

The guide to
better
caregiving.

Presenting

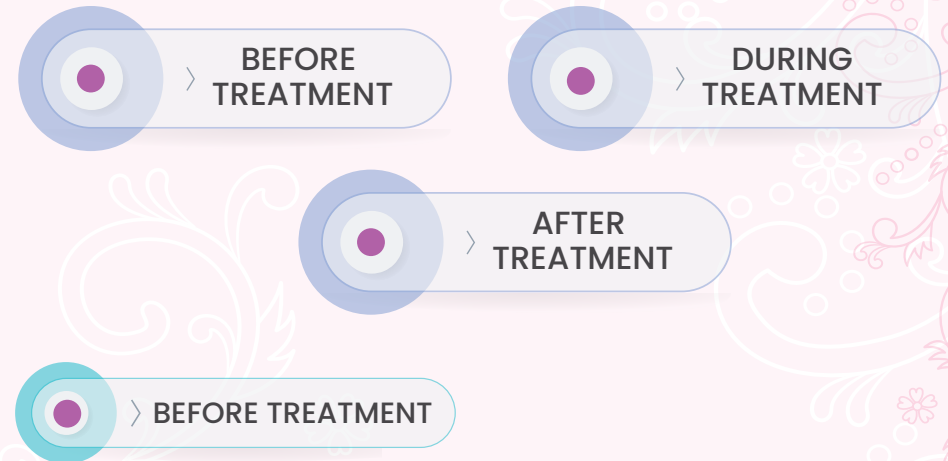
The Caregivers' Handbook



Caregiving is a labor of love. But it can be equally daunting and frustrating. You may feel you are being helplessly swept away by the new responsibilities you didn't necessarily sign up for. You might not know what to expect or you might still be grappling with the fact that your loved one is facing cancer. You might also struggle with guilt if you need to prioritize something for yourself in the midst of your loved one's illness.

All of these thoughts and concerns are normal and valid for caretakers. Caregiving requires an enormous commitment of both time and energy. With this in mind, we created this guide for you to feel healthy, empowered, and gratified in your role as caregiver—no matter what stage of cancer your loved one is facing.

Core areas for caregiving:



Receiving a cancer diagnosis is often shocking, and always unwelcome. After receiving a diagnosis, you and your loved one may need to take some time to process your feelings. Upon receiving a diagnosis, it can be helpful to do three things:

1. Identify potential areas of need
2. Communicate and set expectations with your loved one
3. Begin preparation

Identify potential areas of need

The first stages of caregiving can be the most challenging because you are not yet informed about what will be needed and expected of you. The best way to feel more certain about what your role will require is to educate yourself and find support.

Begin educating yourself: Once a diagnosis is received, you and your loved one should take time to read up on the illness and diagnosis

Talk to your doctor: A wise place to start is asking the doctor what resources you can go to for more information. Here is a list of questions to ask on behalf of the patient:*

- What is their diagnosis?
- How serious is their diagnosis? How will it affect their home and work life?
- What are the short-term and long-term prognoses?
- What symptoms and side effects should we watch for?
- What tests will be involved in further diagnosing the cancer?
- How safe and accurate are the tests?
- When will we know the test results?
- Does he/she need a follow-up visit and if so, when?
- How is the cancer treated?
- What should we expect after surgery?
- What side effects should we expect from treatment (chemo, radiation, etc.)?

Establish a support system for you and the patient:

Another area of need to identify is support. Think of upcoming physical and emotional support needs, and ask for help where needed. No one expects you to deal with this alone, and you may be surprised that what began as asking for help for yourself often leads to helping someone else.



Begin Preparation

Here are a few practical ways you can help yourself and your loved one prepare for what's to come:

Stock up on household items:

Go to the store and stock up on non-perishable items. Think about toiletries, cleaning supplies, clothing items, easy-to-assemble meals, etc. Avoiding late-night or emergency trips to the store can eliminate unnecessary stress.

Stock up on medical supplies:

Ask your loved one's doctor what medical supplies will be helpful for you to keep on hand and gather those items. This may include certain creams and lotions, bandages if surgery is part of the treatment plan, and over-the-counter pain or other medications.

Assist Medical Team

Writing down questions you or the patient have as they arise. Keeping a notebook or note on your phone to add to in real-time is useful. Taking notes or using a voice recorder at appointments to keep track of the new information you are receiving.

Starting a filing system for paperwork. Keep a separate folder for each facility, or file paperwork by month—whatever works best for your situation.

Financial Preparedness

- Get in touch with the medical insurance/claim agency to understand the paperwork, claim limit and reimbursement process
- Discuss with the doctor about the financial implications of undergoing the treatment and mention about the extent to which you and your loved ones can spend
- Ask your doctor about govt. schemes that you could avail to reduce the financial burden

> DURING TREATMENT

Once treatment begins, you and your loved one may feel like you're caught up in a never-ending cycle of appointments and treatments. On those days, it's important to keep in mind these things:

Administrative support

- Keep an updated database of all patient medications, dosages, and allergies, including pictures of each medicine bottle with the label showing and the actual pill placed on the cap. This will be helpful when doctors review the patient's medications and consider drug interactions.
- Keep and share an updated calendar of patient appointments and medication times.
- Keep an updated list of the patient's emergency contact information.

Emotional support

- If possible, make visits consistent same day and time of the week, same location, etc.—so the patient knows what to expect and has something to look forward to.
- Engage with the patient during appointments in order to take their mind off of the treatment. Remind them that you are there for them and that they are doing a great job.

