

FRANKLY SPEAKING

ABOUT CANCER

Caregivers



Family members, spouses, partners, and friends who take on a caregiving role feel cancer's deep emotional impact. They learn how quickly life can become overwhelmed by a cancer diagnosis. They face a new reality of making appointments, managing treatments, and making sense of insurance forms and medical fees.

Yet, all too often, others don't see how much you, the caregiver, are doing. The cancer care is centered on your loved one. So friends and family may not recognize the toll it is taking on you to provide the care your loved one needs.

Taking care of someone with cancer can be challenging. As a caregiver, you may feel a roller coaster of emotions—jumping from joy to sadness or from togetherness to loneliness—maybe even all in one day. This booklet has information to help you be an effective caregiver, reduce stress, get support, and address your own needs.


**CANCER SUPPORT
COMMUNITY.**



HELPING FROM A DISTANCE

There are many things you can do to help a loved one with cancer, even if you don't live nearby. Before jumping in, it helps to ask questions and listen to those who are local. Let them help you assess the situation and determine what you can do.

When a loved one far away has been diagnosed with cancer, you might feel like you want to get in the car or hop on an airplane right away. But that might not be best. If your loved one is having surgery, it might be better for you to come after they've been discharged from the hospital. Or it might be better to wait a few weeks, so that your visit can offer the local caregivers who have been providing the daily care some time to take a break and re-charge.

It also helps to be specific in your offers of assistance. "Can I order you dinner to be brought each Wednesday?" "Would you like me to get information about clinical trials?" "Are there any phone calls I can make for you?" These kinds of questions make things less complicated for everyone. Don't suggest things you can't follow through on. Some other things you can do from afar:

- Listen. Many people with cancer swing between hope and fear, optimism and despair. Sometimes simply letting your loved one 'vent' their frustrations is the most helpful thing you can do. Just quietly listen. You do not need to have the answers or fix all the problems. Sometimes just "being there" is important.
- Provide support with decision-making.
- Identify helpful resources.
- Help keep other family members and friends updated.
- Visit and offer respite to local caregivers.

Finding Support

A Cancer Caregiver:

Anyone who provides physical, emotional, financial, spiritual, or logistical support to a loved one with cancer.

If someone asked you whether cancer patients need support, you'd undoubtedly answer "yes." Facing a potentially life-threatening diagnosis and months of treatments that can result in both short- and long-term side effects would turn anyone's world upside-down.

You might not be as quick to agree that caregivers need support. But they do. The life-threatening diagnosis isn't yours, but many of the things that accompany a cancer diagnosis are likely to land on your shoulders: stress, uncertainty, bills, paper work, phone calls, and many of the mundane tasks that your loved one managed before cancer.

That is a lot for anyone to take on. And as the days and weeks go by, you may feel that your needs are less important because you don't have cancer, feel guilty when doing something just for you, or find yourself envious of all the support your loved one is getting. You may push things aside to focus on them, only to later find you resent all that you have given up.

All of these feelings and emotions are completely normal, and talking about them may help you feel better. Your fellow caregivers are likely to understand your feelings and share your emotions, whether it's stress and uncertainty or loneliness and resentment. And there are now more ways than ever before to connect with others who understand what it is like to be a caregiver.

TYPES OF SUPPORT

Some caregivers choose to seek support one-on-one from an oncology social worker, therapist, chaplain, or clergy member. Others may also or instead turn to support groups. Talking to your fellow caregivers and sharing your experiences with them can not only help you feel less alone or less angry but help you to identify new or better ways to cope with your new caregiving role. Some support groups are available through organizations that provide services specifically for cancer patients and their families or for caregivers. Others are offered by local cancer centers. Still others can be accessed online, via Listservs, group chats, or on Facebook.

