

A guide to

# Researching the best therapy for your treatment goals



## 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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# Looking for answers

You have been given this booklet because you have recently been diagnosed with cancer, or are changing treatment—or perhaps because you are helping someone who has cancer. Of all the questions facing you, one of the most important is, “How can I decide which therapy will work best for me?”

Upon learning that you have cancer, you may want to become very involved in the decision process, or you may choose not to. Most people, however, are more comfortable if they can become educated about their cancer, so that they can participate more fully in the decisions they face.

This booklet is one of a series designed to help you make treatment decisions based on the goals of therapy agreed upon by you and your healthcare team. Please see the information on page 5 to learn about the booklets available in this series and how to obtain them. While much of the information in this booklet uses chemotherapy as an example, the advice it contains about sources of information and how to use them applies to all forms of treatment.

Although you may have already talked with your healthcare team about treatment, there is often more than one effective treatment. You should be aware of your options before you begin therapy. Unless you are in an emergency situation, most people have a few days after their diagnosis to step back and look into their options. Various cancer treatment options include surgery, chemotherapy, biotherapy, radiation therapy, and hormonal therapy. Your treatment may include one or a combination of these therapies, depending on the type and stage of cancer you have.

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 healthcare team have agreed upon. “Goal of therapy” refers to what you and your healthcare team 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 upon a different goal of therapy.



*Setting goals with my treatment keeps me looking forward, moving ahead.*  
—Isabel

## 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.

## **Additional cancer therapy booklets**

In addition to this booklet, there is a range of other information to help you understand and talk with your healthcare team about your goal of therapy before you make a treatment decision. These booklets can be obtained free of charge by calling 1-800-545-5979:

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

#### ***A Guide to Making Decisions About Your Cancer Treatment—***

for anyone newly diagnosed with cancer to provide a road map of how to learn the basics of cancer care.

### ***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 treatment side effects, you may want to read this booklet.

### ***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 or combinations of treatment, or deciding whether you want to undergo further treatment.

# Seeking support

Information about cancer and cancer therapy is not difficult to find, but there is a lot of it!

This booklet will provide many excellent sources for you to explore. The job of reading and evaluating the information, however, can be detailed and time-consuming. It is important to know when to ask for help in researching your treatment options. It is up to you to determine if, when, and whom to ask for help. This person does not have to be the same individual all of the time, but he/she should be someone who can help you gather and evaluate the large amount of information you will receive.

Begin by finding the best sources of information. The most obvious of these are your healthcare team and other members of your healthcare team. The research librarian at your local library can help you find information about cancer and cancer therapies. Additionally, there is a wide range of valuable information available on the Internet. Internet sites include cancer research and support organizations, patient groups, and pharmaceutical companies. Many excellent information sources are listed throughout this booklet, including general cancer information sources and sources with information about clinical trials.

Take a few days to review and understand this important information. Some cancers may require immediate treatment, but in most situations you will have enough time for this basic research. Your goal is to understand what possible therapies are available for your cancer and—in discussions with your healthcare team—to help make a decision about the best treatment for you.



*Cancer changes so much, but it will not change my resolve.*  
—Jean

# Is there a “standard” therapy for your cancer?

“Standard” therapy is a term used to describe a treatment that is clinically accepted and commonly used. Standard therapy can vary depending on the healthcare team. You should start your research by asking the question, “What are the FDA-approved treatments for my cancer?”

The Food and Drug Administration is a government organization that determines whether a new drug is safe and effective. Based on information from clinical studies submitted to the FDA by pharmaceutical companies, the FDA approves the drug for marketing for specific uses, called “indications.” Treatments that have an FDA indication have undergone extensive testing in large numbers of patients and have met FDA standards for effectiveness and safety.

For most cancers, at least one standard therapy is available. The National Cancer Institute’s Web site, [www.cancer.gov](http://www.cancer.gov), contains current information about standard cancer treatments, as well as other cancer information, including a registry of cancer clinical trials.

## New uses for existing treatments

In addition to standard therapies, there are other therapies available that may be of value to you. Most of these treatments have been well studied in clinical trials, but generally these are phase I or II studies in smaller groups of patients (see pages 10 and 11 for more information about clinical trials). Such studies are generally done by research physicians at centers that specialize in cancer research. Finding new uses for existing standard treatments is often the goal.

There are a number of places to learn about the effectiveness of therapies not specifically approved by the FDA for a particular type of cancer but which have been studied in clinical trials. One of the best sources is the Association of Community Cancer Center's (ACCC) Web site. Go to [www.accc-cancer.org](http://www.accc-cancer.org), and in the Related Links box, click on the ACC Drug Bulletin link.

Another good place to look for information about your cancer and treatments being used for it is the patient Web site of the American Society of Clinical Oncology (ASCO), [www.plwc.org](http://www.plwc.org). Remember, if you do not have access to the Internet, the staff at your local library can help you with this. Other sources are listed elsewhere in this booklet.

