

A guide to

# Some things you should know about side effects



## 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.*

# Table of Contents

You have a choice .....	2
Additional cancer therapy booklets .....	3
Therapy for the way you live .....	4
You have a voice .....	6
Tips for communicating effectively .....	7
Understanding your treatment options .....	8
Side effects .....	9
“Paper” side effects .....	10
“Patient-felt” side effects .....	12
Education and support contacts .....	15
Notes .....	18-19
Treatment comparison worksheets .....	20

# You have a choice

Because of advances in chemotherapy and supportive care medications, there are many ways to treat cancer. In fact, clinical studies have shown that for many types of cancers there are several drugs that are similarly effective. Their primary differences lie in the side effects they produce.

Virtually no two people experience chemotherapy side effects exactly the same way. This is because people sometimes respond differently, even to treatment with the same drug, but chiefly because different chemotherapy drugs cause different side effects.

This is good news for patients about to undergo chemotherapy. Good news, because it means you can work with your doctor to help determine a course of treatment with side effects that you are able and willing to live with. You should be aware that patients who choose a more aggressive therapy may experience more side effects or more severe side effects.

## **Additional cancer therapy booklets**

Information booklets from Lilly Oncology are available to help you understand the cancer you have, to help you 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 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 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 or combinations of treatment, or deciding whether you want to undergo further treatment.

# Therapy for the way you live

For some people, a side effect such as hair loss might be particularly hard to cope with. Or perhaps the pace of your day-to-day life would magnify the fatigue associated with some drugs. By carefully reviewing with your doctor the various treatment options you may have, it may be possible to avoid or minimize side effects that would be especially burdensome.

Side effects such as hair loss, fatigue, nausea and vomiting, and others commonly associated with chemotherapy will be referred to in this brochure as “patient-felt” side effects, meaning that you are aware of them if or when they occur. There is another group of side effects, which will be referred to here as “paper” side effects because you may not be aware of them, even though they can affect your health. They will, however, be monitored and managed by your physician. Some of the most common side effects from each group are defined later in this brochure.

Once you and your doctor make a decision about your treatment, it is important that you continue to work as a team to monitor potential side effects. You will be able to more quickly identify “patient-felt” side effects, while your doctor will be monitoring for the “paper” side effects. Both types of side effects could be serious if not treated, so please be sure to keep talking with your healthcare team.



*One “side effect” of cancer was finding courage I didn’t know I had.  
—Lee*

# You have a voice

The key to receiving treatment that is right for you is to participate in the decision-making process. For some types of cancer, there is one clear choice of therapy. More often, though, you will be able to talk with your doctor about different possible drug treatments before you decide on a course of therapy. This will make it possible for you to predict, to some degree, the side effects you'll experience.

Your doctor's first concern is to provide treatment that will effectively combat your cancer. Many doctors may turn first to a drug regimen they are most familiar with or that is most convenient to monitor, with consideration of side effects being a secondary concern.

It is important for you to understand your doctor's rationale for a recommended treatment and to discuss the pros and cons of alternative treatments if they are available. Remember that it is *your* therapy, and you are the one who has to live with the side effects it causes. You are entitled to ask questions and receive clear answers. If your doctor doesn't want to discuss available options or insists on one direction only, you may want to consider seeking a second opinion or speaking with another member of your healthcare team, such as the nurse or pharmacist. Building a comfortable relationship with your healthcare team is an important part of your cancer care.

## 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 or communicating your needs.
3. If you bring books, articles, or information you have printed from the Internet to your appointment, highlight the 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.



*With my treatment team, I feel surrounded by friends.  
And you can never have too many friends.  
—Isabel*

# 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 you and your doctor have agreed upon. 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.

Ask your doctor to talk with you about at least two treatment options. Be sure to ask your doctor questions about how each therapy relates to your goal of therapy. Use the worksheets on pages 20 and 21 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.

# Side effects

Following are some of the chemotherapy side effects you may experience, depending on the type of treatment you receive. Keep in mind that, while some can be permanent, many side effects are temporary. Most will generally disappear once your treatment with chemotherapy stops.

You will be able to more quickly identify “patient-felt” side effects, and your doctor should monitor for the “paper” side effects. Both types of side effects could be serious if not treated, so please be sure to talk with your healthcare team about both types before you make your decision.

