



**CANCER RESOURCE CENTER**  
OF THE FINGER LAKES

# Caregiver's Guide

## Your loved one has cancer and you want to help.

**AT** first, it all seems overwhelming. Everything that you took for granted is suddenly uncertain. Many caregivers are naturally worried about the person with cancer, and also worried about the rest of life—taking care of other family members, paying the bills, maintaining the house, and so much more.

*It's important to realize two things: 1) You're not alone—many other people have been in this situation before, and 2) there are resources available to help.*

We've prepared this booklet to guide and assist you.





# Types of Caregiving

Caregiving can range from 24/7 hands-on assistance to driving someone to appointments to long-distance caregiving. Every situation is different.

Much depends on the needs of the patient, your relationship with the patient, and practical matters such as where you live.

Every caregiving situation has the potential to be both rewarding and stressful—often at the same time.

## The positive aspects of caregiving

In addition to worrying about your loved one's cancer, you may be running the household, struggling with piles of incomprehensible insurance forms, communicating with far-flung family members, and trying to earn enough money to pay the mounting bills. Life doesn't get much more stressful.

We talk with many people who acknowledge this stress, but who also say that helping their loved one through cancer was the best thing they ever did.



What's essential is to understand that the role of the loved one is to support and comfort, not to "fix" the problem. Men tend to have a harder time with this because they somehow expect themselves to fix whatever is broken. Cancer isn't always fixable.

When people are diagnosed with cancer, they don't want their loved

ones to say, "I promise you that you'll be cured."

What they want to hear is, "I love you and I'll be here with you for whatever comes."

## *"Before I went to a support group*

*I felt like my sister's cancer was something that I had to deal with on my own. I thought it would be depressing to talk with others. I was surprised to learn that it actually helped to talk with others who are going through some of the same thing! I would tell other kids to find a support group for sure."*





# Core Elements of Caregiving

*This booklet is broken into a variety of sections, but two themes will keep reappearing: An essential role for the caregiver is to help the patient maintain as much control as possible over his or her care and decision-making. It's also essential that the caregiver practice self-care. You can't help anyone else if you aren't taking care of yourself.*

The best advocates are the quiet forces who support mostly by their steadfast presence. One patient refers to his advocate as his "designated listener." What a perfect description. We should all have designated listeners.

## **Support, but don't direct your loved one's care**

- Cancer patients sometimes say that a spouse or partner is adding stress to their lives by constantly expressing their own opinions as to what is best for the patient.
- If it's your own cancer, you should feel free to make whatever decisions you want. If it's your spouse's cancer, you should pretty much keep your thoughts to yourself.
- There are exceptions to this. Sometimes the patient wants (or needs) the caregiver to make decisions and offer opinions on a regular basis. That's fine—as long as it's at the request of the patient.
- But, in general, once you state your opinion, drop it. Restating that opinion day after day is, at best, annoying, and, at worst, truly destructive.
- One woman with cancer shared that she wanted to spend her energy understanding her options and making the best possible treatment decisions. Instead, she was spending her energy navigating the relationship with her husband because he had very strong opinions about what she should do and he expressed those opinions constantly.
- Most spouses truly want to help. They're trying to guide the patient to what the spouse truly believes is best.
- But what's best for one person is not best for the next person. The individual with cancer gets to decide.
- A wonderful spouse is one who supports the patient's decisions without judgement and without conflict.
- Be present. And be quiet.

# Cancer Basics for the Caregiver

It is common to make many assumptions when you hear the word “cancer.” Cancer is not one disease, but rather a family of diseases. What you know about one type of cancer may not be true for another type of cancer. *Here are some common terms that you are likely to read or hear:*

## Basics

**Cancer:** Abnormal, uncontrolled growth of cells of any organ of the body.

**Benign:** Not cancerous.

**Malignant:** Another term for cancer.

**Tumor:** An abnormal mass of tissue. Tumors may be benign (not cancer), or malignant (cancer).

**Metastasis:** The spread of cancer from one part of the body to another.

## Pathology

**Stage:** The extent of a cancer in the body. It is based on the size of the tumor and whether it has spread. Stage 1 is early stage and Stage 4 is the most advanced stage. (Some cancers have a Stage 0 which means that it is very localized and self-contained).

**Nodes:** If cancer spreads, it often spread first to the nearest lymph nodes. Doctors routinely examine those nodes to see if they contain cancer cells.

**Grade:** How abnormal the cancer cells look under a microscope and how quickly the tumor is likely to grow and spread. High grade tumors tend to be more aggressive than low grade tumors.

