Think about the people in your life who want to help, read the descriptions of the roles below and try to match them with roles best suited for their skills, personality and relationship with your loved one.

**SHOULDER TO CRY ON**
This is someone who is empathetic and a great listener, yet not overly sensitive. They’ll be a great person during challenging times when your loved one needs to be heard and supported.

**NORMALIZER**
This type of person is great at coming up with a list of interesting and engaging activities. This person can take your loved one away from whatever’s going on and help get their mind off of the current situation. The Normalizer sees beyond the illness and treats your loved one as the individual they are and helps them feel “normal” again.

**UNDERSTANDER**
This person is someone who has been in a similar situation and can most relate to what your loved one is going through. If you know someone who’s fought cancer before or cared for someone who has, they are ideal for this role. They identify with the thoughts, feelings and questions your loved one is experiencing, helping your loved one feel understood and supported.

**ADVOCATE**
This is a genuinely positive individual who sees the best in everyone. The Advocate lifts your loved one's spirits, puts a smile on their face and reignites the desire to fight this battle with the hope that better days are just around the corner.
CATALYST

With so many decisions to make regarding treatment and such overwhelming emotions, sometimes the person with cancer may feel like giving up. The Catalyst won’t let them. The Catalyst inspires your loved one to take action because the Catalyst never loses sight of the big picture: helping your loved one get back to fulfilling life goals and all of those things they enjoyed before cancer.

LIFE ADVISOR

Your loved one is going to need help making major treatment and life decisions every step of the way. The Life Advisor helps guide the patient: discussing all of the potential options, weighing the pros and cons and gathering any additional information needed to make informed decisions. The Life Advisor can be involved with treatment-related decisions, as well as those involving everyday life, such as financial and family-related decisions. This job is often best suited for someone who is well-educated, experienced, open-minded and decisive.

Now, what about the other roles that make up the extended care team? Well, when your loved one is a patient at CTCA, we take your entire family’s experience into account. While we’re the doctors and nurses who provide the medical care, we’re also committed to easing your experience as a caregiver—and we do that by fulfilling some of these roles. The dark green circles below represent the roles your loved one’s CTCA care team is ready to fill:
Care You Can Count On

You may remember that Care Managers at CTCA play a central role in coordinating the entire care team. As your constant point of contact before and during treatment, your loved one’s Care Manager is also a source of support throughout the cancer journey—for both your loved one, and you. Care Managers take on many of the caregiving roles so you can focus on others. In countless ways, Care Managers improve your loved one’s experience, as well as yours, along the way. Some of the roles CTCA Care Managers fulfill include Clinical Advisor, Educator, Navigator, Perspective Provider and Problem Solver.

The Care Manager is the first person to contact with any questions or concerns that you might have during the treatment process. As a member of the care team, the Care Manager communicates with a number of people to ensure your loved one’s entire treatment plan runs smoothly. These people include doctors and other clinicians, you and your loved one, as well as the health insurance company.

Care Managers at CTCA also help with symptom management before, during and after treatment. If needed, Care Managers collaborate with a social worker to handle various issues, such as crisis management, applying for disability, assistance with paying for medication and finding community resources. Care Managers are available to you and your loved one and have access to your medical records 24 hours a day, 7 days a week. And, if any questions or concerns come up when you’re away from CTCA, you can always call or e-mail your Care Manager, any time, day or night. Finally, the Care Manager can help organize follow-up visits for your loved one.

So, when you look at that long list of roles your loved one needs, you can rest easy knowing you’re not responsible for performing all of them. At CTCA, Care Managers and the entire care team are dedicated to helping your loved one and you throughout this journey.

Finding Help

When looking at the roles above, it’s likely that you probably checked off more than one or two roles that you are currently filling. That’s because when someone you love is diagnosed with cancer, many people’s first instinct is to take on as much responsibility as they can. Sound familiar? But many experienced caregivers say that they wish they hadn’t done so much by themselves. While it may seem easier at first to take on these roles and responsibilities, over time, over-committing yourself can be exhausting, time-consuming, energy draining and stressful. And not only that—it can also set you up for illness.

This is another important reason to build an extended care team. Having others help fill the roles discussed above can help you maintain your energy and reduce stress. Taking time for yourself may seem difficult at first, but both you and your loved one will benefit from it.
How to Begin

Start with small increments: 30 minutes of exercise, watching your favorite TV show or taking a nap. Consider joining a caregiver support group—either in-person or online—where you can exchange advice and share concerns with other caregivers. You may be amazed at the community of caregivers looking to give and receive support from one another.

