

Lilly Oncology

Before you begin therapy

A guide to

# Making decisions about your cancer treatment



*Lilly*

## Important Phone Numbers

Physician \_\_\_\_\_

Nurse \_\_\_\_\_

Care Partner \_\_\_\_\_

Pharmacy \_\_\_\_\_

Insurance \_\_\_\_\_

Other \_\_\_\_\_

*The information presented in this booklet is not intended to replace discussions between you and your healthcare team, but to serve as a guide to making decisions about your cancer care and treatment—decisions that you can live with and feel good about.*

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# Introduction

A diagnosis of cancer can be devastating. It is almost impossible to prepare for, and difficult to adequately describe, what you may be feeling in response. This booklet addresses some of the feelings associated with the diagnosis of cancer. You might be surprised to learn that you are not alone in your feelings and that many people have the same responses.

Having reliable information about your disease, current research, and your treatment options is important. Choosing a healthcare team, knowing which questions to ask, and understanding how to live with and beyond cancer will help you learn to take control of your situation. Understanding your disease is one of the strongest weapons you have in fighting your illness.

This booklet discusses a variety of ways to get the information you need to become an informed, active participant in your cancer treatment. A glossary of the terms that appear in the text in *italics* can be found in the back of this booklet. Please consult your healthcare team to discuss any questions that may come up after reading the information provided. This information is not intended to replace the advice of your healthcare team.

# Why do I feel this way?

There is no typical way to feel when you are told that you have cancer. Everyone feels and responds differently.

Some people experience several emotions at once, ranging from fear, sadness, or even anger, to motivation and determination. There is, however, one feeling that seems consistent for many people who are diagnosed with cancer—and that is a loss of control. One way to regain a sense of control in your life is by learning as much as you can about your disease so that you can discuss it openly with your healthcare team.

## **Additional cancer therapy booklets**

Information booklets from Lilly Oncology are available to help you understand the cancer you have, to talk with your healthcare professional about your goal of therapy, and to help you make a treatment decision. These booklets can be obtained free of charge by calling 1-800-545-5979:

### ***BEFORE YOU BEGIN CHEMOTHERAPY***

#### ***A Guide to Some Things You Should Know About Side Effects—***

for anyone considering chemotherapy. If your goal of therapy is to consider the side effects of your treatment, you may want to read this booklet.

## ***BEFORE YOU BEGIN THERAPY***

### ***A Guide to Researching the Best Therapy for Your Treatment Goals—***

for the newly diagnosed or newly rediagnosed person to provide information about how to research how well a treatment worked or how effective it has proven to be. If your goal of therapy is to be aggressive with your treatment, this is a booklet for you.

## ***IF ADDITIONAL TREATMENT IS NEEDED***

### ***A Guide to Deciding Your Next Steps—***

for anyone who discovers that they need additional or different cancer therapy. These options may include enrolling in a clinical trial, pursuing different types of combinations of treatment, or deciding whether you want to undergo further treatment.



*Learning about my cancer makes me feel more in control of my life.  
—Frank*

# Seeking support

Becoming a *self-advocate* is one way to approach your diagnosis and treatment. Being self-supportive requires that you understand what is best for you. You may want to consider spending some time evaluating your needs to determine how you would like to approach your treatment.

One way to become acquainted with your needs is through self-assessment. Your experience with cancer is a very personal journey, and it is helpful to try to understand your feelings. Keeping a journal can provide a way for you to document this period in your life, record questions and thoughts, and express concerns about your cancer treatment. Getting acquainted with your needs is a good first step in approaching your cancer therapy. You also need to determine your *goal of therapy*, what you and your doctor expect from your treatment (please see page 19, **Understanding your treatment options**, for more information about the goal of therapy).

Knowing when to ask for help is another important aspect of being a self-advocate. As the primary supporter of your cause, it is up to you to determine when and whom to ask for help. Often an individual's first request for help is when they are scheduled to visit the doctor. You may request that a friend or family member go with you to your first few appointments to help take notes, clarify information, or simply be there as a source of support.