Some of the websites and organizations we recommend include:

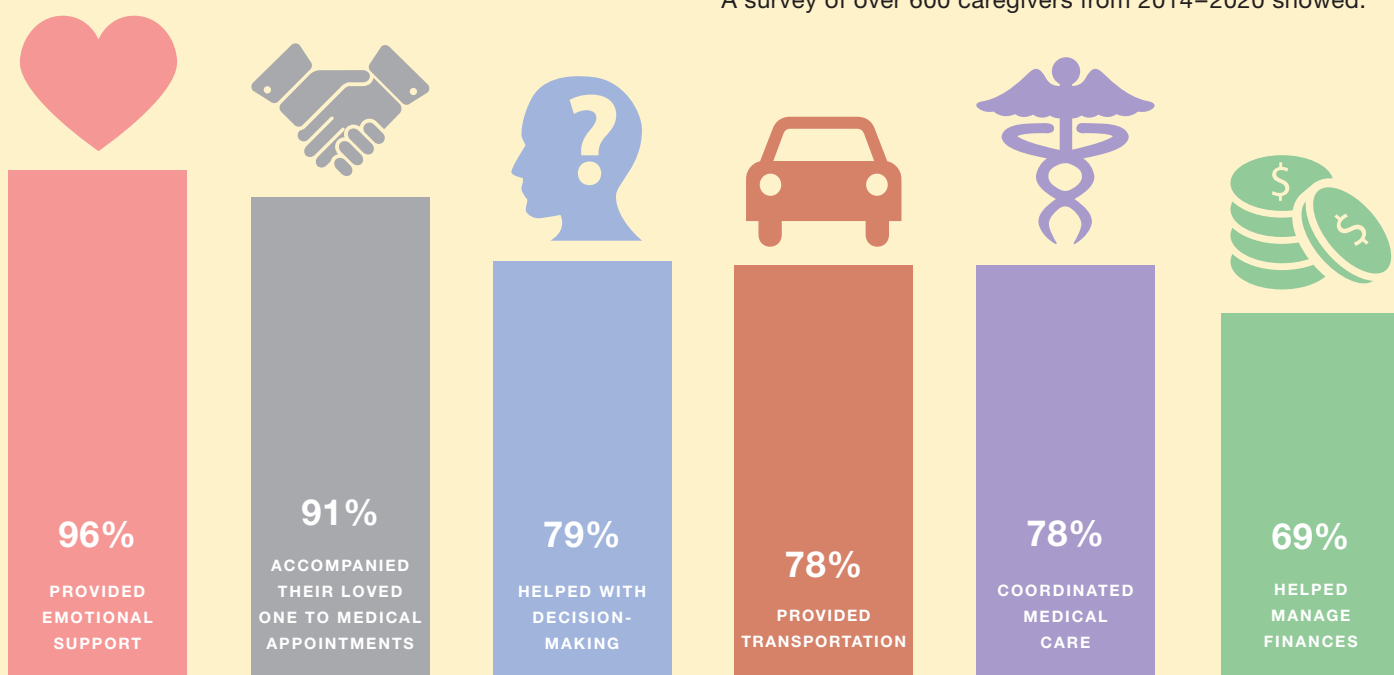
- Cancer Support Community
www.CancerSupportCommunity.org
- Caregiver Action Network
www.caregiveraction.org
- Family Caregiver Alliance
www.caregiver.org

Only you can determine which type of support system works best for your lifestyle, goals, and schedule. It's easy to feel overcome by the responsibilities of caregiving. When this happens, remember that there are many people who know that caregivers need support too, and have spent time thinking about and organizing support that would be right for you. They would love for you to take advantage of what they have to offer.

WHAT DO CAREGIVERS DO?

The CSC Cancer Experience Registry® allows us to learn more about the daily lives of caregivers. Many caregivers report that they are highly involved in medical care tasks.

