

# Caring for Someone with Cancer

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Because many of today's cancer treatments are provided at outpatient centers instead of hospitals, increasing numbers of patients, even those who are actively sick, can be at home, where they may need day-to-day care and support. Patients' needs change with the course of the disease and treatment, so it is not uncommon for caregiver roles to evolve. As a result, a primary cancer caregiver may wear many hats. They may serve as a companion, home health aide, chauffeur, chef, housekeeper, financial manager, or appointment maker. This publication helps caregivers prepare for the evolving emotional and physical demands of cancer caregiving and highlights ways that caregivers may take care of themselves.

## Be a Lifeline

The primary caregiver of a cancer patient is often a spouse, partner, parent, adult child, family member, or close friend. They are not paid or trained to provide care, yet they are often the lifeline of a person with cancer. They provide ongoing care, and they support and encourage survival. According to the American Cancer Society, "good, reliable caregiver support is crucial to the physical and emotional well-being of people with cancer."



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When caregivers take care of the details, patients can concentrate on their fight. Some common helpful day-to-day duties of cancer caregivers include:

- Grocery shopping
- Preparing meals
- Housekeeping and laundry
- Caring for children
- Paying bills
- Offering emotional support and companionship
- Chauffering to and from appointments
- Administering medications and managing side effects





Steve Patton, University of Kentucky

## Form a Caregiving Team

Because cancer caregiving has many roles and demands, it is best to form a team to help ensure that the person's health and best interest come, first. A cancer team should include the patient, health care professionals, family and friends and the primary caregiver. As a crucial member of the team, the primary caregiver is most often in charge. According to the American Cancer Society, as head of the team, it is important to:

- Helping with bathing, grooming, and dressing
- Assisting in the bathroom
- Transferring to and from bed
- Helping with eating
- Managing finances and/or insurance issues

While these day-to-day duties alone may not seem stressful, cancer caregivers balance these demands with existing obligations such as work and other family. In addition, caregiving duties can also instigate role changes that can be challenging to navigate. For example, a person can go from being a spouse or adult child to a nurse, counselor, medical advocate, or housekeeper in addition to still being a husband/wife or son/daughter. Such shifts in roles can be emotional and quickly lead to strain and burnout. In addition to taking care of yourself and managing your own health to prevent burnout, it is also important and acceptable to grieve the losses caused by cancer. The Cancer Treatment Centers of America report that it is normal to miss the life you and your loved one had before cancer. But to proactively move forward, you should not dwell on the past. It is not helpful to ask why this occurred. Understand that there will be good and bad days.

- Educate yourself and others. Learn about the diagnosis, treatment options, side effects, and proper support materials. The more you know, the more confident you and your loved one will feel to make decisions.
- Find health care professionals you trust, who are experienced in your loved one's form of cancer and can provide individualized care, including managing side effects during treatment.
- Coordinate patient care. Keep records of medical history, medications, exams, and test results, and make sure all health care providers are communicating and on the same page, especially if there is a change in patient status such as new symptoms, changes in sleep, mood, bowel habits, or appetite. Communicate infections or hospitalizations.
- Attend appointments, take notes, and ask questions.
- Oversee paperwork to prevent mix-ups and maintain records.
- Know the health care professionals and how to contact them, including pharmacists.
- Keep family members and friends informed.
- Address concerns of family members and friends with facts and logic
- Make sure the patient has everything she/he needs while being treated or in the hospital (prescription and non-prescription medications, pajamas and other comfort items).

- Coordinate scheduled treatment plans, appointments, and therapies.
- Report problems.
- Help decide if treatment is working.
- Help with blogs, web pages or group emails that provide updates about the person's journey/experience. Always respect the patient's wishes and privacy when sharing information.
- Talk about end-of-life decisions and care.

## Take a Break from Cancer

A cancer patient is a vital member of the caregiving team. It is important to listen to your loved one and follow his/her lead. Sometimes they may not want to talk about cancer. Taking an occasional break from it can help make it seem like everything is not always about cancer. The Cancer Treatment Centers of America recommend:

- Spend time together doing something fun.
- Making flexible plans, including future plans for which you and your loved one can look forward.
- Talking about things other than cancer.
- Providing extra encouragement and reassurance that the person is more than cancer. Tell him/her that they are loved and seen as a person.
- Giving gifts that reflect who they are apart from the cancer (tickets to a movie or show, a book, art, etc.).

## Accept the Bad Days

With cancer, there will be good days and bad days. Let your loved one have a bad day. It is not good to ignore uncomfortable topics or feelings. Sometimes a person needs time to feel angry, to cry, or to feel sorry for themselves.

It is unrealistic to think someone can or should always be positive when living with cancer. As a caregiver, it is easy to take a bad day personally or to sugar coat it by saying you know how they feel. Unless you have had their exact cancer, you do not know how they feel, so do not say this. Instead, say something like, "I love you," or "We will fight this together."

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## Be Empathetic

According to the National Cancer Institute, some side effects associated with cancer include: fatigue, hair loss, weight loss, vomiting/nausea, loss of appetite, pain, memory/concentration problems, diarrhea or constipation, fertility issues, mouth/throat problems, sleep problems, and swelling. Sometimes people focus on physical changes when they see someone with cancer. Instead of concentrating on the cancer, start a visit by saying, "It's good to see you."

