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The Cancer Caregiver Guide

For those supporting a loved one facing cancer

Table of Contents

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Caregiving is a labor of love. If you are one of the 20-plus percent of Americans providing unpaid caregiving to another adult, then you have likely experienced uncertainty, frustration, and work-life challenges. You've also likely experienced moments of connection and compassion as well.

Sometimes you become a caregiver overnight after a cancer diagnosis. But oftentimes, your level of involvement and caregiving slowly increases over time. You may start by running a few errands or taking your loved one to appointments, then later on find yourself doing the grocery shopping and even keeping track of treatments and medications. Gradually, you begin doing more and more. While you may not call yourself a caregiver, at some point it becomes clear that life as you know it has changed and that you are committed to taking care of someone else.

You may feel like you have been thrust into a difficult situation, or that 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. However, while certain aspects of the patient's diagnosis are out of your control, there are things you can do to improve your and your loved one's quality of life.

With this in mind, we created this resource after interviewing several experts in the field of cancer caregiving, as well as members of our community who have lovingly cared for a cancer patient. Our hope through this guide is for you to feel healthy, empowered, and gratified in your role as caregiver—no matter what stage of cancer your loved one is facing.

We realize that caregiving looks different for everyone. So, while this guide will not have all the answers, we hope many of the strategies presented will be helpful to you and your loved one. Likewise, not all sections of this guide may apply to you, so feel free to skip around to whichever sections best fit your situation.

Understanding and Accepting Caregiving

Caregivers come in many forms. They can be spouses, partners, adult children, parents, other relatives, friends, and even neighbors. If you find yourself in a caregiving role, it may have come naturally over time. Or you may have become a caregiver overnight after learning of your loved one's cancer diagnosis. No matter how you came to be a caregiver, you may feel unprepared to navigate this new role. But there are things you can do to equip yourself for the journey ahead.

What Does a Caregiver Do?

A caregiver is part of the patient's cancer care team. Caregiving is helping with both physical and emotional needs. Sometimes caregiving looks like:

Meeting Physical Needs	Meeting Emotional Needs
• Being present for doctor's appointments	• Encouraging a positive outlook
• Preparing meals	• Validating feelings of fear or uncertainty
• Housework, such as cleaning and laundry	• Lifting spirits after a hard day
• Grocery shopping	• Maintaining daily activities with modifications
• Assisting with physical therapy	• Connecting loved one with outside support
• Providing personal care, such as bathing	• Extending patience in difficult circumstances

It's important to remember that while the patient needs physical and emotional support, their caregiver does too.

The Emotional Toll of Caregiving

Caregiving is life-altering—both in the moment and after. As a caretaker, it is just as important for you to prioritize your health and wellbeing—physically, mentally, and emotionally—as the loved one you are caring for. Self-care will look different for everyone. For example, for some, a quiet walk in nature may be enough to recharge them; others may need more significant time away in order to feel better equipped and renewed. No matter what self-care and protecting your mental health looks like to you, it's important to prioritize this important aspect of caregiving in order to be the best version of yourself for your loved one.

Taking care of yourself

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.

"Learning how to take care of myself while caring for someone else was definitely a challenge. Most of it was not knowing how to balance my time and feeling guilty or selfish for using my spare time to care for me. I always felt like I had to give that time to my mom or to others. I then realized I would drain myself too much, to the point where I felt that I wasn't giving my best anymore. I decided to change that by giving myself an hour in the morning or at night for self-care. I would do small things like a skin care routine, journal, read, and exercise. **Making sure I was okay before going to take care of someone else really made me understand just how important it is. Taking care of myself is what helps me give her the best care and best of me.**"

-Melenie S.

Before Treatment

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, fears, and reactions. You may find it helpful to start keeping a journal to chronicle your feelings and emotions. Writing about how you feel can be a cathartic and healthy way of processing undesirable news and emotions.

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.

If your loved one has received a breast cancer diagnosis, these resources might help:

- Beyond The Shock video series
- Free NBCF educational guides
- Articles about breast cancer at NBCF.org

If your loved one has received a different cancer diagnosis, these resources might help:

- National Cancer Institute
- American Cancer Society

Talk to your doctor

A wise place to start is asking the doctor what resources you can go to for more information. You should also think of and write down any questions you and your loved one have. You may find that going to appointments with your loved one can help eliminate miscommunications about what the patient needs and how you can help.

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.)?

