FRANKLY SPEAKING ABOUT CANCER
A PROGRAM OF THE CANCER SUPPORT COMMUNITY

Helping Your Loved One Make Treatment Decisions

CANCER SUPPORT COMMUNITY
COMMUNITY IS STRONGER THAN CANCER

GILDA'S CLUB

A cancer diagnosis can feel overwhelming for both patients and caregivers. As a caregiver, you may help gather information, coordinate and attend appointments, ask questions, and support your loved one as they make treatment decisions. This guide is designed to help you understand your role, prepare for conversations with the care team, and support decisions that match your loved one's values, goals, and daily life. It also reminds you to take care of yourself along the way.

In this resource, you'll find:

- Important documents to have
- Questions to ask the care team
- Tips for advocating for your loved one
- A goal-setting worksheet
- Self-care for caregivers

For information and support for caregivers, visit **www.CancerSupportCommunity.org/Caregivers**.

YOUR ROLE AS A CAREGIVER

The ripples of a cancer diagnosis extend to spouses, partners, siblings, children, other family members, and friends. Many people will find they now need to take on the role of caregiver — something they have never done before.

A caregiver (or care partner) is anyone who gives unpaid help to a person with cancer. Help can be emotional, physical, spiritual, financial, or practical.

Caregivers often:

- Give emotional support
- Talk about treatment goals and preferences
- Help manage symptoms and side effects
- Help with medical or nursing tasks
- Schedule and track appointments
- Drive or arrange transportation
- Help with money and insurance tasks

As a caregiver, YOU are a critical part of the care team. There may be multiple caregivers for one patient. A caregiver may be full-time, part-time, or only needed for specific tasks. In your role, you can help your loved one think through options and what matters most to them.

Shared Decision-Making

Your role in the decision-making process is important. Shared decision-making is a process where the patient, caregiver, and care team work together to make decisions about care. Open communication with your loved one will be necessary. This helps to ensure that you are both on the same page and know what to expect.

As a caregiver, you might feel like you need to "take charge." But remember, your goal is to have conversations about your role in decision-making and your loved one's values and preferences. This ensures collaboration between you and your loved one — and being able to advocate for your loved one with the care team.

If your loved one is unable to make decisions for themselves, you may be designated to make decisions on their behalf.
Look for any guidance (advance directives) that details their wishes. If there are no written instructions, follow your loved one's wishes, as far as you understand them. If you need help, ask your loved one's doctor to refer you to the hospital's palliative care team, who can help guide you through the decision-making process.

IMPORTANT DOCUMENTS TO GATHER — AND KEEP UPDATED

The following topics and documents are important to talk through with your loved one as you are planning care. Keep copies of the documents listed throughout your loved one's cancer experience to help guide decision-making.

Medical & Treatment	• Diagnosis details (type, stage, biomarkers if any) • Appointment calendar/log (dates, topics discussed, procedures, decisions) • Pathology and lab reports • Imaging reports • Current treatment plan and medicine list • Allergy list • Symptom log • Names and contact information for doctors, nurses, social workers, and the cancer center; include the best way to reach them • Patient portal (online medical records) log in information
Legal & Preferences	• Advance directives (living will) ◦ Details what kind of medical care the patient does or doesn't want (e.g., life support, organ donation) • Medical power of attorney (health care proxy) ◦ Names the person(s) who can make medical decisions on the patient's behalf, if they are unable • Financial power of attorney ◦ Names the person(s) who can make financial decisions on the patient's behalf, if they are unable • Will (last will and testament) ◦ Names who will get the patient's property, money, and belongings if they die ◦ Funeral and body disposition (e.g., bury, cremate) preferences ◦ Names who will care for the patient's children or pets if they die • Notes on wishes and goals of care
Insurance & Cost	• Insurance cards • Prior authorization notes • Explanation of benefits (EOBs) • Financial navigator or counselor contact information
Logistics	• Calendar of appointments • Transportation plan • Work/leave paperwork

PREPARING LEGAL DOCUMENTS

It is a good idea for all adults, no matter their health situation, to prepare for the future. This can be especially helpful when someone is newly diagnosed with cancer. While these conversations can be difficult, it is important to talk with your loved one and their care team about their wishes. These conversations are just as important as having the appropriate documents, like a living will and healthcare power of attorney.