Your care partner does not have to be the same person all of the time, but it should be someone who can help you gather and understand the large amount of information you will receive.

Consider allowing yourself to depend on others for a while. By building a network of support, your ability to take control of your life will actually be enhanced. Sometimes, learning to ask for help is just as important as receiving it. Accept that people really do want to help you and that by accepting their help, you may both benefit. Keep a list of things that you need help with so that when people ask you how they can help, you can let them know. This list can include such things as shopping, cooking, laundry, childcare, or transportation.

You may wish to keep a calendar and have your family, friends, or members of your community (church members, members of your support group, neighbors) sign up to provide dinner, transportation for you to your appointments or for your children and their activities, or childcare for an hour in the afternoon so that you can take a nap. Save your energy for yourself, your family, and friends. Acknowledging that you need assistance and identifying the specific tasks that need to be accomplished make it easier for others to help you.

You may want to consider sharing your diagnosis with others. Many people feel comfortable telling family and close friends about their diagnosis of cancer, but choosing to share this information and with whom is a personal decision. You may want to consider talking with your employer or anyone else who may be directly affected by your disease or your treatment.

You may find that an even stronger support system will be available to you once you begin to communicate with others.

You may also consider talking to other people who have received treatment. Support groups meet regularly and can provide valuable information for people living with cancer, their families, and significant others. In the back of this booklet, you will find a list of groups that may be a good starting point in your search for information. Some of these groups meet in person, others communicate over the telephone, and all of these groups will send you information through the mail. Please remember that it is important to choose your sources of information and support wisely and to discuss the information you collect with your healthcare team. Gathering information about your cancer and its treatment will reduce uncertainty and assist you in understanding your situation.



*Talking about my cancer helped give me the strength to fight it.  
—Natalie*

# Choosing a healthcare team

Finding the best available healthcare is crucial. Your primary care doctor will have an ongoing role in your cancer treatment and may refer you to an *oncologist*, a specialist in cancer care. Your oncologist should be someone who listens carefully to your needs and concerns, relates to you with consideration and respect, and works with you to select the cancer treatment that is right for you.

Many people seek a second opinion. If you feel that this is an option you would like to pursue, ask your primary care doctor or oncologist for help in referring you to another specialist. Taking a few days to meet with more than one doctor is always appropriate and is a positive step toward taking control of your cancer therapy. Physicians understand that this is necessary for many newly diagnosed patients and should be supportive of your need to explore this option. After meeting with and talking to different physicians, you should feel free to move forward with the healthcare provider who best fits your needs and who will work with you to meet your goals. Remember, building a comfortable relationship with your healthcare team is an important part of your cancer care.

Your healthcare team may also include an *oncology nurse*. This is the person who will administer your chemotherapy treatments, help you understand your disease, and assist you in managing the *symptoms* of your disease or its treatment. Other members of your healthcare team may include a *dietitian* to help with your nutritional needs; a *social worker* to help you with emotional support, financial needs, and identifying other resources; or an *oncology pharmacist* to help explain how you may be affected by the drugs used in your treatment. They are interested in your care and will be able to answer your questions in a way that makes sense to you. You need to make sure that you communicate your needs as clearly as you can to everyone on your healthcare team so they can help you make the best decisions.

### *Some questions to ask when choosing a healthcare team*

1. Am I comfortable with my healthcare team? Do they make me feel like I am a central part of the decision-making process?
2. Does the doctor communicate to me in terms that I can understand?
3. Am I comfortable with the information that is provided to me?
4. Do I feel comfortable asking questions? Does the doctor listen to my concerns?
5. Are the office surroundings comfortable?
6. Do I have to wait long after my appointment time to see the doctor?
7. Besides the doctor, what other specialists are available to me? A dietitian, social worker, nurse, or pharmacist?
8. When and how can I contact my healthcare team?

# Seeking information

There is a wealth of information available to you. Please see the **Education and support contacts** section, pages 31 to 33, for information ranging from general information about your disease to clinical trials to survivor issues.