A survey of over 600 caregivers from 2014–2020 showed:







SHELDA

**Breast cancer survivor
and caregiver for her husband, Chuck,
who is living with kidney cancer**

As a 20-year breast cancer survivor, Shelda thought she was done with cancer. Then, her husband, Chuck, was diagnosed with kidney cancer. “My first instinct was, ‘Wait a minute. This is wrong. I’m the cancer patient,’ ” she says. As she took on the role of caregiver, she feared her work, her activities—her self—would not be important. “I felt like I was drowning,” she says. Gradually, Shelda came to see, “I don’t have to lose myself in this process.” Nor did she have to go it alone. She found a wealth of emotional support through the Cancer Support Community, where she attends a stress-management group and a support group for friends and family members. The other group members, “might not be women, they might not be taking care of spouses,” she says, “but they’re like me in that someone that they love has advanced cancer and they’re trying to do the best they can.”

SHARE YOUR EXPERIENCE JOIN THE CANCER EXPERIENCE REGISTRY®

The Cancer Support Community launched the Cancer Experience Registry: Caregivers in December 2014. Since then, more than 650 caregivers have committed to completing a survey that covers topics such as emotional and physical health, their involvement in medical care, direct and indirect costs of caregiving, access to resources, and unmet needs. As of January 2020, more than 14,500 patients and caregivers have completed surveys about their cancer experience. To add your voice, visit [CancerExperienceRegistry.org](https://www.CancerExperienceRegistry.org)

You, Your Loved One, & The Health Care Team

Cancer is a complicated disease. Caregivers often say that it feels like everyone is speaking a different language after a loved one is diagnosed with cancer.

To get to the point where you speak this language, you are going to need to learn about your loved one's specific diagnosis and how it will be treated. You are also going to need to ask a lot of questions. There is nothing wrong with asking a question over again until you understand the answer. It can also help to know the right person to ask. There will be many people who are part of your loved one's cancer care team, and some of them may be better at explaining certain aspects of your loved one's diagnosis or treatment plan than others.

THE CANCER CARE TEAM

You may have heard the saying “It takes a village...” about the need for many people with different skills to complete a big task. This saying may come to mind as you begin to meet the many people on your loved one's cancer care team. The team is large because cancer requires lots of specific expertise. The people you will come to know might include a surgeon, pathologist, radiologist, medical oncologist, oncology nurse, palliative care specialist, pharmacist, hospital social worker, nurse or

patient navigator, and clinical trial coordinator. Each of these people has a unique role to play, and each can be a resource for you.

These are some questions you may want to ask members of the cancer care team:

- Who is the first person we should call if we have a problem or concern?
- How will each member of the cancer team be communicating with one another?
- What is the best way to reach you? Phone? Email?
- Can you provide me with a copy of the treatment plan?
- How long should we wait for an answer to our question before calling again?
- If you are out of the office or away on vacation, whom should we call?
- If a true emergency develops, what do we do?

LEARN MORE

CSC's Frankly Speaking About Cancer® Series includes the booklet, *Making Treatment Decisions*. For more specific information about your loved one's cancer care team, visit www.CancerSupportCommunity.org/Treatment.

ORGANIZATION IS KEY

These apps for your phone or tablet can help you stay organized and communicate with the medical team by keeping track of questions and concerns, appointments, medical records, and more.

- **Cancer.net Mobile:** Provides a place to save information about prescription medications, a symptom tracker, and an interactive tool to keep track of questions to ask your health care provider and record their voice answers. Developed by American Society of Clinical Oncology.
- **Cancergraph:** Tracks your cancer symptoms and side effects over time to help your team understand and improve your care. Developed by Malecare.
- **Pocket Cancer Care Guide:** Provides tips on questions to ask your medical team, allows you to record answers, and makes it easy to link appointments to your calendar. It also has a glossary of medical terms. Developed by the National Coalition for Cancer Survivorship.