**See the Appendix (page 33) or get a printable list by clicking here*

It may also be helpful to ask the office staff or billing department what the expected out-of-pocket cost for different appointments and treatments will be.

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. People want to help, but often they don't know how until you ask.

There are different ways people can help, from offering their time and actions to providing financial assistance. Think of others' specific strengths, location, and availability when asking them for help.

Ways other people can help:*

- Ask another family member or friend to be a back-up driver, or take over transportation for some appointments.
- Ask friends to make meals that can be stored in the freezer and heated up when needed. Consider setting up a Meal Train for people to sign up to bring meals on specific days.
- Ask a friend or family member to come sit with the patient so you can take a break and care for yourself. It is important for the caregiver to get time alone, even if it's just to grab a cup of coffee or visit the local library.
- Ask a trusted friend or family member to be the person who communicates health updates with the rest of the family and support system members. This keeps the caregiver from getting overwhelmed with communication responsibilities. Another option for this is using Caring Bridge.
- Ask a neighbor to help take care of the patient's yard while they are unable to care for it.
- Ask trusted family members to help with childcare, if needed, during appointment times or difficult days.
- Ask a loved one to help file and organize paperwork. The amount of paperwork received during cancer treatment, from doctor's notes and records to insurance information, can be overwhelming, so ask to be relieved of this behind-the-scenes responsibility.

*See the Appendix (page 38) for word-for-word examples of how to ask for help.

"There is a tendency to not want to be a burden to others, but my advice is **don't be ashamed or feel guilty about asking for help.** Family and friends are usually more than willing to help you. We had meals and transportation provided, and some ladies even made quilts for fundraising. The help was greatly appreciated, though at times I felt I would never be able to repay all the kindness expressed toward us. **Remember, help is given in these circumstances with no thought of repayment by the giver.**"

-Hank H.

Communicate & Set Expectations with Your Loved One

It's important—but sometimes tough—to have an open conversation about caregiving expectations. It might be helpful to frame it as creating a game plan.

Think about sports teams. They study the opponent, make a game plan, call plays on the field, and constantly communicate with each other as things change. You and the patient are a team and communication, no matter how difficult at times, is essential to your well-being.

The following questions are a good starting place:*

Responsibilities

Ask the patient:

- Who will take on the responsibilities of caregiving?
- When the primary caretaker is busy or unavailable, who will fill in?

Communication

Ask the patient:

- How would you like me to communicate about your diagnosis?

The patient is allowed to decide who to tell about their cancer diagnosis, when, and how. This may be a combination of intimate conversations, blog updates, and social media communication.

If the patient is comfortable with open communication, websites like Caring Bridge make it easy to post updates for loved ones to follow along with. This cuts down on relaying the same message to multiple people, and can be therapeutic to write.

Finances

Ask the patient:

- How will we be handling medical bills? Do we need a system for tracking financial documents?
- Can you share information about your medical insurance so I can assist with any needed paperwork?
- What is the status of your job? Are they being understanding and cooperative with your diagnosis? Is there disability paperwork we need to file?

Time commitment

Ask the patient:

- Has your doctor shared how often you will have medical appointments and treatments? Would you feel comfortable if I asked for this information so we can manage our time efficiently?
- For transportation, are you more comfortable riding in my car or your car?
- What is our plan for childcare on days where you have appointments/treatment?

* *See the Appendix (page 36) or get a printable list by clicking here*

"One of the hardest things I had to do was talk to my mom about her future wishes. Although it is scary and sad to have those tough conversations, I'm so glad I was able to prepare and learn more about what my mom would need from me so that I could give her exactly what she wanted and what she needed. At the end of the day, **what matters most is making your loved one feel important, protected, loved, supported, and most of all, heard. To let them know that you hear them and that you will fight for their wishes when they can't on their own anymore."**

-Melenie S.

Begin Preparation

Since much of the cancer journey can seem out of your control, it's helpful to focus on areas you can control, such as preparing for certain situations in advance.

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.

If your loved one is undergoing a mastectomy, read NBCF's Checklist for Recovery After Mastectomy blog post to know what to stock up on before surgery.