**Margins:** When a tumor is removed, it’s examined to determine if the borders of the tumor are cancer-free. If there are cancer cells on the border, more surgery may be required.

## Scans

**CT Scan:** A series of X-rays that are combined by computer into images of the bones and soft tissues inside your body. CT scan images provide much more information than do plain X-rays.

**MRI:** Another imaging device that is especially useful in viewing the brain, spine, the soft tissue of joints, and some other parts of the body. MRIs do not use X-Rays.

**PET Scan:** Unlike CT and MRI which look at structures (i.e., the architecture of the body), PET looks for cancerous activity. Cancer cells often “light up” on a PET Scan because they metabolize glucose differently than do normal cells. PET scans are often used to see if cancer has spread to other parts of the body.

## Treatment

**Chemotherapy:** Treatment with drugs that are designed to kill cancer cells

**Port:** A medical device inserted under your skin that makes it easier to receive chemotherapy.

**Radiation Therapy:** The use of radiation from x-rays and other sources to kill cancer cells and shrink tumors.

**Hormone Therapy:** Treatment that blocks, removes or adds hormones to slow or stop the growth of certain cancers (such as prostate and breast cancer).

**Immunotherapy:** Treatment that is designed to boost the body’s natural defenses to fight the cancer.

## Sources of Information

**Medline Plus** (<https://medlineplus.gov/>)

**CancerNet** ([www.cancer.net](http://www.cancer.net))

National Cancer Institute ([www.cancer.gov](http://www.cancer.gov))

**MacMillan Cancer Support** (<https://www.macmillan.org.uk/>)



*"We've gotten lots of support,*



*and some of it comes from people we expected it from.  
But a lot has come from those we don't know very well.  
And others we do know well have stayed away. You  
just never know with people."*

– Rhonda



*"You cannot serve from  
an empty vessel."*

—Eleanor Brown



# Taking Care of Yourself

## Common signs of caregiver stress

- Exhaustion
- Problems sleeping
- Being irritable or anxious
- Feeling rundown
- Withdrawing from friends and family

## Four Self-Care Tips for Caregivers of Cancer Patients

Cat Koehler

### Here are a few suggestions that may provide relief.

#### Invite others in

As the primary caregiver, no one knows your loved one's situation as intimately as you do. You may find it hard to break away or trust others to take your place, even in the simplest of tasks, but this is exactly why you should. Inviting a friend or family member to pitch in can be a breath of fresh air for all involved, and it gives you a much-needed break.

#### Delegate transportation

Consider allowing a friend or family member to serve as taxi on appointment days. Between treatments, doctor visits and follow-ups, a cancer patient's calendar can be grueling to maintain alongside your other day-to-day responsibilities. Delegating your loved one's transportation to and from appointments to a trusted third party may bring some relief to your strained schedule.

#### Take a coffee break

Or, take a walk, do some yoga, or just do a little bit of nothing at all. No matter how busy and stress-filled the days get, taking quiet moments for yourself is essential to your wellbeing. As a caregiver, what is

essential to your wellbeing is essential to your loved one's wellbeing. Be intentional about carving out a few minutes several times a day to do something that refreshes you, however simple that something might be.

#### Remember

The work you are doing is hard work, but it is also good work. Yes, caring for a cancer patient can be physically, mentally and emotionally draining, but your efforts are vitally important. You are making a real, tangible difference in the life of someone you love. Don't give up, but do take care of yourself.

Excerpted from *4 Self-Care Tips for Caregivers of Cancer Patients*, Cat Koehler, CaregiverStress.com.

#### Resources

**The Cancer Resource Center** offers a monthly group specifically for cancer caregivers. Other groups meet on-line, and we can connect people on a one-to-one basis through our "Peer-to-Peer Network." Please contact the Cancer Resource Center at 277-0960 for more information about these programs and for other assistance.

#### Caregiver Action Network

([www.caregiveraction.org](http://www.caregiveraction.org))

**Well Spouse Association** ([www.wellspouse.org](http://www.wellspouse.org))

**Family Caregiver Alliance** ([www.caregiver.org/](http://www.caregiver.org/))

**CancerCare** ([www.cancercare.org/pdf/booklets/cc\\_caregiver.pdf](http://www.cancercare.org/pdf/booklets/cc_caregiver.pdf))

*Some days I amaze myself.  
Other days, I put the laundry in the oven.*

—Anonymous



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# Practical Matters

## Financial

Cancer is expensive, and the financial systems created by insurance companies and health care providers are often confusing even to people who deal with these systems on a regular basis.

Many caregivers find themselves in charge of organizing bills, writing checks, seeking assistance, and just trying to figure it out.