A CIRCLE OF COMMUNICATION

As a caregiver, you may at times find yourself having to be the voice of your loved one. There may be times when one member of the health care team tells you something that seems to conflict with what another team member said. Or you may find that what your loved one is telling you differs from what the doctor told you. Situations like this may lead you to feel confused, annoyed, angry, frustrated, or even frightened. All of these feelings are completely normal.

With everything else you are managing, it would seem the least you could hope for is clear communication. It might not always happen, but these tips can help:

- If you have received conflicting information, start by calling one of the oncology nurses. They are likely to be easier to get in touch with than the doctors, and may be able to clear the problem up quickly.

- Do the members of the cancer care team use email? Email can be a good way to get clarification on test results, discuss next steps, ask questions about treatment options, or discuss scheduling of future appointments.

- Take a deep breath before you get on the phone. Sometimes what seems like a large problem or a huge error may have a simple explanation and be easily resolved.

- Remember that not everything is as urgent as it may feel. It's nice to get answers as quickly as possible, but there are also times when not getting a call back the same day really is OK.

CAREGIVING TIP: Make a list of all of the names, phone numbers, and email addresses of everyone on the cancer care team and put it in a place where it's readily available, should you need it. Make copies for anyone who is supporting you in your caregiver role.

Practical Concerns

SAY “YES” TO HELP

Helping a loved one with cancer can make your life feel like it is spinning out of control. Your responsibilities as a caregiver will create new routines and demands. Yet at the same time, you are still going to manage everything you were doing before the cancer diagnosis.

As a caregiver, it is important to maintain a balance between managing the needs of your loved one and the daily activities of your life. You might rightfully predict the stress associated with navigating multiple doctors’ appointments in a week, yet you might be surprised at the weariness that comes from mundane, repetitive, and somewhat intimate tasks required of you, such as buttoning each button of the shirt of a loved one who has numbing neuropathy in the fingers. Whether the new tasks are large or small, organization will be key as you integrate new responsibilities with old ones. So will patience. Sometimes the laundry won’t get done. Sometimes takeout meals will replace home cooking. And that’s fine.

Try to prioritize your to-do list. Ask yourself: What is most important to do right now? What can wait until later today, tomorrow, or next week? What can other people help with?

If it doesn’t all get done, try not to be hard on yourself. You are human, and you are doing the best you can.

PRIORITIZE AND DELEGATE

As a caregiver, one of the questions you may hear most is, “What can I do to help?” **MyLifeLine.org** makes it easier than ever for caregivers to get help with meals, carpool, appointments, and other day-to-day tasks. (If you don’t have the

MyLifeLine is CSC’s private, online community where patients and caregivers are able to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. You can use this website to:

- Keep friends and family informed and involved through a personalized blog. You can ask for help with rides, meals, etc. in the Helping Center on your page. As a caregiver, your loved one can give you access as an Assigned Care Coordinator to run their page.
- Connect with other caregivers by joining the Caregiver Support online discussion board. Discussion boards are available 24/7 and are monitored by a licensed professional.
- Learn more about cancer through Frankly Speaking About Cancer® resources.

Sign up at **MyLifeLine.org**.

time to set up the schedule, have someone who wants to help do it for you!) This website won’t only help your loved one with cancer. It will also help you take care of yourself.

CAREGIVING TIP: Encourage your loved one to manage pain as it starts, so the medicine won’t need to play “catch-up” and always have enough medication on hand to control nausea and other treatment-related side effects.



HENRY

Bereaved/Former Caregiver

Henry and his wife, Ruth, had been married 54 years when she was diagnosed with lung cancer. Over the next three years, Henry served as his wife's primary caretaker while also maintaining the family business, a Christmas tree farm. Henry says working was beneficial, because when he was focused on the farm he wasn't thinking about the cancer and the impact it was having on their family. "Life's full of changes," he says, "and what I learned is you had to live with it and go with it and do the best you could do." Recently, Henry took a poetry class offered through the Cancer Support Community. "In addition to writing haiku, now I'm into poetry," he says. "I'm reading a lot and I still miss Ruth."