The care team can refer you to someone who can help you prepare important legal documents. Most of these documents can be prepared without a lawyer and without any cost to you or your family. These documents will help you understand, discuss, and document your loved one's legal and medical decisions. In turn, you will feel more comfortable communicating and advocating for your loved one's wishes with the care team.

QUESTIONS TO ASK THE CARE TEAM

These questions can help you understand, discuss, and support your loved one in making treatment decisions.

About the Cancer

- What exact type, stage, and grade is it?
- Are there **biomarkers** or tests that guide treatment?

About Treatment Options

- What are the treatment options? What is the goal of each option (cure, control, slow growth, relieve symptoms)?
- What are the specific drugs options? How might these options change over time?
- What are the benefits and risks of each option?
- Which option is the care team recommending, and why?
- Are there guidelines that support the treatment recommendation?
- What are the short- and long-term side effects? How will we **manage** them?
- Does the treatment require the support of a caregiver?
- Where is treatment given? How long will it take? How often?
- Are **clinical trials** an option now or later?

Care Team

- Should we get a **second opinion**? How do we do that?
- Are there cancer specialists we should speak to?
- Who makes up the care team? Is this considered **"multidisciplinary" care**?
- Who should we call for urgent questions after hours?

About Daily Life and Costs

- What will be the **costs** of treatment?
- What will insurance cover? Can we meet with the financial counselor?
- How will it impact daily activities?
- How will this affect work, family time, and travel?
- Are there any support services available? How can we work with palliative care?

OPEN TO OPTIONS®

Preparing for your loved one's next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling CSC-867-5309 (or outside the U.S., toll-free 888-793-9355) or by contacting your local CSC or Gilda's Club.

CLINICAL TRIALS

Be sure to ask the care team about any available clinical trials that your loved one may be eligible for. Clinical trials are research studies that test new treatments or explore better ways to use existing treatments, including for different types of cancer. Ask about the potential benefits and risks. It is important to make sure you are aware of all the treatment options. For more information on clinical trials or how to find one, visit **www.CancerSupportCommunity.org/Clinical-Trials**.

COMMUNICATION WITH THE CARE TEAM

As a caregiver, you may at times find yourself having to advocate for your loved one. There may be times when one member of the 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. The tips on the next page can help.

Communicating With the Care Team

- Identify a "team leader" on the care team who will serve as the main point of contact. This can help as specialists and therapists are added to the team.
- Join your loved one to meet with the doctor. Explain you want to know about important test results and medical decisions, with your loved one's permission. Give the doctor your contact information.
- In a hospital setting, if you can't be there when the doctor visits, use the whiteboard in the room to write down questions.
- If you've received conflicting information, start by asking one of the oncology nurses. They can help get the answers you need.
- Sending messages on the patient portal can be a good way to get clarity on test results, discuss next steps, ask questions about treatment options, or discuss appointment schedules.
- Take a deep breath before you get on the phone. Sometimes what seems like a large problem 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.

Advocating for Your Loved One

- Help your loved one prepare for visits. Go with them, take notes, and ask for explanations.
- Help them share what matters to them. Making sure the care team understands your loved one's values, daily life, costs, and travel limits helps guide the plan.
- Break the decision-making process into smaller steps. This can help you and your loved one feel more in control.
- Coordinate with the team, and know the best contact methods. Ask about how to reach oncology social workers, navigators, and palliative care.
- Develop a system for keeping track of important documents and notes, organized and in one place.
- Connect with a counselor and support groups to address mental health and reduce isolation — for both you and your loved one.

TREATMENT GOALS & PERSONAL PRIORITIES

Use these prompts to guide a short "what matters most" talk with your loved one. Write brief answers to help guide conversations with the care team.