Even though many of these side effects may be tolerable and even manageable, there are a few of them that, if severe, may make it necessary to interrupt or stop therapy. Once you begin your therapy, it’s important that you let your healthcare team know if you think you may be experiencing a side effect.

It’s important to discuss with your doctor, before you begin treatment, the potential side effects associated with the treatment options you are considering, so that you can make an informed treatment decision.

## “Paper” side effects may occur without you being aware of them.

Generally speaking, “paper” side effects refer to laboratory test results that are outside the range of normal. Abnormal results can be caused by the effects of chemotherapy or by the cancer itself. Chemotherapy drugs have an effect on rapidly dividing cells in the body, which in addition to cancer cells include such areas as the mucous membranes, hair, and blood. Chemotherapy drugs must also be eliminated by the kidney, liver, or both. Therefore, blood tests to monitor the levels of blood cells, as well as kidney and liver function, are routinely done before chemotherapy is given. Blood tests will also be done to see whether any imbalances exist in your electrolyte levels (concentrations of certain minerals in your blood, such as sodium and potassium). All these levels will continue to be monitored by your doctor throughout treatment.

Although you may not be aware of “paper” side effects, your doctor will monitor for them throughout your treatment. After you have made your therapy decision and started your therapy, it is important that you work closely with your healthcare team to manage any side effects because they could be serious if not treated.

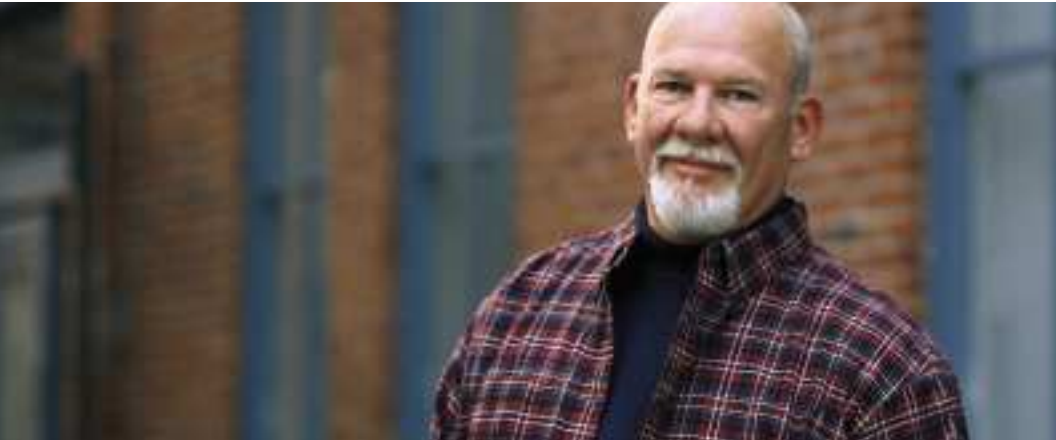
**Blood cells**—Chemotherapy can affect blood cells in a number of ways:

- **Anemia**—A low number of red blood cells. If the red blood cell count drops low enough, a patient feels fatigue or dizziness. There are medicines available that can minimize the severity of anemia.

- **Neutropenia** (leukopenia)—A low number of white blood cells. A patient usually does not feel direct effects of this, unless infection—with or without fever—develops. There are medicines available that can minimize the severity of neutropenia.
- **Thrombocytopenia**—A low number of platelets (a type of blood cell associated with clotting). This is generally not noticeable but may sometimes be associated with abnormal bleeding (nosebleeds, rectal bleeding, gums bleeding) or bruising.

**Kidney** (renal)—Some anticancer drugs can irritate the bladder or cause temporary or permanent damage to the kidneys. Dysfunction can be detected by blood tests.

**Liver** (hepatic)—Liver function may be affected by some chemotherapy drugs. Dysfunction can be detected by blood tests.



*Knowing what to expect helps me feel more in control of my cancer — and my life.  
—Frank*

## “Patient-felt” side effects are ones you are generally aware of if they occur.

You will usually be aware of “patient-felt” side effects if they occur. If any of these potential side effects are worrisome to you, be sure to discuss the subject with your doctor before making a treatment decision. After you have decided on a course of therapy, it is important that you continue to work closely with your healthcare team to manage any side effects because they could be serious if not treated.