In addition to the resources listed at the back of this booklet, you will find that information is readily available from such places as libraries, bookstores, your doctor's office, the Internet, community centers, and pharmaceutical companies. These materials can be found in various forms, such as pamphlets, booklets, Internet Web sites, books, audiotapes, and videotapes. You should select the formats from which you are most comfortable learning. It is important to work with your healthcare team to make decisions that are best for your particular situation, and there is no need to rush those decisions. Most important decisions do not have to be made in one day. Take some time to think about your options. You may find that you need a little extra time to make your decisions. Be patient with yourself.

Seek information in quantities that you can manage. We all feel overwhelmed when presented with too much information at one time. As you review information and think of questions, write them down and take them to your next appointment. You may want to make a special appointment with your doctor just to devote time to this. Before your appointment, discuss these questions with your care partner and give them a copy so he/she can help to ensure that you get the answers you need. Refer to the **Tips for communicating effectively** section, page 12, to help you with this.



*For me, the first hurdle in my cancer diagnosis was finding out what I was up against.*  
—David

## Tips for communicating effectively

1. Prepare for your appointment. Write down questions when you think of them, and take them with you to discuss with your healthcare team.
2. Be as clear as you can when asking questions and communicating your needs.
3. If you bring books, articles, or information you have printed from the Internet to your appointment, highlight important information that you would like to discuss.
4. Listen carefully to what you are being told. Take notes or make an audiotape of your conversation.
5. Do not be afraid to ask for clarification if you do not understand some of the information that you receive. Ask questions until you are satisfied that you understand the information being provided to you.

# What you need to know about clinical trials

One of the first decisions you may want to make is whether to participate in a *clinical trial*. It is important to make this decision prior to starting any treatment because you may not qualify for certain clinical trials (also known as studies) if you have already received treatment for your cancer. If your doctor does not bring up this subject with you, you may want to ask him/her if participating in a clinical trial is an option for you.

If you take part in a clinical trial, you will receive treatment in your doctor's office, a clinic, or a hospital. As part of the study, your healthcare team will carefully monitor your progress. With clinical trials, you may be asked to fill out questionnaires in order to gather information about the way you feel while you are on treatment. It is important that you fill out these questionnaires if it is requested. These questionnaires provide valuable information to cancer researchers about how your cancer treatment is affecting your condition as well as your daily life.

Clinical trials are carried out following a plan of very strict, scientific guidelines, called a *protocol*. The protocol explains everything that will happen in the study. It must be approved by review boards composed of healthcare professionals and other qualified individuals before the study can enroll patients. Following preclinical or laboratory phases of studies, there are four possible phases of cancer clinical trials in humans, each addressing different questions about the treatment being studied.

**Preclinical studies**, which are conducted in a laboratory setting, help to assess whether an experimental drug is safe to test in humans. During this stage, the drug is usually studied in animals to answer questions about how a drug works, how it is eliminated, and how the drug might affect pregnancy and offspring.

In **phase I** clinical trials, doctors (also called investigators) study the safety of giving drugs to humans along with looking for the best way to give a medication (for example, as a pill, an injection, or an *infusion*). They will usually study how the drug is eliminated from the body in humans. In addition, doctors look to determine appropriate doses for further testing, and they carefully watch for any *side effects*. Phase I study drugs are usually given to small groups of humans. During this phase, for drugs used to treat cancer, doctors may be able to identify in which *tumors* a treatment might work.

In **phase II** clinical trials, the drug is studied in a larger group of humans. The focus is to study specific cancers to see how well the drug or treatment works. The doctor will watch closely for side effects and will also watch how the disease responds to the treatment.

In **phase III** clinical trials, a study drug or treatment is generally compared to a standard existing treatment. Patients are usually randomly assigned to receive either the standard treatment or the new treatment. During the trial, patients are not told which treatment they are receiving but are told what to expect and what to watch for. Also, sometimes the doctor will not be aware of which treatment each patient is receiving so that he/she can remain objective about how the disease is responding to the treatment and any side effects that patients may be experiencing.