Become part of the medical team

You are a valuable member of the medical team since you likely know a lot about the patient. Your contribution is extremely important. Some ways you can assist the medical team are:

- Gathering relevant patient medical information and records ahead of appointments.
- 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. Bring this list of questions to each appointment.
- Taking notes or using a voice recorder at appointments to keep track of the new information you are receiving.
    - It may be helpful to bring another person to appointments as well, if allowed by your medical facility. It can be useful to get a second set of ears and a second perspective on the course of treatment being outlined by the doctor.
- Starting a filing system for paperwork.
    - Keep a separate folder for each facility, or file paperwork by month—whatever works best for your situation.
    - Ask doctors and nurses what paperwork is important to keep and what isn’t.

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. Some days, you both may feel more like machines or robots as you work to check tasks and appointments off your to-do lists. On those days, it's important to try to reconnect with each other and give yourselves time to rest and recharge, physically and emotionally.

As treatment begins, these three things become vital:

1. Caring for the patient
2. Caring for yourself
3. Navigating the hospital

Caring for the Patient

A caregiver is often the patient's lifeline. As such, you have influence over how the person with cancer handles their illness. There are many things to keep in mind as you work to keep the patient's treatment on track.

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 an updated list of the patient's emergency contact information.

- Keep an updated list of all treatment centers and doctors, along with their corresponding contact information.
- Keep and share an updated calendar of patient appointments and medication times.

Emotional support

- Talk about tasks that the patient can do to still feel involved. For example, during treatment appointments, the patient may be "in charge of" watching the news to be able to update the caregiver later. Not only does this give the patient something to do during their appointment, it helps them focus on something other than the treatment, relieving anxiety.
- 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?

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.
    - o 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?"
    - o 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.
    - o 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. Communicate to your loved one why you need to leave them for a while, so that you are on the same page. Remind them that if you are not well, it will be harder to care for them.
    - It is normal for caregivers to feel some guilt for needing to take time for themselves. You may feel that you are the only person who knows how to care for the patient, or that taking time for yourself and not being with them is selfish. This guilt reaction is often unfounded. It may be helpful to acknowledge the feeling and then try to move past it.
- 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. Join an in-person caregiver support group in your area, or find a group that meets online or over the phone.

- Keep normality going. Maintain routines. Separate work from home, and keep your focus strong on each at the appropriate time.
- Plan things that you look forward to so there is always something positive on the horizon.
- Remember that it’s okay to laugh and enjoy the good things in life! Humor and positivity can release pressure that has been building up.

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.

"When my wife was going through her journey with breast cancer, it was critical that we made time to recharge and focus on something other than treatment or feeling sick. She needed what I called 'positive distractions,' having moments where both of us could have fun and do our favorite things together. Sometimes it was a massage in between treatments. Sometimes it was taking a walk around the lake. The key element in any activity was that it was a sacred time to avoid thinking or talking about anything related to breast cancer. It needed to be a **time and space where the patient and the caregiver could both unplug and recharge their emotional bank accounts.**"

-Greg E.

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.

Stay aware

- Hospitals can be large and confusing places, and if you have a lot on your mind or are tired, it can be easy to get disorientated. Take notes or leave yourself reminders of things like where you parked, which hospital building/room number the patient is in, where the cafeteria is, and where you can go if you need a moment to yourself.

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.
- Hospitals often have patient navigators to help with finances, insurance, human resources, social work, therapy, etc. Ask to speak with a patient navigator or social worker at any time for any reason.
- 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

A "new normal" refers to what life looks like after cancer treatment ends. For some, not much may change. For others, life may be totally different after cancer.

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. Remember, you don't have to completely throw out everything from your "before" life. Likewise, you don't have to ignore certain changes you may have experienced during treatment. 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. It's possible to still be available for the patient as needed, while setting boundaries that work within your physical and emotional capacity. If you will no longer be operating in a caregiver capacity after treatment ends, be sure to clearly communicate that change to your loved one.

- 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. A useful starting place could be to suggest downloading the Nutrition Care for Breast Cancer Patients eBook or signing up to receive Weekly Healthy Living Tips.
- Keep in mind that emotional needs can persist or even arise after a patient's treatment is over. During treatment, you were likely focused on the patient's well-being. Now that treatment is over, don't be surprised if some of the trauma you also experienced catches up with you and needs attention.
- Consider joining a support group that can help you with what to expect when finding and adjusting to a new normal after caregiving.

Explore helping others

- After an extended period of caring for another person, you may feel a void in your life. If you do and wish to continue helping, there are many ways to support a cause that is close to your heart. You can donate money, volunteer at support groups, and advocate for awareness of the disease in your community and on social media. These can feel like new ways to give back and honor your experience.

