

Stranger in a Strange Land

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.



**CANCER SUPPORT
COMMUNITY**

SUPPORT FOR HELP WITH TREATMENT DECISIONS

National Cancer Institute 1-800-422-6237 www.cancer.gov

Cancer Support Community 1-888-793-9355 www.cancersupportcommunity.org

National Comprehensive Cancer Network www.nccn.org

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.*

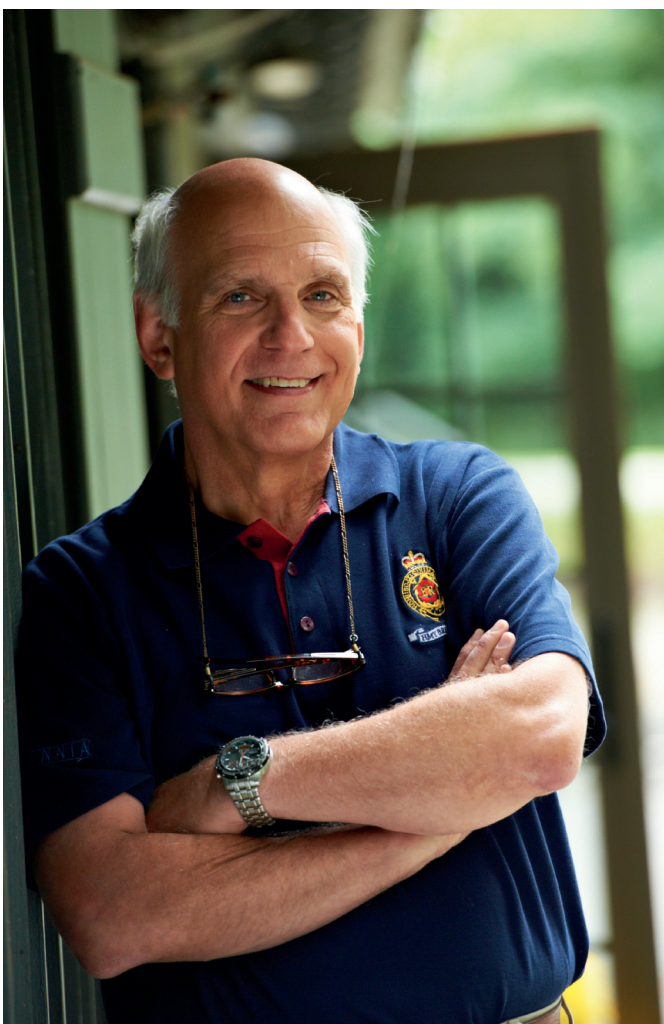
“Patients have to be advocates for themselves because there are a number of treatment options and it’s up to you to decide which one fits your life.”— Rick, prostate cancer patient

What Kind and Stage of Cancer Do You Have?

Knowing the exact type and stage 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.



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.*

NEED SUPPORT IN MAKING A TREATMENT DECISION?

If you are facing a cancer treatment decision, Cancer Support Community's Open to Options™ research-proven program can help you prepare a list of personalized questions to share with your doctor. Our Open to Options specialists can help you create a written list of specific questions about your concerns for your doctor. Call 1-888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.



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 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.

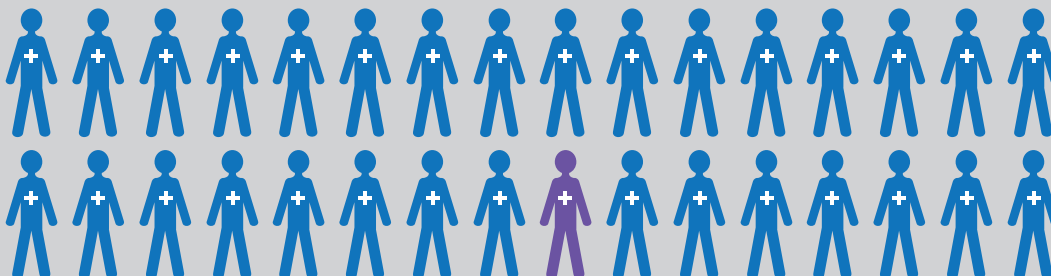
“You need better communication with the doctor. I still don't know if the reason I was not given an option was that none exists or if the doctor decided that was my best option.”

— Member of the Cancer Experience Registry

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?

WHICH DOCTOR IS RIGHT FOR YOU?



Making a Treatment Decision with Your Doctor

Cancer research and treatment are constantly evolving. The progress being made against many types of cancer is encouraging, but it can also complicate the decision-making process. 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. Understanding the potential benefits and having realistic expectations is related to the goals of treatment.