In **phase IV** clinical trials, doctors study a drug that has already been approved by the Food and Drug Administration (FDA). Pharmaceutical companies often sponsor these trials to study expanded uses of drugs already available to treat other types of cancer.

Before patients enter a clinical trial, all of the procedures that are to be done in the trial will be explained, and patients will be asked to sign an *informed consent*. By signing the document, a patient is acknowledging that he/she understands the potential risks and benefits of the treatment they are to receive or of any tests that may be required. It is important to remember that patients may change their minds and withdraw from a clinical trial at any time. Non-English-speaking patients may ask for consent documents in their own language.

Some people have said that they chose to not participate in a clinical trial because they thought that their health insurance would not cover the cost of their treatment. There are a number of new laws and programs, which vary from state to state, that may help pay for all or part of the costs of treatment. It is important to have all of your questions answered by your insurance representative, your healthcare team, or one of the groups listed in the resource list at the back of this booklet before agreeing to participate in a clinical trial. To obtain additional information about clinical trials, contact the organizations listed in the following section. These Web sites are independent from Eli Lilly and Company, and Lilly does not control or endorse the content of these sites.



*Cancer is what I have, not who I am.*  
—Jean

## Additional information about clinical trials

### National Cancer Institute—clinical trial results

[www.cancer.gov/clinicaltrials/results/](http://www.cancer.gov/clinicaltrials/results/)  
1.800.4CANCER (1-800-422-6237)

### Centerwatch

[www.centerwatch.com](http://www.centerwatch.com)

### National Institutes of Health

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

### Association of Cancer Online Resources

[www.acor.org](http://www.acor.org)

### Pharmaceutical company Web sites

Your decision to take part in a clinical trial is up to you, your family, and your healthcare team. There are potential risks and benefits associated with clinical trials that you will want to discuss with your doctor before deciding to participate in a clinical trial. A list of questions to guide your discussions with your doctor about clinical trials appears on the next page. If you choose to not participate in or do not qualify for a clinical trial, treatment options are still available for you, which are discussed in the next section, **Understanding your treatment options**.

*Some questions to ask your healthcare team about clinical trials*

1. Do you participate in clinical trials?
2. Do I qualify (meet the eligibility criteria) for any current clinical trials? If so, what is the purpose of these trials?
3. If I do qualify for a clinical trial, what is known about the effectiveness of the treatment being studied? What are the side effects?
4. How long does the clinical trial last? Can I stop participating in the clinical trial at any time I choose?
5. What costs am I responsible for if I participate in a clinical trial?
6. If I do not qualify for any current clinical trials, what are my options?
7. Will my privacy be protected?

# Understanding your treatment options

Determining which particular treatment is right for you depends on several factors, including your general physical health, the type of cancer you have and at what *stage* it was diagnosed, and the goal of therapy that you and your doctor have agreed upon.

*Goal of therapy* refers to what you and your doctor expect from your treatment. If your goal of therapy is to treat your cancer as aggressively as possible, your treatment may be different from that of someone who decides on a different goal of therapy.

Treatment options could include *surgery, chemotherapy, biotherapy, radiation therapy, hormonal therapy, and targeted therapy*, or a combination of any of these, depending on the type and stage of cancer that you have. With some tumors, surgical removal of all, or as much of the tumor as possible, is considered the best treatment. This depends on the size and location of the tumor and whether the cancer cells have spread (referred to as *metastasis*) to other parts of your body. If there is evidence that tumor cells have spread or if some of the tumor could not be removed during surgery, then one or more of the other available therapies may be used.

You should ask your doctor to talk with you about at least two treatment options. These options may be a combination chemotherapy regimen, chemotherapy with other kinds of therapy, or some combination of the above therapies. After your doctor has provided this information, ask about the potential benefits and risks associated with each therapy. Be sure to ask your doctor questions about how each therapy relates to your goal of therapy. Ask your doctor to write down the information he/she shares with you about how effective a therapy is and what the side effects are—regardless of which is most important to you. Take time to compare this information to your goal of therapy, and then discuss it with your doctor.