# The importance of clinical trials

Many sources of information are available about ongoing clinical trials. There are two reasons that you may be interested in clinical trials: You may want to consider the results of completed clinical trials as you make your treatment decision, and you may want to consider participating in a clinical trial as part of your treatment.

This section is intended to help you learn the basics of clinical trials and clinical trial information so you can talk with your healthcare team if you are interested.

In most cases, FDA approval of a new cancer therapy is granted only after thorough testing. There are different phases of testing that a therapy goes through in order to determine whether it works and is safe for use. First, it is tested in laboratory studies, and then in a series of clinical trials involving people. These trials, or research studies, are conducted in three separate steps, referred to as phase I, phase II, and phase III trials. Clinical trials are used to test many types of treatment, including new drugs, vaccines, new approaches to surgery or radiation therapy, or new combinations of treatment.

As you are learning about your treatment options, you should be aware that a phase III clinical trial yields the most reliable results. In a phase III trial, a study drug or treatment is usually compared to a standard existing treatment in large numbers of people. Phase III trials are called “randomized” studies because patients in them are usually assigned at random (by chance) to receive either the standard treatment or the new treatment. Using this method is thought to be a more fair comparison of treatments and allows the trial to show whether the new treatment is better than, the same as, or inferior to the standard treatment.

Many drugs undergo clinical trials not only to obtain their original FDA approval, but also for use in treatment of other types of cancer. So, regardless of what the standard therapy or common clinical practice for your cancer may be, you should find out—through your healthcare team or your own research—how the therapy you are considering performed in phase III clinical trials. If you have a rare type of cancer, there may not be phase III trial information available. If phase III trial information is not available, you should consider results from randomized phase II trials, in which a new therapy is also tested against another accepted cancer therapy, but generally in smaller numbers of patients than in phase III trials. For additional information about types of trials, see the next page.

## Sources of information about ongoing clinical trials

- American Cancer Society: [www.cancer.org](http://www.cancer.org) or 1-800-ACS-2345\*\*
- Association of Cancer Online Resources: [www.acor.org](http://www.acor.org)\*
- Centerwatch: [www.centerwatch.com](http://www.centerwatch.com)\*\*\*
- National Cancer Institute: [www.cancer.gov](http://www.cancer.gov) or 1-800-4-Cancer\*\*
- National Institutes of Health: [www.clinicaltrials.gov](http://www.clinicaltrials.gov)\*\*\*
- Oncolink: [www.oncolink.org](http://www.oncolink.org)\*
- Trial Check: [www.trialcheck.org](http://www.trialcheck.org)\*\*\*
- Pharmaceutical company Web sites: search under company or product name

\* Easiest to understand

\*\* Moderate medical content

\*\*\* Heavy medical content

## Sources of information about completed clinical trials

- American Cancer Society: [www.cancer.org](http://www.cancer.org)\*\*
- American Society of Clinical Oncology: [www.ASCO.org](http://www.ASCO.org)\*\*\*
- Cancer Consultants: [www.cancer411.org](http://www.cancer411.org)\*
- FDA-approved uses for cancer drugs: [www.fda.gov](http://www.fda.gov)\*\*
- National Comprehensive Cancer Network Treatment Guidelines: [www.nccn.org](http://www.nccn.org)\*\*
- Association of Community Cancer Centers: [www.accc-cancer.org](http://www.accc-cancer.org)\*\*
- NCI: [www.cancer.gov/clinicaltrials/results](http://www.cancer.gov/clinicaltrials/results)\*\*
- PubMed/Medline: [www.nlm.nih.gov](http://www.nlm.nih.gov)\*\*

\* Easiest to understand

\*\* Moderate medical content

\*\*\* Heavy medical content

# How to compare clinical trial results

If you are comparing results from different clinical trials for the treatment of patients with the same type of cancer, you should think about whether results from one trial are consistent with results from the other trials.

The following definitions provide important points you should become familiar with as you are researching your options:

- **Comparative therapy**—in randomized trials, one group of patients receives a standard therapy plus a new therapy
- **Time to disease progression**—length of time after diagnosis or beginning of treatment until the treatment was no longer effective or the cancer returned
- **Median survival**—a measure of the survival time from diagnosis or beginning of treatment until death
- **Response rate**—percentage of patients whose cancer shrank or disappeared after treatment
- **Side effects**—unwanted effects (toxicities) of the therapy

## Should you participate in a clinical trial?

Depending on the type or severity of your cancer, you may decide that the best course of treatment for you is to participate in a clinical trial for a new therapy. It is important to make this decision before starting any other treatment, because you may not qualify for certain clinical trials if you have already received treatment for your cancer. If your healthcare team does not mention this subject, you may want to ask him/her whether participating in a clinical trial is an option for you.

