

FRANKLY SPEAKING ABOUT CANCER

Helping Your Loved One Make Treatment Decisions

Companion to
**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. Your days are suddenly filled with doctor's appointments, scans, lab work, and bills. Your family and friends all want to help, give advice, tell you their stories about people they know or something they read. Helping your loved one make treatment decisions may feel overwhelming. This

booklet has information to help you be an effective caregiver during this time. Additional information can be found in our *Frankly Speaking About Cancer: Caregivers* booklet. For information about reducing stress, finding support, and addressing your own needs, visit

www.CancerSupportCommunity.org/Caregivers.


**CANCER SUPPORT
COMMUNITY.**



What is your role as a caregiver?

A cancer caregiver is anyone who provides physical, emotional, financial, spiritual, or logistical support to a loved one with cancer. Being a caregiver allows you to be an active participant and essential team member in the fight against cancer. You can be a tremendous resource and advocate to help your loved one think through treatment options, goals, and priorities during this difficult period.

WHAT YOU CAN DO:

Respect the patient's wishes while they make decisions

If your loved one makes a decision that you disagree with, remember it is their decision to make. Your loved one may ask you for your opinion, but they make a different decision. Even when you disagree, continue to communicate and support your loved one in their choices.

If your loved one is incapacitated and you are making decisions on their behalf

If you are a caregiver for an adult patient who is unable to make medical decisions, look for any advance directives that indicate their wishes. If there are no written

instructions, follow the intent of the person'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.

WHAT YOU CAN DO

Cancer treatment decisions are stressful and important. You can prepare with some of these tips:

- You can offer to help weigh the pros and cons of each treatment option with your loved one – including elements like time, where treatment will be given and cost.
- You can help your loved one think through reasonable short- and long-term expectations.
- If your loved one needs help navigating insurance issues, you can offer to contact the insurance company to learn about what is covered and what isn't. Pose questions about coverage beyond standard treatment, such as for transportation to/from clinics for treatment; in-home medical assistance following treatment; out-of-network care; medications; etc. If you are assigned this role, arrange a multi-party phone call, so your loved one can

give the insurance company permission to speak with you.

- Use an oncology social worker at the cancer center or affiliated with the oncologist. They offer a wealth of information and can answer many logistical and financial questions.
- Communicate with your loved one's treatment team. Let them know what is important to your loved one.
- Encourage your loved one to talk to a therapist or counselor. A professional can help them sort through their personal goals and think about treatment decisions.

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. You can give a loved one access to run your page as an Assigned Care Coordinator.
 - Connect with others through an 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.



IMPORTANT DOCUMENTS

It is a good idea for all adults, no matter their health situation, to prepare for the future. While these conversations can be difficult, it is important at any point to talk with your loved one and their health care team about their wishes. These conversations are just as important as having the appropriate documents. The following legal documents are important tools to prepare:

- A **living will or advance directive** lets the doctor know what kind of medical care your loved one wants if they can no longer speak for themselves. Enforcement of advance directives vary by state. Check with your health care team to determine what documents are recognized in your area.
- A **durable power of attorney for health care** is a person who will make health care decisions if your loved one is unable to make them themselves. This can be you or anyone in their life who they trust and have discussed their health care wishes with. This person does not need to be an attorney.
- A **financial power of attorney** is a person who will make financial decisions for your loved one's home and medical care in the event they are unable to do so themselves. Many people choose separate people to be their financial and durable medical attorneys.
- A **do not resuscitate (DNR), do not intubate (DNI), or allow natural death (AND) order** tells the doctor if your loved one would like heroic measures to be taken in the event of cardiac or respiratory arrest. An example is deciding that they do not want a machine (a ventilator) to breathe for them or to have their heart shocked if their lungs or heart stop working.
- A **will** designates who will receive their money and belongings and who will be responsible for their children (in the absence of another parent). If there is no will in place, an agent of the state may make these decisions.

The health care team can often refer you to someone experienced to help you prepare these documents. Most of these documents can be prepared without a lawyer and without any cost to you or your family. These documents will help reduce confusion and you will feel more comfortable knowing that the legal and medical decisions made are by your loved ones.

If you are supporting someone making decisions

These questions can help you support your loved one in making a treatment decision.

- Does your loved one understand the risks of treatment and the potential consequences of the treatment they are choosing?
- Are your loved one's wishes openly stated and being respected?
- Is the treatment in line with your loved one's beliefs and values?
- Is the treatment your loved one is considering recommended by their oncologist and health care team?