**Constipation**—Occurs with some chemotherapy drugs, but can usually be controlled with diet and/or laxatives.

**Diarrhea**—May occur when chemotherapy drugs affect the lining of the intestines, but can usually be treated with over-the-counter or prescription antidiarrhea drugs.

**Other gastrointestinal reactions**—Depending on the type of treatment, a patient may experience side effects ranging from weight loss and anorexia (loss of appetite) to weight gain.

**Fatigue**—Including asthenia (feeling of weakness or lack of bodily strength). Tiredness is one of the most common side effects of chemotherapy. It can range from feelings of mild fatigue to feeling completely exhausted.

**Fever/Chills**—Chills and sweating, as the body tries to control its temperature, are often the first symptoms of infection. Some drugs may cause fever and chills without infection.

**Fluid retention**—Some chemotherapy drugs cause the body to retain fluid, which causes swelling or puffiness in the face, hands, feet, or abdomen.

**Hair loss (alopecia)**—Not all chemotherapy drugs cause hair loss. Some cause only thinning while others can cause the complete loss of hair including body hair. Hair loss from chemotherapy is usually temporary.

**Hand-foot syndrome**—Hand-foot syndrome may take the form of numbness, tingling, reddening, swelling of the hands and feet, or peeling of the skin.

**Heart (cardiac)**—Some chemotherapy drugs may have short- or long-term effects on the heart, including high or low blood pressure. Some effects, such as arrhythmias (irregular heart rates), are noticeable to the patient, while others may go unnoticed but usually can be detected and treated by the doctor.

**Hypersensitivity reactions**—These are primarily allergic reactions caused by an exaggerated immune response to chemotherapy, which usually take the form of a rash or shortness of breath. In rare instances, these reactions may be severe and require emergency care.

**Lung (pulmonary)**—Impaired lung function, usually accompanied by shortness of breath, is a side effect of some chemotherapy drugs and is usually temporary. Rarely, lung damage that is more severe may be permanent.

**Mouth sores**—Chemotherapy may irritate mucous membranes (mucositis) and lead to mouth sores (stomatitis). It can also affect the lining of the throat (esophagitis) or stomach (gastritis) and can also be a cause of diarrhea.

**Muscle pain/Joint pain (myalgia/arthritis)**—Some patients experience generalized, nonspecific pain or tenderness of muscles or joints.

**Nausea and vomiting**—Two of the most common side effects of chemotherapy. Usually nausea and vomiting start a few hours after treatment and last a short time, although some people experience more prolonged effects. Anti-nausea medicines are usually given when a drug known to cause nausea or vomiting is used. Some that are taken before or at the start of treatment can minimize or prevent these effects.

**Nerve damage (neurosensory/peripheral neuropathy)**—Certain chemotherapy drugs can cause damage to the nerves and result in symptoms, especially in the legs and hands, such as pain, a tingling sensation, or loss of sensation. Other symptoms may include loss of balance or hearing loss. Though these effects are generally temporary, in some instances they may be cumulative.

**Sexual/Reproductive**—Chemotherapy may have direct and indirect effects on sexual function and fertility for men and women. It is important that the patient discuss these potential effects with his/her doctor prior to treatment. In most instances, the patient will require family-planning measures.

**Skin**—Rashes and dry skin are common occurrences. Some patients may experience minor skin rashes or darkening of some areas of the skin or nail beds. Less commonly, loss of fingernails and/or toenails may occur.

# Education and support contacts

As a convenience, contact information is provided for the organizations listed on pages 16 and 17. 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 may be useful to you in your discussions with your healthcare team.



*The more I learn about my cancer, the more I learn how to live with it.  
—David*

## 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)





# 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?

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4. What are the potential benefits of this treatment?

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

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6. What are the potential side effects?

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

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

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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?

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4. What are the potential benefits of this treatment?

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

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6. What are the potential side effects?

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

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

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9. Does this option meet the goal of therapy?

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The International Society of Nurses in Cancer Care (ISNCC) endorses this educational offering. The approval of ISNCC does not imply product endorsement.



This booklet meets Oncology Nursing Society (ONS) guidelines for quality educational content. ONS endorsement does not constitute medical advice. Healthcare providers should exercise their own independent medical judgment.

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