Use the worksheets on pages 38 and 39 as a tool to help you and your doctor decide which treatment is best for you, based on a comparison of benefits, risks, side effects, and treatment schedules for the alternatives suggested.

## Types of cancer treatment

**Surgery**—the most direct way to remove a visible tumor or cancer cells that have invaded a specific area.

**Chemotherapy**—treatment with medication, sometimes given orally, but more commonly by injection, into a vein or muscle to destroy cancer cells. It is a systemic treatment that reaches every organ of the body through the bloodstream.

**Biotherapy**—treatment to stimulate or restore the ability of the immune system to fight infection and disease. Also used to lessen side effects that may be caused by some cancer treatments. Also known as immunotherapy, biological therapy, or biological response modifier (BRM) therapy.

**Radiation therapy**—a treatment method that uses high-energy x-rays to destroy cancer cells.

**Adjuvant therapy**—may be any of the above therapies when used to treat “microscopic” cancer that is not yet visible and, hopefully, to prevent the disease from returning.

**Hormonal therapy**—treatment or prevention of cancer by removing, blocking, or adding hormones that affect the growth of a tumor.

# Other considerations

Information about symptom management can be very lengthy and is specific to every individual. A symptom is something you experience that is different from what is normal for you.

It may be the result of the disease or may be due to the treatment. Some examples of common symptoms that you may experience include pain, nausea, vomiting, diarrhea, fatigue, rash, hair loss, numbness or tingling in the extremities, mouth sores, or changes in taste. Be sure that you inform your healthcare team of any symptoms that you may be experiencing. Your healthcare team members are experts in providing information and individualized ways to manage your symptoms so that you can resume your usual daily activities.

# Alternative and complementary therapies

Alternative and complementary therapies have many different definitions. A general definition of an alternative or complementary therapy is a treatment used for the control of cancer in place of, or in addition to, conventional medical therapy.

One type of complementary therapy is supplementation of your diet with herbs or vitamins. Other alternative and/or complementary therapies involve using mental or physical techniques that may reduce stress, enhance your health, or stimulate the release of hormones that may be helpful in boosting your immune system. Some techniques include meditation, listening to motivational tapes, imagery, massage, acupuncture, yoga, and Tai Chi, among many others. Information on alternative or complementary therapies can be found in the media, in books, and on the Internet. Because of the large volume of information available, this information is not discussed in detail in this booklet. Although some patients feel uncomfortable discussing these therapies with their doctor, your doctor should be willing to discuss alternative or complementary therapy options with you.

*It is important that you let your healthcare team know if you are currently participating in any alternative or complementary therapies. These may have an unwanted effect on you or may alter the effectiveness of the cancer treatment you are receiving. By being aware of these additional therapies, your healthcare team can better monitor your progress.*

For additional information about topics discussed here, and more, visit [www.cancersurvivaltoolbox.org](http://www.cancersurvivaltoolbox.org) and ask for a free copy of their audio program, **The Cancer Survival Toolbox®**.



*Adding meditation and relaxation exercises to my cancer therapy gave me a real boost when I needed it most.*  
—Isabel

# Living beyond a cancer diagnosis: Finding your “new normal”

You have prepared yourself, made informed decisions, and actively participated in your treatment. As your treatment nears its end, you may experience many feelings, just as you did when you were first informed of your cancer diagnosis.

You are not alone. Recent studies show that there are nearly 9.8 million *cancer survivors* in the United States.<sup>1</sup> As your last treatment is completed, you may expect that your daily routine will suddenly return to normal and you can go back to your life as you knew it before you were diagnosed with cancer. You may discover, as many cancer survivors do, that you need to establish a “new normal.” Of course you would like your daily routine to return to the way it was before your illness, but you may find that you are more likely to have a new set of expectations and priorities as a result of your cancer, its treatment, and redefining your life after diagnosis.