Once you are comfortable taking a small break, consider extending the amount of time you are away—a few hours every couple of days, one day every week or a week every few months. It’s important to take these opportunities to energize and replenish your body, mind and spirit because doctors may be unable to tell you exactly how long your loved will be in this phase of treatment—and you want to stay strong so you can continue caring for your loved one.

Asking for Help

It may not be in your nature to ask for help, but reaching out to family and friends for assistance is essential when you’re caring for someone with cancer. As we mentioned above, many caregivers don’t reach out at all and end up taking on everything themselves. However, this often leads to higher stress levels and the feeling of being burnt out.

Asking for help might be easier than you expect and make managing day-to-day tasks less demanding on you. Many times family and friends want to help, but just don’t know how. Think about the loyal, generous and dedicated people in your life, and consider asking them for help. Examples include:

- Family Members/Relatives
- Friends
- Neighbors
- Colleagues
- Church Members
- Social Worker

Once you know the people you want to reach out to for help, you can have a conversation with them about the kind of help you need. It’s good to have a one-on-one conversation in a quiet place so you can be clear and specific about the areas in which you need help.

TIPS FOR ASKING FOR HELP

- Create a list of needs.
- Discuss which tasks you think the person would be best suited to help.
- Request their assistance with the task(s).
- Ask if they have any questions or concerns.
- Make sure they understand how valuable their help is for you and your loved one.

Soliciting help with everyday responsibilities is extremely beneficial when caring for someone with cancer. If you and your loved one are traveling for treatment, you need to lean on your support system even more when you’re away.
Medication Tracker

One of the best ways to help your loved one is to keep track of their medications. However, with all of your day-to-day tasks, it can be challenging to keep all of the information organized. Plus, your loved one may take several different medications to help with the cancer treatment and side effects, in addition to any over-the-counter or prescription drugs they take for conditions that existed prior to starting treatment. For these reasons, it’s important to track medications so that your loved one can stay on schedule and know what medications to take at a particular time.

Additionally, having all your loved one’s medicines and the related side effects listed in one place helps the doctor, pharmacist and other care team members take better care of your loved one and help prevent medication interactions.

The medication tracker worksheet allows you to maintain a complete, up-to-date list of all the drugs your loved one takes, including dosage amounts, related side effects, instructions on how to take medications and prescription refill information. A great way to relieve some of the stress you or your loved one may feel prior to an appointment is to bring this list with you. Having this list relieves you and your loved one of having to remember all of this information at each appointment.

Check the labels on each bottle or package of medication to fill in the information in worksheet 7.
Taking Care of You

As you’ve probably already noticed, caring for someone with cancer can be completely absorbing, leaving you with little time for anything else. But, as we’ve mentioned, it’s important to continue making your health a priority too. Staying healthy is crucial for your own physical and mental well-being and ensures you have the strength and ability to continue caring for the person who needs you most.

However busy you are, there are little ways to make things easier on yourself. Sometimes you may find you need to let small things go in order to find that time for yourself. For example, perhaps you can postpone doing the dishes or the laundry to take a walk, catch up with a friend or read a book. All of those things are worth your time because they help calm your mind, reduce your stress level and help you stay positive. Consider finding people to handle things that you just don’t have time or energy for right now, such as mowing the lawn or grocery shopping. As mentioned in the section above, don’t hesitate to tell friends or family members exactly what you need when they offer to help. Just as you want to do everything you can to help your loved one, they want to help, too. Saying “Yes” to help can make a significant difference in your day-to-day life.

GET ACTIVE TOGETHER

Although staying in shape may sound like a tall order when your loved one’s battling cancer, it’s an important way to contribute to the success of treatment. Eating a wholesome diet, getting enough sleep and staying as physically active as possible makes your loved one feel healthier, calmer and more confident. In fact, a strengthened body tolerates conventional therapy better and heals more quickly. As a key player in your loved one’s support system, teaming up to adopt a healthier lifestyle benefits you both, makes you feel closer to one another and increases the likelihood that you’ll both stick to these good-for-you changes.
The three components of a comprehensive fitness program include cardiovascular training, strength training and stretching. These components can be adapted to a wide range of activities and fitness levels—so the level you start from doesn’t matter. Although increasing physical activity is important for almost anyone, be sure your loved one discusses starting a new exercise program with their physician beforehand to be sure it’s safe. Remind your loved one to start out slow and increase the length and intensity of the exercises gradually over time. “No pain, no gain” is not the phrase your loved one should rely on at this time. If they experience pain or difficulty breathing, stop the activity immediately until they feel better.

A customized fitness program can support your loved one through all phases of treatment and recovery. The program should include:

**CARDIOVASCULAR TRAINING (AEROBIC EXERCISE):** Raises the heart rate. This type of exercise increases stamina and may protect the heart and lungs from some of the toxic effects of chemotherapy. Examples include walking, cycling, dancing and swimming.