Loved One's Top 3 Goals for Treatment

Goal 1 *(for example: cure, live longer, feel better, keep independence)*

Goal 2

Goal 3

Daily Life Priorities

Important activities to keep doing
(work, school, spending time with family or friends, hobbies)

Limits we have
(time off, travel distance, transportation)

Treatment Preferences

Willing to accept these side effects:

Not willing to accept:

Support & Costs

Who can help with rides, meals, childcare? List names:

Questions for insurance/financial counselor:

Appointment Prep

Top 5 questions to ask at the next visit:

❶
❷
❸
❹
❺

TREATMENT DECISIONS

Learn about the different options available for cancer treatment, and find tips, tools, and resources to help you make your treatment decisions. Visit **www.CancerSupportCommunity.org/Treatment-Decisions**.

SELF-CARE FOR CAREGIVERS

At times, caregivers may find that they put their own needs aside as they care for someone else. You might not even notice it happening. Caregiver stress and burnout are very real and common. As you try to support another person, be sure to also think about how to best support your own needs. What you need to feel supported may change over time, and that is OK.

- Ask for help from friends, family, faith communities, and caregiver support groups. You are not alone.
- Join a caregiver support group or the CSC MyLifeLine® Caregiver Support forum to share tips and feelings. Sign up at **www.MyLifeLine.org.**
- Set small routines. This can include naps, movement, regular meals, and short breaks — even 10 minutes at a time can help you recharge. Take time to do activities you enjoy.
- Talk with your school, employer, or human resources department about your options and resources for managing your caregiving responsibilities. Some workplaces offer flexible hours, remote work, family medical leave (FMLA), or employee assistance programs that can provide additional support.
- Your caregiving role can lead to changes in your relationship with your loved one. It is normal to feel sadness, frustration, or uncertainty during this time. Be gentle with yourself and your loved one as you both adjust.
- Talk with a counselor, social worker, or CSC's Cancer Support Helpline when you feel overwhelmed. Call CSC-867-5309 for free information, resources, and decision support.

For more resources about coping with mental health concerns, visit **www.CancerSupportCommunity.org/Coping-Mental-Health-Concerns**.

Supporting a loved one through cancer treatment decisions is not about having all the answers. It's about showing up, asking questions, and helping ensure that choices reflect what matters most to them. By using the tools and guidance in this resource, you can feel more prepared, confident, and connected as part of the care team.

RESOURCES

CAREGIVING RESOURCES

Cancer Support Community
CSC-867-5309 (or outside the U.S., toll-free 888-793-9355)
www.CancerSupportCommunity.org/Caregivers

National Alliance for Caregiving
202-918-1013 | www.Caregiving.org

Caregiver Action Network
855-227-3640 | www.CaregiverAction.org

Family Caregiver Alliance
800-445-8106 | www.Caregiver.org

Triage Cancer
TriageCancer.org

National Cancer Institute
800-422-6237 | www.Cancer.gov

Cancer Support Community Resources

Cancer Support Helpline® — Have questions, concerns, or looking for resources? Call CSC's toll-free Cancer Support Helpline (CSC-876-5309 or outside of the U.S., toll-free 888-793-9355), available in 200 languages.

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.

Services at Local CSCs and Gilda's Clubs — With the help of over 200 locations, in 50 markets, CSC and Gilda's Club centers provide services free of charge to people impacted by cancer. Attend support groups, educational sessions, wellness programs, and more **www.CancerSupportCommunity.org/FindLocation**.

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

MyLifeLine® — CSC's secure, online community welcomes anyone impacted by cancer to easily connect with community to reduce stress, anxiety, and isolation. Create a personal network site and invite friends & family to follow your journey. And participate in our discussion forums any time of day to meet others like you who understand what you are experiencing. Join now 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**.

This publication is available to download and print yourself at **www.CancerSupportCommunity.org/Caregivers**.

For print copies of this publication or other information about coping with cancer, visit **Orders.CancerSupportCommunity.org**.

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Caregiving Program Partner:

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This publication was made possible through generous support from:

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