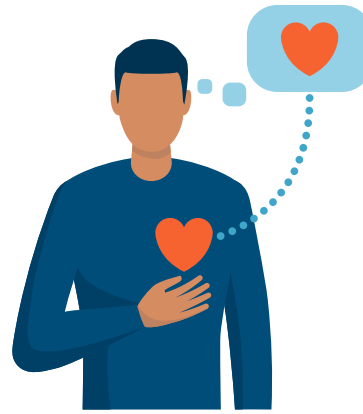
Think about a time when you were sick or scared. What did you want to talk about? What did you wish people said to you? How did you want to be treated? When you try walking in someone else's shoes, you can learn valuable lessons, such as empathy, new perspectives, more understanding, less judgment, and patience. Learn about the diagnosis, prepare yourself for the expected changes during and after treatment, and process your feelings so that you can acknowledge and cope with your own emotions about the diagnosis and changes.

## Take Care of Yourself

Because primary caregivers carry a lot of weight, one's mental and physical health can be jeopardized. Therefore, it is important for caregivers to take care of themselves and recognize signs of stress. Signs of stress are not a sign of weakness; rather it is your body telling you that you are not balanced. Over time, stress can lead to caregiver burnout. According to Help for Cancer Caregivers, stress and burnout can make you feel irritable, anxious, angry, depressed, frustrated, and fearful. Stress can also cause weight gain, muscle and joint tension, headaches, weight gain/loss, fatigue, problems with digestion, chest pain, hair loss, issues with skin, and a weakened immune system. It can even increase risk of alcohol and substance abuse. To help you reduce caregiver stress, the American Cancer Society suggests that caregivers:

- Get involved with family and community gatherings.
- Be physically active.
- Eat healthy.
- Take 10 minutes for “me” time.
- Identify a sense of purpose or accomplishment away from caregiving (finish a project, tackle a goal).
- Engage in an activity that makes you feel good or relaxed (watch a movie, take a walk).
- Set limits on what you can do and ask for help for what you can't do.
- Seek help from a mental health professional.

There is no recipe for cancer caregiving. It is not easy. It is normal to have good days as a caregiver and on these days, you will know you did well. You will have other days that you want to give up, and that's okay too. If feeling overwhelmed becomes a constant problem, seek



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*Seek help from a mental health professional.*



*Be physically active, eat healthy, relax.*

*Get involved with family and community.*



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professional mental health. Signs that you need help include:

- Feeling depressed, physically sick, or hopeless
- Feeling like hurting yourself or your loved one
- Yelling at your loved one
- Depending on alcohol and drugs
- Fighting with your family
- Neglecting your own health/hygiene

## **Turn Pain into Gain**

When you become the primary cancer caregiver, you become an integral member of the cancer team. The role is demanding and can at times create conflict with your own schedule and ability to take care of yourself and meet your own needs. The diagnosis of a loved one's cancer can cause a wave of emotions. The American Cancer Society reports that it is not uncommon for caregivers to feel shock, pain, frustration, sadness, and anger. There may be times when you are so grief stricken or emotionally and/or physically overloaded that it becomes too overwhelming to manage daily tasks and caregiving challenges.

But caregivers can also experience joy, satisfaction, and meaning in their roles. It is not uncommon for cancer caregivers to find a hidden inner strength, which can contribute to sense of purpose, confidence, accomplishment, and even pride. In this way, providing care demonstrates love and respect, and it helps you give back or do something at a time when you may feel helpless. Despite the demands, being a good caregiver and knowing how to take care of yourself will help you endure and continue in the caregiver role for the long run.

## **Caregiver Gains**

- Establishing new friends and relationships (support groups, networks, other patients/families)

- Drawing families together at a time of need
- Finding new meaning and enrichment in life
- Feeling a sense of pride
- Recognizing a sense of purpose
- Developing inner strength
- Enjoying a deep sense of satisfaction and intrinsic reward
- Demonstrating devotion, love, respect
- Feeling needed

## **Caregiver Pains**

- Feeling unprepared (we train for a lot a of things...driving, jobs, even marathons...but we don't seek or receive caregiving training)
- Physical symptoms (exhaustion)
- Emotional symptoms (sadness, grief, frustration, burdened, anger, feeling overwhelmed)
- Depression
- Feeling guilty or feeling trapped
- Time conflicts that affect work (cutting back hours, turning down job opportunities/promotions, early retirement, loss of employment)
- Neglecting family responsibilities
- Uncertain future, including unexpected and unwanted lifestyle changes
- Seeing a loved one in pain
- Making stressful medical decisions and other decisions
- Feeling you have to do it all
- Financial worries
- Guilt
- Fear
- Hopelessness
- Confusion
- Doubt
- Anger

## Questions to Ask Healthcare Providers

As a team, strong communication may help the primary caregiver and the patient feel more comfortable. In some instances, the primary caregiver may be the person asking questions on behalf of the patient. The following questions, from the American Cancer Society, may be helpful to ask:

- What kind of cancer is it?
- Where is the cancer located? Has it spread beyond where it started?
- What are the treatment options? Which do you recommend? What is the goal of this treatment?
- How long will treatment last? What will it be like? Where will it be done?

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