**STRENGTH TRAINING:** Builds muscle strength and tone. Strengthening can protect against the loss of muscle mass during treatment and may combat osteoporosis (bone loss), which can occur with chemotherapy. Some ways you can build strength include using your own body weight, lifting weights, using weight machines and using resistance bands (stretchy rubber bands you can use almost anywhere).

**STRETCHING:** Boosts flexibility, reduces soreness and can help prevent injury. These exercises improve blood and oxygen flow to the brain, which may help combat some of the neurological effects of cancer therapy such as fatigue or forgetfulness.

Staying active is good for the body and the brain! That’s because exercise releases endorphins, feel-good brain chemicals that also act as natural painkillers and mood-boosters.

Physical activity can also improve confidence and self-esteem. Best of all, research shows that even a modest change in activity level can significantly improve your quality of life.

The oncology rehabilitation therapists at CTCA can help your loved one build strength and endurance, regain independence, reduce stress and maintain the energy needed to participate in the activities important to you both. Our oncology rehabilitation team includes licensed physical therapists, occupational therapists and speech pathologists.

“Exercise was a huge part of my daily routine (as a caregiver), and it helped me get away from the 24/7 role of caring for Bruce.”

— Sarah Cooper, wife to CTCA patient, Bruce Cooper
Staying Well Today, Tomorrow and Every Day

Maintaining a healthy diet along with exercise and stress management is always important. For you, it’s especially critical at this point in time when you’re experiencing increased responsibility, pressure and daily challenges. Before committing to a healthier way of life, it’s important to know that every day will be different. The key is to do the best you can, every day. If some of the new habits you begin feel different from what you’re used to, take it slow and make small changes as you go. In the long run, you’ll be more successful at embracing small changes if you approach them gradually rather than trying to change everything all at once. Start with changes that feel the most feasible for you to tackle now and continue practicing the behavior until it becomes a habit.

What’s in store for you? In the short term, you’ll help fend off illnesses, such as a cold or flu that could prevent you from being able to care for your loved one. In the long run, you’ll reduce risk factors for serious diseases such as heart disease, diabetes and cancer. While you might not notice your blood pressure or blood sugar decrease right away, you may notice smaller changes that make a big difference in how you feel. For instance, you may find that you sleep better at night and have more energy during the day. If needed, you may also lose weight and your skin may appear brighter and healthier. Finally, you might notice you don’t get stressed as easily or feel as irritable as you did in the past.
Living a Healthier Life

Here are some important ways you can live a healthier life each and every day:

**EAT WELL**

- Eat fruits, vegetables, lean proteins and whole grains every day.
- Aim for variety: Fruits and vegetables contain different vitamins and nutrients. The more variety you eat, the greater the array of vitamins and nutrients you consume.
- Create a healthy plate: At each meal, draw an invisible line down your plate. Fill half of your plate with fruits and vegetables. Divide the other half in two and fill half with whole grains and half with lean protein.
- Limit your consumption of foods and drinks that contain high amounts of calories, fat, sugar and alcohol.

**INCREASE PHYSICAL ACTIVITY**

- Target 30 minutes of physical activity most days of the week. You don’t have to go to the gym—walking, riding a bike, swimming, dancing and any other activity that increases your heart rate for that duration counts.
- Include muscle-strengthening activities in your routine at least two days a week. Activities that strengthen muscles include lifting weights, using resistance bands, body-weight exercises (such as push-ups and sit-ups) and yoga.

**CONTROL STRESS**

- Get seven to nine hours of sleep per night.
- Ask family and friends for help.
- Take time to relax and do activities that make you feel replenished.
- Seek counseling if needed.

**OTHER HEALTHY HABITS**

- See your health care provider as often as instructed or needed. Make an appointment if you’re sick, experience pain, notice changes in your well-being or have problems or questions about your medications.
- Ask your health care provider what exams, tests, screenings and vaccines you may need and when you should get them.
- If you smoke, get help quitting. Talk to your doctor or visit smokefree.gov for information and support.
- Control your alcohol intake. Women should consume no more than one drink per day. Men should consume no more than two drinks per day.
- Minimize time spent in front of a computer and TV.
Support List

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<tr>
<th>Task</th>
<th>Name of person who will help while I’m at home</th>
<th>Name of person who will help while I’m traveling for treatment</th>
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<td>Childcare</td>
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<td>Grocery shopping</td>
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<td>Preparing meals</td>
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<td>Pet care</td>
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<td>House care/cleaning</td>
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<td>Spiritual support</td>
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<td>Planning activities</td>
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<td>Recognizing and managing side effects (e.g., fatigue, nausea)</td>
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Medication Tracker

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<td>Reactions or side effects</td>
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