The Financial Burden of Cancer

COPING WITH THE COST OF CARE

For many families facing cancer, financial worries are a significant source of stress. As a caregiver, you may find yourself shouldering the burden of some—or even most—of this stress as your loved one goes through cancer treatment.

Even with health insurance, treatment for cancer in the United States is expensive. There are out-of-pocket costs, including co-insurance, deductibles, co-pays, out-of-network costs, and non-covered services. There are ways to manage these costs, but first you must understand what they are, so you can avoid potential issues.

Naturally, you want the best care for your loved one. Gathering information about the expenses associated with treatment is not about accepting less than the best treatment options. It is about being able to make an informed decision and a plan to obtain the best care while maintaining the highest quality of life possible.

LEARN MORE

CSC's Frankly Speaking About Cancer[®] Series includes the booklet, *Coping with the Cost of Care*. For more specific information about managing the cost of cancer care, visit www.CancerSupportCommunity.org/Cost.

PRACTICAL TIPS

If you have been asked to help with billing or insurance issues, be prepared to jump privacy hurdles to access information from your loved one's health insurance company, or workplace human resources department. There may be requests for written (or oral) permission forms,

or you may need to know personal details such as social security number, date of birth, address, phone, and policy number. Be sure to:

- Submit any bills to your insurance company in a timely manner. Many insurance companies will not pay a claim submitted after the time period specified in the policy.
- Submit all medical expenses even if you aren't sure whether they are covered.
- Review bills and keep accurate records of claims submitted.
- Keep copies of anything related to your claims.
- Get a notebook or accordion folder to record all of your expenses, conversations with the insurance company, doctor's appointments, exams, and other information (such as the date, time and with whom you spoke, what he or she said, contact information, and how long spent on the call).

HELPFUL FEDERAL BENEFITS

There are federal laws that provide protections and benefits for people with cancer and their caregivers:

Americans with Disabilities Act (ADA): Some people with cancer can be considered disabled and receive reasonable accommodations to perform essential job functions. www.ADA.gov

Family and Medical Leave Act (FMLA): Allows an ill person or family member caring for them to take up to 12 weeks off from work (without pay but with no loss of benefits). Time off can be taken a little at a time or all at once. Talk with your Human Resources Department about your specific situation. www.dol.gov/whd/fmla

Social Security Disability: If your loved one can no longer work, she or he may be eligible. For information about Social Security Disability Insurance (SSDI) call 800-772-1213 or www.ssa.gov.

RESOURCES FOR FINANCIAL AND LEGAL ASSISTANCE

Cancer Legal Resource Center: A national program of the Disability Rights Legal Center. Provides free and confidential information on cancer-related legal issues for cancer patients, caregivers, and others. 866-999-3752 or www.thedrlc.org/cancer

Health Insurance Marketplace: If you don't have health insurance coverage through a job, Medicare, Medicaid, the Children's Health Insurance Program (CHIP), or another source, the Marketplace helps you find and enroll in a plan that fits your budget and meets your needs. 800-318-2596 or www.healthcare.gov

Patient Advocate Foundation: Helps patients access care while preserving their financial stability. 800-532-5274 or www.patientadvocate.org

United Way: The United Way is an excellent source of information about local charities and programs that may be able to provide financial and resource support. www.unitedway.org

RESOURCES FOR TRANSPORTATION ASSISTANCE



The following organizations offer air travel assistance options:

- **Miracle Flights**
800-359-1711 or www.miracleflights.org
- **Air Charity Network**
877-621-7177 or www.aircharitynetwork.org

DON'T BE AFRAID TO ASK

To help manage expenses, consider asking your health care team, pharmacist, hospital personnel, or insurance company representative the following questions:

- Who can I speak with to see if I'm eligible for Medicaid or other health insurance options?
- What is the estimated total cost of the prescribed treatment plan?
- Are there less expensive options for treatment?
- Does this facility have a free or reduced-cost care program? What are the requirements?
- Who should I see to discuss a payment plan?
- Does the manufacturer of my recommended medication offer a free or discounted drug program for uninsured patients?
- Are there charitable foundations that can help me with the cost of medications or care?
- Can we go over my list of medications to see if there are ways to lower my prescription drug costs?
- Is there a less expensive drug (generic medication, over-the-counter, or brand name) that will be equally as effective?
- If a medication is not covered, how can I apply for an exception for coverage?