It seems overwhelming at first, but there are many sources of assistance. Financial advocates from the Cancer Resource Center can help you organize and prioritize bills, find assistance, and advocate on your behalf. Call us at 277-0960.

## Legal

Everyone should have a will and a health care proxy. If you don't have them, get them. If the patient is hesitant, the caregiver should take the lead. You can say that it's important for your own peace of mind. Once it's done, it's one less thing to worry about.

Nearly any law firm can create these documents at a modest cost. Free legal assistance (including simple wills) is available through the Cancer Legal Advocacy & Services Project in Syracuse. Please call 315-703-6500 for more information.

**Cancer and Careers:** Your Legal Rights in the Workplace: Cancer and ADA, FMLA <http://www.cancerandcareers.org/en/at-work/legal-and-financial/cancer-and-the-ada-fmla>

## Organizing Help from Others

Your friends and family members may want to bring over meals or help in other ways. There are some excellent online resources that help organize this assistance:

**Lotsa Helping Hands**  
([www.lotsahelpinghands.com](http://www.lotsahelpinghands.com))

**Share the Care**  
([www.sharethecare.org](http://www.sharethecare.org))

**Take Them a Meal**  
([www.takethemameal.com](http://www.takethemameal.com))

**Meal Train** ([www.mealtrain.com](http://www.mealtrain.com))

*"If you can't change your fate,  
change your attitude."*

—Amy Tan

# Your Children

Children start to understand the world around them at a very young age. It's important to be honest with them about your loved one's cancer.

## Common reactions kids may have are:

- Confusion, anger, loneliness, guilt, or being overwhelmed
- Act scared or unsure about how to act around your loved one
- Act clingy or miss attention they're used to getting
- Have trouble eating, sleeping, keeping up with school, or relating to friends. Children need to know the truth about your loved one. Otherwise they will think the worst. Understand their actions and feelings, and let them know how you feel too.

## Some tips for talking with kids:

- Tell them about cancer. Let them know that there is nothing they did to cause cancer, and they can't catch it from someone else.
- Let them know their feelings are okay. Tell them you understand if they are upset, angry, sad, or scared. Remind them that no matter what happens, you will always love them.
- Tell them the truth with love and hope. Let them know that your loved one is getting good care and that you hope he or she will get well again. But don't try to promise them a good outcome if you aren't sure of one.
- Listen to them. Ask them how they feel and what they are worried about. If they're young, ask them to draw a picture or play with dolls to show you how they feel.

- Stay involved. You may be with your loved one who is sick more often right now. Try to spend time with your kids in any way you can. Take them to the store with you or eat meals with them. Ask them about their day. Leave them notes or call them when you can.

**SOURCE: Caring for the Caregiver**, National Cancer Institute, 2014.

## Resources

**The Cancer Resource Center** offers a program titled, *CRC Cares for Kids* which provides support to families with a parent (or other caregiver) with cancer, including supervised play for children whose parents attend the Young Adult Support Group on the 4th Tuesday of each month from 5:30-7:00 pm.

We have also compiled resources geared towards helping children understand and cope with a parent's cancer diagnosis. Some resources are for young children and others are for pre-teens and teens. <http://www.crcfl.net/index.php/cancer-info/for-caregivers/helping-your-children/>

*"When I get home from class, my mom and I take turns running while one of us stays with my dad. My run is my time for me, and the only way I can keep it together.*

—Gail





# Setting Boundaries

A woman who was clearly frazzled stopped in to see us. She said that she's been caring for her husband who's been in treatment for cancer. He wants her near him all of the time. It's not that he actually needs her all of the time. He just wants to be sure that she's there —just in case. She wants to get out of the house on a regular basis. She craves having a little time for herself. This is not an unusual situation. The caregiver may feel compelled to stay with the patient at all times, or the patient may demand constant attention.

All caregivers should reserve some time for themselves. If they don't get it, they burn out, become resentful, and aren't helpful to anyone. Cancer treatment has rhythms. There are days when the patient feels sick, but there are also days when the patient feels reasonably well. After a while, these rhythms become clear and are reasonably predictable. When the patient is likely to have a good day, the caregiver should schedule some time to get away from cancer.

The timing can be negotiable. If the patient demands full-time attention, the caregiver should set boundaries and say, "I need to get out of the house twice a week. We can work together to decide the days and times." If the patient truly needs full-time attention, the caregiver should bring in other resources. Family members, friends and volunteers may be able to provide some assistance. Funds may be available to hire a home health aide for a few hours a week. It can be a good investment.