*Many things about my life changed after cancer,  
like the meaning of the word “survivor.”*  
—Lee

*Consider the following tips from the American Cancer Society:*

- Be kind to yourself. Focus on what you *can* do.
- Reach out to others. Reaching out to someone else can reduce stress.
- Don't be afraid to say no. Polite but firm refusals help you stay in control of your life.
- Talk about your concerns.
- Learn to pace yourself. Stop before you get tired.
- Give in sometimes. Not every argument is worth winning.
- Get enough exercise. It's a great way to get rid of tension in a positive way.
- Take time for activities you enjoy.
- Set priorities. You can't do everything at once.
- Take one thing at a time. If you're feeling overwhelmed, divide your list into manageable pieces.
- Having a plan can reduce the stress of the problem.
- Eat properly.
- Get enough sleep.

# Survivorship issues

As a cancer survivor, you may be introduced to a whole new set of concerns such as fear of cancer recurrence; body image changes; issues related to sexuality and spirituality; and insurance, financial, and work-related concerns. Some cancer survivors have even reported feeling guilty that they made it through their cancer treatment while others they have met on their journey have not.

What people commonly fear most is the unknown. Share your fears with your healthcare team, your family, and your friends. Knowledge is powerful. Once you have identified your fears, accurate information can help to reduce them. A major concern for cancer survivors is that their cancer will return. As your cancer treatment comes to an end and the time for your checkup approaches, or as the anniversary date of your cancer diagnosis nears, you may feel anxious. Be sure to ask your doctor what symptoms you should watch for and immediately report anything unusual. Whether you are still being monitored by your oncologist or have been referred back to your family doctor, follow their advice and continue to get regular checkups.

Your physical appearance may change as a result of your cancer or its treatment. You might have lost weight, and your hair might have fallen out or noticeably thinned. Though these physical changes may be hard to accept at times, it is important for you to try to accept these changes as part of your “new normal.” You may want to consider seeking the assistance of a therapist, another cancer survivor, or a loved one to help you adapt to these changes. In some cases, your healthcare team may be able to provide suggestions to help your particular situation.

If you experience sexual difficulties as a result of your cancer treatment, discuss this with your healthcare team. You do not have to give up intimacy and affection during cancer therapy. Communication with your significant other is extremely important during this time. Providing each other with love, support, and comfort is important at this time in your life.

Many people find comfort in spiritual inspiration. Some turn to prayer or to a house of worship, while others turn to nature or the arts (such as painting, writing, or music) or meditative exercise (such as yoga). The form of expression you use is very personal and unique, and whatever form of expression you choose, you may find an inner strength to help you through this difficult time.

If you plan to return to work, consider communicating your wants and needs with your employer or others who are directly affected by this change in your life. Maintaining honest, open communication can be healing. Many resources are available to help you through this time, including those listed in the **Education and support contacts** section, pages 31 to 33.

# Finding your focus. Building a network. Embracing the future.

You may have read this booklet from cover to cover, or you may have chosen to focus only on the parts that were important to you. Your journey may not be a continuous progression and you may have to make several decisions at once, or you may have to re-evaluate and adjust your decisions.

The network of support that you have developed may have long-lasting effects. The people you have met along the way, friendships you may have developed, and connections with your family and friends are all a part of your future. *Embrace the future.*

# Education and support contacts

As a convenience to readers, Lilly is providing contact information for the organizations listed on pages 32 and 33. Because these organizations are independent from Eli Lilly and Company, Lilly does not control the content of the programs and services they offer. The information available from these resources should be useful to you in your discussions with your healthcare team.