“Finding a ‘new normal’ was and still is challenging. The patient’s life is never the same after cancer. And in reality, their immediate loved one’s lives are often not the same either. Part of the new normal is focusing on the cancer not coming back through being proactive about health and lifestyle choices and practicing self-advocacy. The rest of the family has to find their part in it as well and foster a new normal that is as normal as it can be. **In many ways our whole family now has a different mindset and perspective, for the better in many circumstances."**

-Michael B.

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. Rather, caregiver depression often stems from the caregiver continually sacrificing their own physical and emotional needs over time. The resulting feelings of resentment, isolation, sadness, and fear can lead to depression.

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.
- Thoughts of hurting yourself or suicide. In this case, seek immediate mental or medical intervention or call 988 (Suicide & Crisis Lifeline).

It is important to know that caregiver depression is not a sign of weakness.

If you notice that you are becoming depressed, there are several things you can do to prevent those feelings from deepening or worsening, including:

- Consistently participate in activities that bring you joy or make you feel better, such as exercise, reading a favorite book, meeting with friends, or even going to a see a movie.

- Break overwhelming tasks into small chunks; prioritize those chunks and complete them as you are able.
- Set realistic goals and assume only reasonable amounts of responsibility—remember that no one expects you to do everything on your own, or right away.
- Seek the help of a licensed counselor or therapist—talking through feelings of depression with a professional can be hugely beneficial.

Remember that people are rarely able to just "snap out of" depression. But you can begin to feel better day by day. Remember to keep your mental and emotional health a top priority, and take one day at a time.

If you feel like you may be affected by caregiver depression, it is important to ask for help. An example of how to ask a friend, loved one, or trusted advisor for help is by saying, "I haven't felt like myself lately. I think I may be experiencing depression. Will you please help me find some tools to manage this, or help me find a mental health professional I can talk to?"

"From my experience, I would advise a new caregiver to also take care of themselves. Eat healthily and don't forget to take your own daily medicines and vitamins. Try to do things that bring you some kind of joy and relaxation, emotionally and physically. Be as positive as you can for your own emotional wellbeing and for the person you are caring for. **If you start feeling too tired physically and mentally, it's time to start asking for help.**"

-Sulma S.

What if You Don’t Want to be a Caregiver?

It can be hard to admit, but many people feel overwhelmed, inadequate, unprepared, or burdened to take on the role of caregiver. These are normal feelings. However, in the absence of another caregiver, you may have to take on the caregiving role despite these feelings. Be aware that resentment is also a normal thing to feel as you are thrust into a caregiving role.

While it’s important to acknowledge these feelings, it is necessary to find healthy ways to process and deal with them. Seeking help from a licensed counselor or therapist can be helpful for both you and the patient when dealing with complex emotions and drastic life changes. Therapists often provide actionable tools to help you reframe your thinking and cope with your situation.

If necessary, make plans to:

- Address problems early to get the help you need, or make alternative plans for care.
- Find someone to help you care for the patient.
- Join a caregiver support group for a safe place to admit and talk through your feelings with people in your same situation.

Caring for a Terminally Ill Patient

Caring for someone with advanced cancer or a terminal diagnosis presents unique challenges to both caregiver and patient. In these situations, it is still important to prioritize your own mental and emotional health, as well as the physical, mental, and emotional health of the patient. Sometimes, planning ahead can make the disease progression less stressful, giving you more quality time with your loved one.

Prepare mentally and emotionally

Advanced cancer often changes the way a person looks and acts. Be prepared for your loved one to change in several ways.

- **Physical changes** may include becoming thinner and more fragile, losing their hair from treatment, the appearance of being sick, and feeling unwell most of the time. The patient is likely aware of these changes in their appearance as well and may be sensitive to them. It is important to encourage them by saying things like, “I admire you—you’re doing great job,” or “I love spending time with you.”
- The patient’s **personality or mood** may also be affected. They may not be as upbeat as they once were. They may struggle with remembering things or their sleep patterns may change. While it can be startling to experience someone’s personality change, it’s important to remember that their mood likely has little to do with their feelings toward you, but rather is brought on by the stress of their condition and prognosis. Perhaps their personality or mood change is also in part attributed to side effects from the medications they’re taking.

If any of these physical, mental, or emotional changes become critical, contact the patient's care team immediately.

Prepare medically and financially*

Many critically or terminally ill patients may choose to outline plans for end-of-life care. While patients may ask friends and family their advice, end-of-life care details and preferences are ultimately the patient's decision to make. As their caregiver, it is your responsibility to make sure their requests are honored.