If you are making the decisions on their behalf

If you are a caregiver for an adult patient who is unable to make medical decisions, look for any advance directives that indicate their wishes. If there are no written instructions, follow the intent of the person'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.

Communicating with the health care team & advocating for your loved one

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 may 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.

If your loved one is in the hospital:

- Get to know the nurses who are caring for your loved one. Tell them you'll be the point of contact.
- Meet with the attending doctor and explain you want to know about important test results and medical decisions. Give the doctor your contact information. This should be in your loved one's hospital record. Find out the best way to reach the doctor.
- Find out when the doctor visits patients so you can be there to ask questions. If you can't be there, use the whiteboard in the hospital room to write down questions. If you don't understand what the doctor tells you, feel free to ask them to give a clearer explanation.

- Ask to meet with a social worker or case manager to talk about insurance issues, coordinating care between doctors, or caregiving resources. They can also help with follow-up care when your loved one leaves the hospital.

What kind, stage, and subtype of cancer do they have?

Knowing the exact kind, stage, and subtype of your loved one's cancer will help you find useful information and make treatment decisions.

Their doctor can provide you with this information and explain what it means. You can also ask for a copy of your pathology report—and any later lab or test results. This information drives the decision-making process.

Many cancer centers now work with patients to develop a treatment plan—a written document that explains your cancer and the course of treatment. This is very useful in helping to understand where you are and where you are going—a kind of road map.

Biomarker testing helps your doctor understand your subtype of cancer on a molecular level. A biomarker is a molecule in your body that your doctors can measure to tell them something specific about you and your cancer. Biomarkers can let doctors

know if your tumor has a good chance of responding to a certain treatment. Some biomarkers may include EGFR, BRCA, HER-2, KRAS, and BRAF.

HELPING YOUR LOVED ONE PREPARE FOR CANCER TREATMENT DECISIONS

Open to Options® is a free program designed to help:

- Create the list of questions you have for your doctor or health care team
- Organize your questions to bring with you to your appointment
- Communicate your questions and concerns clearly

IT WORKS! Patients who participated in the program:

- Were less anxious about their doctor's appointment
- Felt that their appointment went more smoothly
- Felt better about the care decision made

- It is easy and FREE to participate! 888-793-9355

www.CancerSupportCommunity.org/Open2Options

WHAT YOU CAN DO

- Go to appointments with your loved one to listen and take notes.
- Ask the doctor to tell you exactly what kind of cancer your loved one has and to write it down for you.
- Ask questions if you don't understand. Ask for a copy of your loved one's pathology report and for results of their lab work and tests.
- Ask the doctor what their treatment recommendations are based on. Talk with their nurses. They can help answer your questions.
- Talk to other people who have taken care of a loved one with cancer. They can be a great source of support.



QUESTIONS ABOUT YOUR LOVED ONE'S TREATMENT OPTIONS

- What is the goal of treatment?
- Why is the doctor recommending one treatment over another?
- What are the benefits of each viable treatment?
- What are the risks?
- Are clinical trials an option?
- How can we manage or prepare for side effects associated with each treatment?
- How often will treatment be given, and where?
- How long does each treatment last?
- Does the facility where treatment will be given also offer resources for emotional support?
- If cost is a problem, are there ways to help our family with the costs of treatment?
- What is the goal of the treatment you are recommending?

Choosing the treatment team

One of the most important decisions your loved one will make about their cancer treatment is choosing a doctor, a team, and a cancer center that has the expertise to treat their cancer. It's critical to feel confident in the people who are treating your loved one and to be able to communicate with them. Remember your loved one can always seek a second opinion or change doctors if their situation changes and they need a different level of care.

The choice of a doctor and cancer center will depend on many factors including:

- Cancer type, subtype, and stage.
- Insurance coverage.
- Logistics such as transportation, distance, and costs.
- Personal preference. Some people are more comfortable being treated in a community cancer center close to home while others may choose an academic medical center.

WHAT YOU CAN DO

- Find out whether your loved ones' doctors are board certified in oncology, hematology, and radiology, or in their specialty.
- Find out if the doctor specializes in treating your loved one's cancer type. Ask if your loved

ones' doctors and cancer center use a multidisciplinary team approach in coordinating their treatment plan.