## All Cancers

AMERICAN CANCER SOCIETY  
1.800.ACS.2345 (1.800.227.2345)  
[www.cancer.org](http://www.cancer.org)

CANCER CARE  
1.800.813.HOPE (1.800.813.4673)  
[www.cancercare.org](http://www.cancercare.org)

CANCER RESEARCH  
PREVENTION FOUNDATION  
1.800.227.CRFA (1.800.227.2732)  
[www.preventcancer.org](http://www.preventcancer.org)

fertileHOPE  
1.888.994.HOPE (1.888.994.4673)  
[www.fertilehope.org](http://www.fertilehope.org)

NATIONAL CANCER INSTITUTE  
1.800.4.CANCER (1.800.422.6237)  
[www.cancer.gov](http://www.cancer.gov)

THE NATIONAL COALITION FOR  
CANCER SURVIVORSHIP  
1.877.NCCS.YES (1.877.622.7937)  
[www.canceradvocacy.org](http://www.canceradvocacy.org)

PATIENT ADVOCATE  
FOUNDATION  
1.800.532.5274  
[www.patientadvocate.org](http://www.patientadvocate.org)

PEOPLE LIVING WITH CANCER  
[www.plwc.org](http://www.plwc.org)

THE WELLNESS COMMUNITY,  
NATIONAL HEADQUARTERS  
1.888.793.WELL (1.888.793.9355)  
[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

VITAL OPTIONS INTERNATIONAL  
1.818.508.5657  
[www.vitaloptions.org](http://www.vitaloptions.org)

## Breast Cancer

NATIONAL BREAST CANCER  
COALITION  
1.800.622.2838  
[www.stopbreastcancer.org](http://www.stopbreastcancer.org)

SISTERS NETWORK INC.  
1.866.781.1808  
[www.sistersnetworkinc.org](http://www.sistersnetworkinc.org)

THE SUSAN G. KOMEN  
BREAST CANCER FOUNDATION  
1.800.I'M AWARE (1.800.462.9273)  
[www.komen.org](http://www.komen.org)

Y-ME NATIONAL BREAST  
CANCER ORGANIZATION  
1.800.221.2141  
[www.y-me.org](http://www.y-me.org)

YOUNG SURVIVAL COALITION  
1.212.206.6610  
[www.youngsurvival.org](http://www.youngsurvival.org)

## Brain Cancer

NORTH AMERICAN  
BRAIN TUMOR COALITION  
[www.nabraintumor.org](http://www.nabraintumor.org)

## Colon Cancer

COLON CANCER ALLIANCE  
1.877.422.2030  
[www.ccalliance.org](http://www.ccalliance.org)

NATIONAL COLORECTAL  
CANCER RESEARCH ALLIANCE  
1.800.872.3000  
[www.nccra.org](http://www.nccra.org)

## Leukemia and Lymphoma

THE LEUKEMIA AND  
LYMPHOMA SOCIETY  
1.800.955.4572  
[www.leukemia-lymphoma.org](http://www.leukemia-lymphoma.org)

LYMPHOMA RESEARCH  
FOUNDATION  
1.800.235.6848 OR 1.800.500.9976  
[www.lymphoma.org](http://www.lymphoma.org)

## Lung Cancer

THE LUNG CANCER ALLIANCE  
1.800.298.2436  
[www.lungcanceralliance.org](http://www.lungcanceralliance.org)

LUNG CANCER ONLINE  
[www.lungcanceronline.org](http://www.lungcanceronline.org)

## Ovarian Cancer

NATIONAL OVARIAN CANCER  
COALITION  
1.888.OVARIAN (1.888.682.7426)  
[www.ovarian.org](http://www.ovarian.org)

OVARIAN CANCER  
NATIONAL ALLIANCE  
1.202.331.1332  
[www.ovariancancer.org](http://www.ovariancancer.org)

## Pancreatic Cancer

PANCREATIC CANCER  
ACTION NETWORK  
1.877.272.6226  
[www.pancan.org](http://www.pancan.org)

## Prostate Cancer

US TOO! INTERNATIONAL—  
PROSTATE CANCER EDUCATION  
AND SUPPORT NETWORK  
1.800.808.7866  
[www.ustoo.com](http://www.ustoo.com)

# Glossary

## Biotherapy:

Treatment to stimulate or restore the ability of the immune system to fight infection and disease. Also used to lessen side effects that may be caused by some cancer treatments. Also known as immunotherapy, biological therapy, or biological response modifier (BRM) therapy.