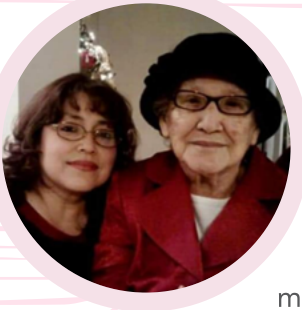
End-of-life care decisions can include completing and filing *advance directives* such as:

- **Living will:** This document outlines specific conditions of end-of-life care measures, including the use of machines to keep the patient alive, "do not resuscitate" (DNR) orders, feeding options, and organ donation wishes.
- **Healthcare or medical power of attorney:** This document names the patient's legal representative, or health care proxy, and empowers them to make medical decisions for the patient if/when the patient is no longer able to make decisions for themselves.
- **Last will & testament:** This document names beneficiaries and outlines how the patient wishes their personal property to be distributed after their passing.

* *For more information on end-of-life care for terminally ill patients, view this resource by Lillie D. Shockney and Dr. Tyler J. Trahan*

Seek counsel

Processing the news that your loved one has a terminal illness that will ultimately result in their passing is painful, as is seeing the health of your loved one decline over time. Grief can be a very heavy burden to bear if you try to bear it on your own. It is important that you and the patient find trusted advisors—a close friend, loved one, support group, or mental health professional—to confide in and seek counsel from as you walk through this journey.



"When your loved one passes, try to go back to your regular routine slowly. Rest as much as possible. Stay close to family, try to get involved in activities that keep your mind occupied on things that bring you joy. Know that it's really hard to move on, but **if it becomes impossible to heal and it starts affecting you to where you can't handle it on your own, then seek the help of family, your faith, or professional counseling."**

-Sulma S.

Caregiving is a hard yet worthy job. While many aspects of the patient's care may be out of your control, there are ways you can help improve your loved one's quality of life.

Caregivers play an essential role in the cancer journey. Through this guide, our wish is that you feel seen, understood, and supported in your dedication and sacrifice. We hope the tools provided help you navigate this time with greater ease and that the strategies shared serve to support you and the person you're caring for.

Appendix

Medical Team Questions

You can either fill in the answers below, or print a copy by clicking here.

- 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.)?

- *Ask the office or clinical staff rather than the doctor:* What is the expected out-of-pocket cost for different appointments and treatments?

Setting Expectations Worksheet

You can either fill in the answers below, or print a copy by clicking here.

- Who will take on the responsibilities of caregiving?

- When the primary caregiver is busy or unavailable, who will fill in?

- How would you like me to communicate about your diagnosis?

- How will we be handling medical bills? Do we need a system for tracking financial documents?

- Can you share information about your medical insurance so I can assist with any needed paperwork?

- What is the status of your job? Are they being understanding and cooperative with your diagnosis? Is there disability paperwork we need to file?

- Has your doctor shared how often you will have medical appointments and treatments? Would you feel comfortable if I asked for this information so we can manage our time efficiently?

- For transportation, are you more comfortable riding in my car or your car?

- What is our plan for childcare on days where you have appointments/treatment?

How to Ask for Help with Caregiving

I have a scheduling conflict during Annie's appointment next week. Are you available to take her to treatment on Wednesday morning?

We are wiped out from all the doctor's appointments and treatments lately. Will you please reach out to our family and friends to set up a Meal Train to cover our evening meals for the next 2 weeks?

I need some time to run a few errands. Is there a day this week that you can come spend some time with Annie while I get out of the house for a little bit?

It can be exhausting to communicate health updates with all of Annie's family and friends. If I send you a list of contacts, can you be the one to send updates to everyone?

Hi neighbor! Due to Annie's illness, neither of us are able to keep the lawn in good shape at this time. Would you be able to help with some light yard work every once in a while?

Annie has chemo this week so likely will not be feeling well for a few days. Is there an afternoon or two that you could pick the kids up from school and help them with their homework and dinner?

I'm feeling overwhelmed with all the paperwork from the hospital and doctors. Can I pass it off to you to sort through and organize?"

Additional Resources

- American Cancer Society
- Cancer Support Community
- Stupid Cancer Support Groups
- GriefShare
- Guys for Good
- The Light Between Shorelines: A Resource, Education, and Support Guide for Patients with Advanced Cancers