- Find out if the cancer center offers clinical trials.
- Find out if the cancer center is designated as a comprehensive cancer center or community oncology program by the National Cancer Institute.
- Ask your loved ones' doctors what the best way is to reach them. Do they have an oncology social worker or navigator available?
- Do they use a patient portal where you and your loved one can track your medical information?

Making a treatment decision with your loved one's doctor

When your loved one is facing a treatment decision, here are some factors to consider and discuss with the doctor:

- **GOALS OF THE TREATMENT:** As a general rule, the goal for most early-stage cancers is to cure the cancer. There are many cancers, however, that cannot be cured. In those cases, the intent of

treatment is to keep the cancer under control for as long as possible. Before beginning any therapy or at points where the treatment plan changes, ask the doctor what their goals for treatment are.

■ **POTENTIAL BENEFITS:** There is wide variation in how much potential benefit anyone can expect from a specific treatment. Some treatments reduce the risk that a cancer will return, others cure cancers or extend survival. Others reduce symptoms and improve the quality of life.

■ **SIDE EFFECTS:** Every cancer treatment has some kind of side effect. Before beginning any treatment, your loved one’s doctors will explain the potential side effects. They will have the opportunity to ask questions and think about how to balance their life with those side effects. Many side effects can be treated effectively. For more about coping with side effects, visit www.CancerSupportCommunity.org/SideEffects.

■ **REASONS BEHIND A TREATMENT CHOICE:** Why did the doctor choose this treatment as opposed to another? Was the decision based on specific information about your loved one’s cancer? Was it influenced by the insurance company or by cost factors—and if so, what are they? Are there guidelines or treatment pathways that support this decision? These are all important issues, and your loved one has every right to ask the doctor about them.

■ **COSTS:** Cost can be a factor in making decisions about cancer treatment. Some options are very expensive. Others may require frequent doctor’s visits or have side effects that make it difficult to work. It is important to know about both the possible direct and indirect costs before beginning a treatment. For more about coping with the cost of care, visit www.CancerSupportCommunity.org/Cost.

WHAT YOU CAN DO

- Ask to sit down with the financial or insurance counselor at the cancer center. They can help you and your loved one understand what the costs may be and a plan to pay for it.
- Take advantage of resources, such as the Cancer Support Community’s Open to Options® program.
- Understand that things will change. The way your loved one feels at diagnosis will be different than how they feel when they complete their initial treatment, or if the cancer recurs.
- Try to stay focused on what is happening now—rather than trying to make all the decisions at once.

THINK ABOUT TREATMENT AND PERSONAL GOALS

When you talk to your loved one’s doctor about their treatment options, ask about the goals of each treatment and how it may affect your loved one’s personal goals. Possible goals may be to choose the option with the fewest side effects, live as well as possible, contribute to progress by taking part in research, be healthy enough to attend a special event/milestone, or find cutting-edge treatments.

When making treatment choices, it is important to talk about personal goals with your loved one’s health care team. Remember your loved one’s goals may change over time.

Physical Health and Well-Being:	<i>What is most important for your loved one to be able to do?</i>
Family and Social Relationships:	<i>What’s going on in the lives of others that is important to you? Are there important milestones in your loved ones’ lives coming up?</i>
Work/School:	<i>Do you want to continue working? Can you adjust your schedule or responsibilities? Do you want to explore retirement or disability?</i>
Community/Involvement:	<i>Are you getting the support you need from your community? Are you able to stay active/involved in your community?</i>
Other:	<i>What else is important to your loved one?</i>

WHEN YOUR LOVED ONE IS MAKING TREATMENT DECISIONS, CONSIDER:

- **SIDE EFFECTS.** Will it be worth enduring the treatment’s side effects, or will they be too much to handle? Ask the doctor to explain common side effects for each treatment and how to manage them.
- **EFFECT ON DAILY LIFE.** How will the treatment affect your loved one’s life? How much time will treatment take? Will they need to take time off from work? How much? Will they need to travel for treatment?

■ **COSTS.** Will treatment be covered by insurance? If not, can your loved one afford it?

■ **EFFECT ON OVERALL HEALTH.** If your loved one has other health conditions, how will treatment affect those conditions?

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.

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.

Be sure to ask about clinical trials. Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's newest treatments were studied in yesterday's clinical trials.

Today's clinical trials may become tomorrow's newest treatments.