Taking Care of You

Caregiving is stressful and can take up a great deal of personal time. A great way to reduce this stress is to remain involved with parts of your life that don't include caregiving. For some, this may mean maintaining a role in school, faith, or community functions. For others, this may mean weekly visits with a best friend.

CAREGIVING TIP: You are still allowed to have a life of your own when you are caring for someone with cancer.

SET LIMITS

Define what you can reasonably do and what you can't do to help. It's OK to tell yourself that there are limits to your caregiving.

It's easy to get caught in the whirlwind of appointments, daily errands, and medication doses for your loved one. Come to terms with feeling overwhelmed (it will happen) and be firm when you can't do something to help.

One way to cope with this is to keep a journal (especially when you feel like you are hitting your limits). Writing in a journal can give you a place to vent frustrations, list priorities, and problem solve without causing conflict. It will keep your feelings private, while helping you release your feelings of distress. Another way is to keep a list handy with the phone numbers of people who will let you vent without judgment or will step in to help when you can't.

PACE YOURSELF

Some caregivers say that cancer caregiving is like running a marathon. And how do marathon runners manage to keep going for such a long distance? They pace themselves, knowing that they can't run full speed every mile and successfully finish the race.

CONTROL STRESS

As a caregiver, it is important to find ways to control the stress associated with the daily

demands of caregiving. If you don't, you may find that stress starts to control you.

Find ways to relax—and make time to do it. Some people find that they like relaxation or stress-reduction techniques like tai-chi, yoga, meditation, imagery, deep breathing, prayer, and therapies that use creative outlets such as art, music, or dance. Your cancer center may offer relaxation classes for caregivers. You might also find classes at a local community center or YMCA. Others may find that a walk in the woods or on the beach helps them relax. Do what works best for you.

R-E-L-A-X & B-R-E-A-T-H-E

Imagery is a relaxation technique that you can do at any time. The basic concept of imagery is: take a deep breath, think of something positive—specific thoughts and images—and then let your emotions be led in that direction, allowing you to experience the same good feelings you felt when the event or moment first happened.

MAKE YOUR NEEDS A PRIORITY

As a caregiver, you need to take time to take care of you. Doing so is not selfish. It also doesn't detract or take away from your loved one. Taking care of yourself can help give you the balance you need to be a good caretaker. Taking a break can give you a chance to re-focus. Sometimes you may need a whole day, weekend, or even longer. Other times, you can give yourself a balance boost by taking 10 minutes to go for a walk, make a phone call, or do yoga. These mini-breaks can do wonders for your stress levels. Every bit of relaxation counts, whether it comes from sitting on a bench looking at some flowers for five minutes or taking a 5-day trip.

TAKE A BREAK

Be sure to put some planned breaks on your calendar. If you feel yourself getting anxious, tired, or distracted, try taking a mini-break. Here are some ideas:



It may be possible to ask a close friend, neighbor, or family member to care for your loved one so you can take the time you need for you. There also are professional respite organizations that can help with caregiving for your loved one. Valuable information about how to access respite care for you or another caregiver can be found by contacting:

- Arch National Respite Network and Resource Center: www.archrespite.org
- Caregiver Action Network: 855-227-3640 or www.caregiveraction.org
- Family Caregiver Alliance: 800-445-8106 or www.caregiver.org

CAREGIVING TIP: “Respite care” is organized short-term care that makes it possible for a caregiver to take a break from the daily routine and stress of caregiving. Take time to learn about the respite services near you.