## Cancer survivor:

Anyone who has been diagnosed with cancer, from diagnosis to end of life, is considered a cancer survivor.

## Chemotherapy:

Treatment with medication, sometimes given orally, but more commonly by injection, into a vein or muscle to destroy cancer cells. It is a systemic treatment that reaches every organ of the body through the bloodstream.

## Clinical trial:

Research study that seeks to answer scientific questions and to find better ways to prevent or treat cancer.

## Combination therapy:

The use of more than one therapy to treat cancer.

## Dietitian:

A specialist trained to prescribe specific diets or additions to your diet.

## Goal of therapy:

The result that you and your doctor want to achieve from your treatment.

## Hormonal therapy:

Treatment or prevention of cancer by removing, blocking, or adding hormones that affect the growth of a tumor.

## Informed consent:

The process in which a person learns key facts about a clinical trial and voluntarily agrees to take part in it by signing a consent form describing the potential risks and benefits of treatment.

## Infusion:

Slow and/or prolonged delivery of a drug or fluids through a vein or artery.

## Metastasis:

The spread of cancer from one part of the body to another.

## Oncologist:

A doctor who specializes in treating cancer.

## Oncology nurse:

A nurse with special training in caring for cancer patients and administering cancer treatments.

## Oncology pharmacist:

A pharmacist who specializes in preparing and dispensing cancer drugs and who can provide information about how a drug works or its side effects.

## Protocol:

An action plan for a clinical trial. The plan states what will be done in the study and why. It outlines how many people will take part in the study, what types of patients may take part, what tests they will receive and how often, and the treatment plan.

## Radiation therapy:

A treatment method that uses high-energy x-rays to destroy cancer cells.

## Self-advocate:

Working on behalf of oneself to take an active role in one's own cancer care treatment.

## Side effects:

Signs or symptoms that can occur with treatment. Common side effects of cancer treatments may include fatigue, nausea, vomiting, diarrhea, decreased blood cell counts, hair loss, numbness or tingling in the extremities, rash, mouth sores, and changes in taste.

## Social worker:

A professional who works with patients to help them with emotional, financial, insurance, and other resources that they may need during the course of their cancer care.

## Stage:

A term used to describe the extent of a cancer and whether it has spread from the original site to other parts of the body.

## Surgical intervention:

An operation to remove a tumor or to decrease the symptoms caused by the tumor.

## Symptom:

Something a patient experiences that is different than normal for them, and may be the result of the disease or its treatment.

## Targeted therapy:

Treatment that uses specific cancer drugs to block the growth and spread of cancer by attacking specific areas in the cancer cell. They interfere with specific elements needed by the cancer cell to survive and grow.

## Tumor:

An abnormal growth of tissue. A tumor may be either benign (not cancerous) or malignant (cancerous).

# Treatment Comparison Worksheet—Option 1

1. What specifically will I receive?

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2. How often will I receive treatment?

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3. How long will the treatment last?

---

4. What are the potential side effects of this treatment?

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5. Are the side effects associated with this treatment serious enough to interfere with continuing therapy?

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6. If I experience side effects, how long will they last and how can they be managed?

---

7. What are the potential benefits of this treatment?

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8. What are the potential risks associated with this treatment?

---

9. Does this option meet the goal of therapy?

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# Treatment Comparison Worksheet—Option 2

1. What specifically will I receive?

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2. How often will I receive treatment?

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3. How long will the treatment last?

---

4. What are the potential side effects of this treatment?

---

5. Are the side effects associated with this treatment serious enough to interfere with continuing therapy?

---

6. If I experience side effects, how long will they last and how can they be managed?

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7. What are the potential benefits of this treatment?

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8. What are the potential risks associated with this treatment?

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9. Does this option meet the goal of therapy?

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#### Reference

1. American Cancer Society. *Cancer Facts and Figures 2005*. Atlanta, Ga: American Cancer Society;2005:1.

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