Physical support

- Make a hospital bag for the patient with comfort items from home. This can include favorite books, magazines, electronics, movies, hobbies, pillows, blankets, family photos, etc.
- Encourage (and go with) the patient to exercise, according to doctor's orders.
- Check in with the patient often to make sure their physical needs are met: Are they drinking enough water? Is the temperature of the room okay? Do they need a snack?

Navigating the Hospital



It may be necessary for your loved one to spend some time in the hospital during the course of their treatment. If a hospital stay is required, there are a few things you can do to make that time easier on you both.

Don't live at the hospital

- If the patient is sleeping or otherwise unavailable, it is a good time for you to leave to get other things done.
- The hospital setting may not allow you to get good quality rest. It's okay to go home to sleep for the night, then come back refreshed the next day.

Take charge of the patient's care

- Hospitals are hectic places with busy staff, so it is important to be assertive and advocate for the patient. Keep track of the medications and dosages the patient may be on, and check in with nurses before they administer medications.
- Hospitals can often be slow-paced. Be polite but persistent and follow up with staff, doctors, and nurses to make sure things get done in a timely manner.

Find helpful hospital staff

- Find out who to contact in certain situations, as well as the best way to get in touch with the head doctor or charge nurse.
- Ask and re-ask questions. If you don't get an answer the first time, keep asking.

> AFTER TREATMENT

The end of treatment doesn't always signal the end of trauma or side effects caused by a cancer diagnosis and treatment. Oftentimes, it becomes necessary to find a "new normal," both for you and your loved one.

- Finding a new normal
- Define your new normal
- It's okay to bring parts of your "before cancer" life into your "after cancer" life. This goes for both the patient and the caregiver as the caregiver is likely to have experienced some emotional trauma from the diagnosis as well
- Try to find a balance between your pre-cancer and post-cancer lives.

Engage in post-treatment care

- Follow-up appointments are very important so the doctor can keep an eye on the patient's condition. Just because treatment has ended doesn't mean cancer care is over. If you plan to continue operating in a caregiver role post-treatment, you may need to set some new boundaries with the patient.



- Continue to help the patient organize their medications, appointments, insurance and bills, etc. When appropriate, pass this system off to the patient so they're empowered with the information you've been keeping.
- Help the patient stick to healthy habits recommended by the doctor, such as nutrition and exercise.

The Emotional Toll of Caregiving

As a caregiver, it is vital that you also take care of yourself. This looks like:

- Staying up to date with your own medical needs, such as annual physicals, necessary doctor's appointments, taking prescribed medications, etc.
- Seeking mental health care from a caregiving support group, counselor, therapist, or trusted advisor, when needed.
- Taking care of your physical needs by eating a healthy diet and exercising or moving your body.
- Taking time to yourself to recharge.

Remember: Taking care of yourself helps you better care for others. You don't have to be a superhero, so relieve yourself of that pressure.

Long-term Caregiver Depression

It is common for caregivers, especially those who have been caring for a loved one for an extended period of time, to feel a sense of depression. Caregiving itself does not cause depression, nor will all caregivers experience it.

Common symptoms of depression include:

- A change in eating habits and appetite, as well as unexpected weight gain or loss.
- Becoming easily angered or irritated (irritable).
- Feeling tired much of the time.
- A change in sleep patterns; sleeping too much or too little.
- Experiencing a loss of interest in things or people that once brought you joy/pleasure.
- Feelings of worthlessness, or that nothing you do is good enough.

Caring for Yourself

As a caregiver, it is important to also care for yourself as you walk with your loved one through their diagnosis and treatment. In addition to taking care of your physical health, try to do one special thing for yourself each day to avoid caregiver burnout and keep a healthy mindset. There are additional ways you can care for yourself as well.

Administrative support

- Keep everything organized and file it away as soon as possible. This will eliminate undue stress later from searching for documents or having to get replacements.
- Ask for help when you need it.

Ask people to help you in concrete ways that are also appropriate for them. Instead of vague requests like, “Can you help me?” try specific requests like, “Can you bring your truck to my house this Saturday afternoon to help me move something?” or “When you go to the store this weekend, can you pick up a few items for me?”

Create an organizational calendar/website where you can post your needs and others can sign up to help. Think meals, groceries, transportation, visits with the patient, childcare, etc.



- Accept help when it's offered.

Remember that no one expects you to be able to do everything by yourself, and accepting help is not a sign of weakness. Also keep in mind that by allowing others to help, they will also feel involved and invested in the patient's well-being and recovery.

Emotional support

- Be deliberate about your actions and thoughts. You can't control everything that happens, but you can control how you prepare yourself in advance.
- Keeping your head clear allows you to easily identify next steps.
- Give yourself permission to take care of yourself. Sometimes the patient will want you to stay with them, but it's okay to take a break if you need to.
- Tap into your faith or spirituality as a source of inner strength. Faith and spiritual practices often have a calming and positive effect.
- Lean on those close to you for support. People will step up in amazing ways if you let them. Be prepared—you may have to ask!
- Support groups are a way to receive (and give) emotional support from people who understand your situation.

Physical support

- Listen to your body. If you need a break, take one. Don't be afraid to cancel a stressful commitment if it means staying healthy and rested.
- Take care of your physical health. Make and attend doctor's appointments when necessary, and don't put off your own routine health screenings like annual physicals, colonoscopies, mammograms, etc.
- Pour your energy into the things you can control. Find places and situations that are comfortable. If a chore makes you overly tired or stressed, find a different way for it to get done, such as outsourcing or asking a friend for help. If weekends are family time, don't leave chores for then.