## Which types of oncology clinical trials are the most helpful?

- **Randomized phase III trials**—the “gold standard”—randomized phase III trials are the most strictly monitored. Because they are done in large numbers of patients, they give the best indication of how a treatment will work in clinical practice.
- **Randomized phase II trials**—next best thing to phase III trials. Because they usually involve a smaller number of patients, the results are less reliable than phase III results. These trials may or may not be comparative.
- **Non-randomized phase II trials**—generally do not include a comparison with a standard therapy. Result statistics are generally higher and not as reliable as results of phase III trials.
- **Phase I trials**—are often studies of a single drug, which generally look at how the drug can be given (dose, schedule, method) and the side effects. Although they may also look at the effectiveness of the therapy, they are usually not considered good evidence of this because they involve small numbers of patients.

# Finding the best therapy for you

As you are learning, there is no shortage of information about cancer therapy.

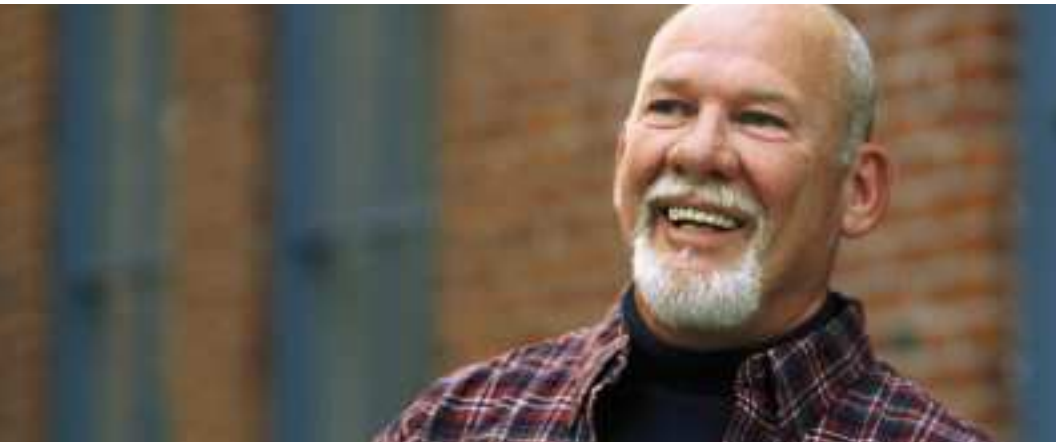
The question is, then, how to work with your healthcare team to identify from all the available information what therapy will work best for you.

## Step 1

As you explore the information sources provided in this booklet—as well as others you may discover—keep notes about your research. Think about each option you find as it applies to your individual situation and how well it meets your goal of therapy. Specifically, think about how well the therapy works, side effects, and the impact that treatment may have on your daily life.

## Step 2

Schedule an appointment to talk with your healthcare team about the results of your research and the treatment options you want to discuss. If you had someone helping you research, you might take your support person to the appointment with you—two heads are definitely better than one for remembering all the things you will be talking about. Another option is to tape-record your appointment with your healthcare team's permission. Prepare carefully for your appointment: write down questions, information you've discovered, and therapies that you are interested in, and arrive at your appointment ready to talk. After you talk with your healthcare team, one option may be clearly a better choice for you. The worksheets at the back of this booklet are meant for you and your healthcare team to use in discussions.



*Planning ahead helps me make sure I'm up for what lies ahead.*  
—Frank

# Continuing your research

If you find that the research process helps you, by all means continue with it once you have finished looking into your treatment options.

In addition to continuing to search for different therapies, you can find a wealth of information about survivor issues to help answer the question of what to do after your therapy is over. Also, there are many areas in which you can put your research experience to work—for instance, to help other cancer patients or in other volunteer roles.

## 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 the 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.

# Sources of information about cancer support groups

You are not alone in your efforts to manage your disease as well as you can. Many special organizations are dedicated to helping people who are living with cancer. A wealth of resources exists, and you probably will benefit from learning more about them.

Emotional support can be an important part of your medical treatment, too. It is important that you discuss any information you are interested in with your healthcare team. If you do not have access to the Internet, contact your local library for help. You may also call these organizations at the following toll-free numbers.

The following resources are independent from Eli Lilly and Company, and Lilly does not control the content.



*Sometimes, “taking action” means finding someone to talk to.  
—Natalie*

## 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)

*The questions in these worksheets can be useful in discussing treatment options with your healthcare team.*

## Treatment Comparison Worksheet—Option 1

1. What were the response rates shown by the therapy?

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2. What was the time to disease progression?

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3. What was the median survival?

---

4. What were the side effects?

---

5. Were the side effects better, worse, or the same as the therapy it was compared with?

---

6. How well do you think you will be able to tolerate the side effects, and how will they affect your life?

---

7. Were results similar in all of the trials?

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8. How many phase III clinical trials has this therapy been tested in?

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## Treatment Comparison Worksheet—Option 2

1. What were the response rates shown by the therapy?

---

2. What was the time to disease progression?

---

3. What was the median survival?

---

4. What were the side effects?

---

5. Were the side effects better, worse, or the same as the therapy it was compared with?

---

6. How well do you think you will be able to tolerate the side effects, and how will they affect your life?

---

7. Were results similar in all of the trials?

---

8. How many phase III clinical trials has this therapy been tested in?

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