KEY THINGS TO KNOW:

- A clinical trial may be the only way to get some of the newest, most promising treatments.
- The US Food and Drug Administration and local review boards oversee all US clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Most often, the trial pays the costs of the drug being studied and your health insurance only has to pay for "standard" treatment costs. However, your health insurance may not pay for everything. Be sure to ask.

To find out more about clinical trials, visit **ClinicalTrials.gov**, a database of privately and publicly funded clinical studies conducted around the world.

Additional information can be found in our *Frankly Speaking About Cancer: Caregivers* booklet. For information about coping as a caregiver, visit www.CancerSupportCommunity.org/Caregivers.

Guidelines & pathways

Guidelines help your care team make decisions about the right treatment for your loved one. Guidelines contain treatment recommendations based on factors like cancer

subtype, biomarker test results, stage of cancer, and overall health. Cancer treatment is always improving. Guidelines help make sure that the care team is using the most up-to-date treatment information, also known as Standard of Care.

Most often, guidelines are developed by associations of health professionals using experts in that cancer type. The experts look at recent cancer research results to weigh the benefits and risks of each treatment studied. Guidelines do not take cost into account



"Some ways that I have coped with my mom's cancer is making sure that I have a good support system. People to lean on or just bounce ideas off of and talk about my concerns. And keeping an open dialogue with my mom and making sure that we can be there for each other and support each other."

— Jenn, CLL Caregiver

when recommending treatments. Also, drug companies do not help pay for guideline development.

Clinical pathways are another set of recommendations that the care team may use when offering treatment options. (Clinical pathways can also be called care pathways, critical pathways, or care maps.) Pathways are different from guidelines because they do take cost into account. Pathways are developed to ensure up-to-date care but also to control costs by offering specific treatment choices. Pathways are often created by health insurance plans or used by health care institutions to keep costs down. Doctors may get paid less if they don't follow clinical pathways.

You can ask your care team if the treatment options they offer are based on specific guidelines or pathways.

LEARN MORE ABOUT GUIDELINES AND PATHWAYS

Guidelines are recommendations for “best practices” in cancer care. Your doctor may be using a Cancer Treatment Guideline to decide your treatment options. Learn more about Treatment Guidelines by watching our quick video guide:

<http://bit.ly/CancerGuideline>.

Clinical pathways are tools used to manage cancer care at a lower cost. Knowing if your doctors are using pathways can help you with treatment decisions. Learn more about clinical pathways by watching this quick video:

<http://bit.ly/ClinicalPathways>.

TAKING THE NEXT STEPS

The cancer journey has many decision points along the way. Helpful tips to making good decisions are as follows:

- Break the process into smaller bites—one step at a time.
- Locate your loved one in the process—think about who they are, their goals, and their life situation.
- Whether your loved one is an information seeker or someone who chooses to let the doctor make the decisions, know enough about your loved one's cancer to help them be as active as they would like to be in helping to choose their treatment.
- Work with your loved one and their doctor to develop a written treatment plan.
- Remember that nurse practitioners, nurses, social workers, and navigators are there to help you. Be selective about where you seek information. Use proven, reliable sources.
- Benefit from other people's experience, but don't assume your loved one's experience will be like theirs. Help your loved one choose a doctor they can trust and communicate with.



CHUCK'S CAREGIVER STORY

Learning to Accept and Adapt

In July 2015, we got a call that my son had a seizure in San Francisco. We got in touch with him and found out that they had found a brain tumor. My wife and I scrambled to figure out what was going on. He was operated on right around the 4th of July in 2015 by a great surgeon. They were able to get about 95% of the tumor.

We got him home, he did radiation and chemotherapy. He was doing very well for a while. Then he started having trouble walking in November. That is when we found out the tumor had spread to his spine. At that point, the doctors started him on Immunotherapy. It worked for a while and gave us hope.

My advice if you are helping a loved one with cancer is to ask about treatment options. There are other options besides the standard treatment. Get a second opinion. Make sure that you're in the right facility to provide that treatment. Look into clinical trials. Don't be afraid to ask for help from your loved ones and your health care team.

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

CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge. To access any of these resources below, call 888-793-9355 or visit www.CancerSupportCommunity.org.

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. If you have questions specifically related to COVID, the Helpline can help.

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.

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

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.

THIS PROGRAM WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:



This book is available to download and print for yourself at www.CancerSupportCommunity.org/Treatment. 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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