■ **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. Some people are willing to tolerate higher levels of side effects than others. You should also remember that many side effects can be treated effectively.

■ **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.

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.*

Clinical Trials

Clinical trials are the engine that drives progress in cancer treatment. These studies compare the existing standard of care—the best known available treatment for any cancer—with new drugs, agents or procedures that may offer improved outcomes.

Never hesitate to ask your doctor whether there is a clinical trial that might benefit you.

If you participate in a clinical trial, you will:

- Receive either the standard of care or the new treatment being studied
- Be fully informed before entering the trial of any potential side effects
- Be fully informed of the goals and aims of the trial
- Receive a very high level of ongoing care and monitoring for your cancer

Your doctor should be your partner in working with you to find a trial that fits your cancer and your goals. For more information or to find a clinical trial, visit www.cancersupportcommunity.org

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

— Member of the Cancer Experience Registry

What Are Guidelines and Pathways?

In recent years, there has been a focus on developing evidence-based standards of cancer care to help both doctors and patients make treatment decisions. There are two basic approaches to developing these standards: Guidelines and Pathways.

■ **GUIDELINES** are treatment algorithms that use the best available clinical data to guide treatment decisions for a specific cancer type, such as lung, breast, colon or thyroid. They are complex matrices that examine options by the specific subtype, genomic profile and stage of a cancer.

Guidelines are usually developed by professional organizations using panels of experts that include specialists in that cancer type, as well as experts in psychosocial care or symptom management and often patients. The recommendations are based on what is known to work best, and are not influenced by the cost of any drug or therapy, nor is their development supported by any pharmaceutical or insurance company.

■ **PATHWAYS** also provide specific treatment recommendations for different types of cancer and are developed by expert panels. They differ from guidelines in that they are produced by insurance companies, for profit companies or individual oncology practices. Pathways often include preferred drug choices and can be influenced by the costs of using a specific drug or treatment. In some instances, oncologists receive financial incentives for adhering to these pathways.

Guidelines are more of a resource for doctors and patients while pathways are a prescription or formula for making and paying for treatment decisions.

■ **HOW DOES THIS AFFECT YOU?** It is important for people facing cancer to know that guidelines and pathways exist and they may have a bearing on treatment recommendations.

These tools are becoming more common, and are useful in setting standards of care, assuring consistency and providing measures of quality. Insurance companies often use guidelines to make their own decisions about what to pay for in cancer treatment. It is important to note, however, that treatment recommendations for individual patients can vary. There are many factors that go into doctors' treatment recommendations.

You have the right to ask your doctor if he/she is using guidelines or pathways to manage your cancer care. You can also ask who develops these guidelines or pathways and whether there are any cost factors or incentives involved.

If you would like to use guidelines as a tool in evaluating your treatment options, the best thing to do is to take them to your doctor and ask for help in interpreting them and applying them to your situation. If you feel that your treatment departs from these guidelines or does not represent the standard of care, ask your doctor why he/she is not following the guidelines and consider seeking a second opinion.



“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:

- *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.*

General Cancer Information, Survivorship & Support

American Cancer Society 1-800-227-2345 www.cancer.org

National Cancer Institute 1-800-422-6237 www.cancer.gov

National Comprehensive Cancer Network www.nccn.org

OncoLink www.oncolink.org

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 1-888-793-9355 or visit www.cancersupportcommunity.org.

CANCER SUPPORT HELPLINE ®

Whether you are newly diagnosed with cancer, a long-time cancer survivor, caring for someone with cancer, or a health care professional looking for resources, or support, CSC's toll-free Cancer Support Helpline (1-888-793-9355) is staffed by licensed professional counselors available to assist you Mon - Fri 9 am- 9pm ET.

OPEN TO OPTIONS™

If you are facing a cancer treatment decision, Open to Options™ is a research-proven program that can help you prepare a list of questions to share with your doctor. In less than an hour, our Open to Options specialists can help you create a written list of specific questions about your concerns for your doctor.

FRANKLY SPEAKING ABOUT CANCER ®

CSC's landmark cancer education series provides sound medical and psychological information for cancer patients and their loved ones. Information is available through books, online, and in-person programs.

AFFILIATE NETWORK SERVICES

Over 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

CANCER EXPERIENCE REGISTRY

The Cancer Experience Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families throughout the cancer journey. To join, go to www.CancerExperienceRegistry.org

The Cancer Support Community and its partners provide 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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