

FRANKLY SPEAKING

ABOUT CANCER

Making Treatment Decisions



They say that cancer is a journey, but if that is true, it means crossing into a strange, new land. You don't speak the language. Your old world seems to disappear. Your days are suddenly filled with doctor's appointments, scans, lab work, and bills. You want to understand what is happening but you either have too little or too much information. Your family and friends all want to help, give advice, tell you their stories about people they know or something they read.

Making treatment decisions about your cancer may seem like a very complicated problem. But it can be broken down into smaller "bites," a series of decisions that you make at different points, from diagnosis through the end of your treatment.



Locating Yourself

When you are diagnosed with cancer, or facing a recurrence, it is natural to feel lost in the process—but this is actually a very important time to think about who you are and what your goals are in life. The decisions you and your medical team make about your treatment should take into account not only your medical condition but your personal situation too. Here are some things to consider and discuss with your team.

THE PERSONAL PERSPECTIVE

- Your age
- Your point in life including your family and work situation
- Your overall health
- Your expectations for treatment
- Your information needs
- Your available resources and support
- Logistics: For some people, issues such as transportation or distance can be major factors in determining treatment options, including where you choose to be treated.
- Cost: Unfortunately, cost of care is an issue for many people. Costs can be direct—bills that result from treatment, or indirect—losing work, paying for childcare, gas money, etc.

WHAT YOU CAN DO

- Communicate with your treatment team. Let them know what is important to you. You may find that the nurses or social workers have more time, but the crucial thing is to make sure the discussions happen.
- Communicate with your family, friends, and colleagues. Let them know what you want and need. The people around you want to help but sometimes have different goals or ideas about the “right thing to do.”
- Talk to people who have been in your shoes. Many people find it very helpful to talk to others who have the same kind of cancer and get their perspective and support.
- Talk to a therapist or counselor. Having a professional who can help you sort through your personal goals and think about treatment decisions can be very useful.

“Patients have to be advocates for themselves because there are a number of treatment options and it’s up to you to decide which one fits your life.”

– Rick, prostate cancer patient

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**.

HELPING YOU 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



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 ones and your health care team about your 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 your doctor know what kind of medical care you want if you cannot speak for yourself. 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** is a person who will make health care decisions for you if you are unable to make them yourself. This person does not need to be an attorney. It can be anyone in your life who you trust and have discussed your health care wishes with.
- A **financial power of attorney** is a person who will make financial decisions for your home and medical care in the event you are unable to do so yourself. 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** is an order for your doctor if you determine that you would not like heroic measures to be taken in the event of cardiac or respiratory arrest. An example is deciding that you do not want a machine (a ventilator) to breathe for you or to have your heart shocked, if your lungs or heart stop working on their own.
- A **will** designates who will receive your money and belongings and who will be responsible for your children (in the absence of another parent). If there is no will in place, an agent of the state may make these decisions. Your health care team can often refer you to someone experienced to help you prepare these documents. Most of these documents can be prepared without the use of a lawyer and without any cost to you or your family. These documents will help reduce confusion and your loved ones will feel more comfortable knowing that the legal and medical decisions made are yours.

What Kind, Stage, and Subtype of Cancer Do You Have?

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

Your 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.



WHAT YOU CAN DO

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

QUESTIONS ABOUT 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?

Choosing Your Treatment Team

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

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

- Your cancer type, subtype, and stage.
- Your insurance coverage.
- Logistics such as transportation, distance, and costs.
- Your 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.

“Ask for information and know the right questions to ask your health care team. This is really important when deciding on a treatment plan. Especially ask about the short- and long-term effects of any treatment.”

– Dave, Head and Neck Cancer Patient

WHAT YOU CAN DO

- Find out whether your doctors are board certified in oncology, hematology, and radiology, or in their specialty.
- Find out if your doctor specializes in treating your kind of cancer.
- Ask if your doctors and cancer center use a multidisciplinary team approach in coordinating your treatment plan.
- Find out if your cancer center offers clinical trials.
- Find out if your cancer center is designated as a comprehensive cancer center or community oncology program by the National Cancer Institute.
- Ask your doctors what is the best way to reach them. Do they have an oncology social worker or navigator available?
- Do they use a patient portal where you can track your medical information?

Making a Treatment Decision With Your Care Team

If you are facing a treatment decision, here are some factors to consider and discuss with your 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 your doctor what their goals for your 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 doctors will explain the potential side effects. You will have the opportunity to ask questions and think about how to balance your life with those side effects. You should also remember that 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 your doctor choose this treatment as opposed to another? Was the decision based on specific information about your 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 you have every right to ask your 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 your cancer center. They can help you 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 you feel at diagnosis will be different than how you feel when you complete your 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 doctor about treatment options, ask about the goals of each treatment and how it may affect your 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 health care team. Remember your goals may change over time.

Physical Health and Well-Being:	<i>What is most important for you 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?</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 you?</i>



CLINICAL TRIALS

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 a way to get new treatments still being studied.
- 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.

Learn more about Clinical Trials by visiting www.CancerSupportCommunity.org/ClinicalTrials.

What Are Guidelines and 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 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.

"Be prepared to ask questions. Bring someone with you to the appointments who is prepared to ask questions."

— Member of the Cancer Experience Registry

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>.



“I would tell anyone diagnosed with cancer, take a deep breath, if you have to cry, then cry. Then put on your thinking cap and get to work.”

— Lori, Neuroendocrine Tumor Patient

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 yourself in the process—think about who you are, your goals, and your life situation.
- Whether you are an information seeker or someone who chooses to let the doctor make the decisions, know enough about your cancer to be as active as you would like to be in choosing your treatment.
- Work with your 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 yours will be like theirs.
- Choose a doctor you can trust and communicate with.



MARIAN’S STORY

Learning to Accept and Adapt

“I try to keep a positive attitude and move on.” Since her diagnosis with metastatic breast cancer, Marian has had surgery, chemotherapy, radiation therapy, hormone therapy, and targeted therapy. She has experienced hair loss, radiation burns, bone pain, and medication delays due to insurance.

Prayer, meditation, a good diet, and exercise help her cope. Marian credits exercise with preventing lymphedema, a long-term side effect of radiation.

Marian has learned to “adapt, lower her standards, and make the best of situations.” When getting out of bed is too hard, she sleeps on a recliner. She has also learned to accept help. “This can be hard for a person who takes care of things for other people. After a while, it gets easier to ask”, she says.

Importantly, Marian accepts that life is different.

She advises those who are newly diagnosed: “It’s very important to ask questions and keep a journal. Educate yourself.”

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

National Comprehensive Cancer Network • www.nccn.org

National Cancer Institute (NCI) • 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.

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:



**FOUNDATION
MEDICINE®**



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.

© January 2021. Cancer Support Community. All rights reserved. Photography by Danny Wilcox Frazier, Ed Cunicelli, and Mark Lozano.

“PP-ONC-USA-2335 /March 2021”