MANAGING NEGATIVITY

You may feel guilty when you choose to address your own needs first. You may feel angry about the injustice of your loved one’s illness. You may believe that your own needs are insignificant compared to those of your loved one. Or you may even feel angry at your loved one for getting sick. These negative thoughts are common, and they can diminish your ability to be a good caregiver and cope with the cancer. The trick is not to let negative feelings determine your decisions. These tips for managing negative emotions can help:

- Recognize feelings such as guilt, resentment, and anger. Admit them. It will help you address the problem rather than ignore it or let anger grow.
- Be compassionate with yourself. There’s no one way a caregiver should feel. Give yourself permission to separate your feelings from your actions.

- Take positive action. Needs are not bad or good; they just are. If you can’t be there because you don’t live close, find someone else to help or plan a future trip when you can be together.
- Consider the positive impact of small gestures. For example, if you can’t call every day, send a quick email, text “hello,” or drop a card or funny gift in the mail.
- Reach out to your own support network for some coping ideas.
- Take time on a regular basis to care for you. It will make you a better caregiver.

*“It was just go, go, go
and my friends would say,
‘Okay, take a break.
It’s okay to leave him.’
But you feel guilty doing
that because you’re in
charge and nobody can do
it as well as you can.”*

*—Colleen, caregiver for husband
with stage III melanoma.*

GROW WHERE YOU ARE PLANTED

Some caregivers develop an inner strength they didn’t know was possible. Some develop new organizational skills. Some grow deeper spiritually. Some develop a new level of intimacy with their loved ones and others. And some can say, “I know that caregiving has made me a better person.”



SHERI

Bereaved/Former caregiver for a close friend

When a close friend was diagnosed with multiple myeloma, Sheri stepped up to be her caregiver. “People talk about a caregiver, but you don’t really know what a caregiver is until you’re really in that role,” she says. “I learned that a caregiver wears many hats: listener, observer, protector, planner, anticipator, the backup brain to the patient, the organizer, the strong one, the levelheaded one. The caregiver is the go-to person all the time.” Knowing she was supporting her friend while working a full-time job, other friends, family members, and coworkers reached out to help. Initially, it was difficult to ask for or accept assistance. But “I quickly realized that I could not do it all and that I needed help,” she says. “I also realized that people wanted to help me and my friend and that I needed to let them in. I learned help comes in a lot of ways.”

General Cancer Information, Survivorship & Support

Cancer Support Community • 888-793-9355 • www.CancerSupportCommunity.org

American Cancer Society • 800-227-2345 • www.cancer.org

CancerCare • 800-813-4673 • www.cancercare.org

Cancer.net • 888-651-3038 • www.cancer.net

Caregiver Action Network • 855-227-3640 • www.caregiveraction.org

Family Caregiver Alliance • 800-445-8106 • www.caregiver.org

National Alliance for Caregiving • 202-918-1013 • www.caregiving.org

National Cancer Institute • 800-422-6237 • www.cancer.gov

Patient Advocate Foundation • 800-532-5274 • www.patientadvocate.org

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

Cancer Support Helpline®—Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon–Fri, 9 am–9 pm ET.

Open to Options®—Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Frankly Speaking About Cancer®—Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

www.CancerSupportCommunity.org/FranklySpeakingAboutCancer.

Services at Local CSCs and Gilda's Clubs—With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

MyLifeLine—CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Connect with other caregivers by joining the Caregiver Support online discussion board. Sign up at www.MyLifeLine.org.

Grassroots Network—Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

Cancer Experience Registry®—Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:



This book is available to download and print yourself at www.CancerSupportCommunity.org/Caregivers. For print copies of this booklet or other information about coping with cancer, visit orders.cancersupportcommunity.org.

The Cancer Support Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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