We've heard a few patients tell the spouse/caregiver, "I don't want those other people in the house. I want you to take care of me." When that happens, the caregiver should also set boundaries and say, "I can take care of you better when we have help. Let's work together to decide how to arrange it."

Being a caregiver for someone with cancer is stressful and exhausting. It can also be rewarding and one of life's most meaningful experiences. The positive is more likely to emerge when the caregiver gets a regular break from caregiving.

*You can do anything,*

—Anonymous



*but not everything.*



## Intimacy/ Relationships

*"I used to discuss all of life's big decisions with her. Now, I can't. She's so focused on her illness and trying to get better. I don't want to bother her with my worries."*

Cancer suddenly trumps everything in a couple's relationship. "It's almost like we've gone from a relationship of two to a relationship of three—me, her, and her cancer. Her cancer gets the time I used to get."

The effects of cancer vary from couple to couple. Most couples will experience changes in a variety of aspects of their relationship. These can include changes in roles and responsibilities, sexuality, intimacy, parenting, and plans for the future.

For many couples, facing the challenges of cancer together strengthens their relationship. Uncertainty about the future can reinforce a couple's love and commitment. It may allow them to reevaluate their priorities and reinforce the importance of their partnership. In other situations, a cancer diagnosis can strain the relationship. For these reasons, it is important for you and your partner to talk about your concerns and challenges with each other. It may also help to talk with a counselor if cancer is causing stress in your relationship.

**SOURCE: CancerNet**

*"Some days there won't  
be a song in your heart.  
Sing anyway."*

—Emory Austin



*"Being strong meant learning to rely on others.*



*I found that friends wanted to be there for our family, I just needed to ask. I also met with a counselor who gave me insights and listened in ways that friends could not."*



# Long-distance caregiving

There are ways to help and support, even if you can't be there in person:

Send notes of support. Let them know that you're sending positive thoughts.

Realize that people with cancer often receive lots of cards when they are first diagnosed. The cards that they receive weeks and months later—when they're tired of cancer and its treatment—are especially treasured.

Don't be discouraged if you don't receive a response. People in the middle of treatment often don't have a lot of energy.

Educate yourself about their cancer. Acquiring a basic knowledge will help you understand what they're going through and facilitate communication.

Call, even if it feels awkward at first. It's OK to say simply, "I'm sorry you have cancer." People don't usually remember what you said, but they'll remember that you called. And don't worry about waking someone up or disturbing them. They have an answering machine.

Small gifts, unrelated to illness, are always welcome.

More than anything, the person with cancer will appreciate the sense of staying connected with you and staying connected with his or her "normal" life. Cancer tends to throw everything into upheaval. Distant friends and family can help people with cancer maintain their sense of who they were before cancer and, hopefully, the life to which they will return when treatment ends.

## Resource

**CaringBridge** ([www.caringbridge.org](http://www.caringbridge.org)) is a free and easy method of sharing updates with family members and friends via the Internet.

*"The best and most beautiful things in the world cannot be seen or even touched—they must be felt with the heart."*

—Helen Keller



# End of Life Considerations

*We sometimes get asked various versions of this question:*

*“My father has advanced cancer, but they don’t seem to be treating him very aggressively. Why aren’t they doing surgery to remove the metastases in his liver and in his brain?”*

This is always a difficult question because the news is sometimes hard to absorb. When cancer spreads—or metastasizes—from its original location, the focus generally shifts from curing the cancer to controlling the cancer.

The primary treatment for metastatic cancer is chemotherapy because it affects cells throughout the body. Stopping the progression of the disease is often the goal.

Treatment generally goes on for as long as the benefits of the treatment (extending one’s life and/or reducing symptoms) outweigh the harm caused by the treatment (generally, the side effects of chemotherapy).

When someone asks us why the doctors aren’t doing more to aggressively treating their father’s cancer, we gently ask them what their father wants. More often than not, the father is more interested in the quality of his life than in extending his life.

The most aggressive cancer treatment is not always the best cancer treatment. The person with cancer ultimately decides how much treatment is enough. The most fortunate patients make these decisions with the understanding and support of their loved ones.

We often find that patients keep pursuing aggressive treatment because they think it’s what their family wants. The patient is often relieved when family members explore discussions of palliative and/or hospice care.

It’s ok to say, “Dad, I’m here for you if you want to continue treatment and I’m here for you if you want to stop treatment. Just know that I’m here for you.”

*“The only way to make sense  
of change is to plunge into it  
flow with it...  
and join the dance.”*

—Alan Watts





*"We're all just  
walking each  
other home."*

*—Ram Dass*





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