



After Diagnosis

A Guide for Patients and Families



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A diagnosis of cancer presents many challenges. You probably have many questions about what it means to have cancer. Can my disease be cured? What are the best treatment options? Will treatment hurt? How long will treatment take? Will I have to stay in a hospital? How much will it cost?

In this booklet, we provide the answers and information you need after you have been diagnosed with cancer, such as what treatment options are available and what questions you should ask your doctor. We also offer a description of the expectations you should have of the people and services that are available to help you cope with cancer. We hope this information will help you and your family manage some of the fears and concerns you may have.

This booklet provides general information and is not meant to replace advice from your doctor. Talking openly and honestly with your doctor is the best way to understand what is happening to your body and how treatment will try to control the disease.

Many other materials on various aspects of cancer and cancer treatment are available from the local office of your American Cancer Society, on our Web site at www.cancer.org, or by calling 1-800-ACS-2345.

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What Is Cancer?

Cancer is a group of many related diseases. All forms of cancer involve out-of-control growth and spread of abnormal cells.

Normal body cells grow, divide, and die in an orderly fashion. During the early years of a person's life, normal cells divide more rapidly until the person becomes an adult. After that, normal cells of most tissues divide only to replace worn-out or dying cells and to repair injuries.

Cancer cells, however, continue to grow and divide and can spread to other parts of the body. These cells accumulate and form tumors (lumps) that may compress, invade, and destroy normal tissue. If cells break away from such a tumor, they can travel through the bloodstream or the lymph system to other areas of the body. There, they may settle and form "colony" tumors. In their new location, the cancer cells continue growing. The spread of a tumor to a new site is called metastasis. When cancer spreads, though, it is still named after the part of the body where it started. For example, if prostate cancer spreads to the bones, it is still called prostate cancer, and if breast cancer spreads to the lungs, it is still called breast cancer.

Leukemia, a form of cancer, does not usually form a tumor. Instead, these cancer cells involve the blood and blood-forming organs (bone marrow, lymphatic system, and spleen) and circulate through other tissues where they grow.

Not all tumors are cancerous. Benign (noncancerous) tumors do not metastasize and, with very rare exceptions, are not life threatening.

Cancer is classified by the part of the body in which it began and by its appearance under a microscope. Different types of cancer vary in their rates of growth, patterns of spread, and responses to different types of treatment. That's why people with cancer need treatment that is aimed at their specific form of the disease.

Most cancer falls into five major groups. Within each group there are subtypes.

- **Carcinoma** is a cancer that develops from cells that cover the surface of the body (skin), glands (breast, prostate), and internal organs (lungs, stomach, and intestine). Eighty to ninety percent of all cancers fall into this category.
- **Sarcoma** is a cancer that occurs in connective tissues such as bones, tendons, cartilage, fat, and muscle.
- **Leukemia** is a cancer that develops from cells in bone marrow that make blood.
- **Lymphoma** is a cancer that develops from cells in the immune system. Hodgkin's disease (Hodgkin's lymphoma) and non-Hodgkin's lymphoma are in this group.
- **Myeloma** is a cancer that develops in the plasma cells of bone marrow.

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Who Gets Cancer?

More than one million people get cancer each year. Approximately one of every two American men and one of every three American women will have cancer at some point during their lifetimes. Anyone can get cancer at any age; however, about 77% of all cancers occur in people over the age of 55.

Although cancer occurs in Americans of all racial and ethnic groups, the rate of cancer occurrence (often called the incidence rate) will vary from group to group. Overall, African Americans are more likely to develop cancer than whites. African Americans are also more likely to die of cancer than whites. Much of this difference is because African Americans are more likely to be diagnosed at a later stage of disease.

Today, millions of people are living with cancer or have been cured of the disease. The sooner a cancer is found, and the sooner treatment begins, the better a patient's chances are of a cure.

What Are the Risk Factors That Can Lead to Cancer?

A risk factor is anything that increases a person's chance of getting a disease. Different cancers have different risk factors. For example, unprotected exposure to strong sunlight is a risk factor for skin cancer. Smoking is a risk factor for cancers of the lung, mouth, larynx, bladder, kidney, and several other organs. Smoking causes almost one-third of all cancer deaths.

Having one or more risk factors, however, does not necessarily mean that a person will get the disease. Some people with one or more cancer risk factors never develop the disease, while other people who do develop cancer have no apparent risk factors. Even when a patient has a risk factor, there is no way to prove that it actually caused the cancer.

There are different kinds of risk factors. Some, like a person's age or race, can't be changed. Others are linked to cancer-causing factors in the environment. Still others are related to personal lifestyle choices such as smoking, drinking, and diet.

Research shows that about one-third of all cancer deaths are related to dietary factors and lack of physical activity.

The American Cancer Society estimates that this year about 170,000 cancer deaths will be caused by tobacco use, and about 19,000 cancer deaths may be related to excessive alcohol use, frequently in combination with tobacco use.

Research shows that about one-third of all cancer deaths are related to dietary factors and lack of physical activity.

Risk of breast cancer relates to several factors that affect hormone levels throughout life, such as age at first menstrual period, number of pregnancies, obesity, and physical activity. Some studies have also shown a connection between alcohol consumption and an increased risk of breast cancer.

While all men are at risk for prostate cancer, several factors can increase the chances of developing the disease, such as age, race, and diet. The chance of getting prostate cancer increases

with age. Prostate cancer is more common among African American men than among white men. We do not yet know why this is so. A high-fat diet may play a part in causing prostate cancer. Also, men with close family members who have had prostate cancer are more likely to get prostate cancer themselves.

Environmental factors that are known to cause cancer include some viruses (most viruses do not cause cancer, and unlike viral infections, cancer is not contagious), radiation (from sources such as the sun and radon), asbestos, benzene, and formaldehyde.

Can Cancer Be Inherited?

Many people believe that cancer runs in families. They think that if one family member has it, others are likely to get it. Most people with cancer have not inherited the disease, nor do they pass it on to their children.

People whose close blood relatives have certain types of cancer may be at increased risk for those cancers. Examples of this include a small percentage (5%) of people with breast cancer, colon cancer, prostate cancer, ovarian cancer, a type of skin cancer called melanoma, Wilms' tumor (a kidney cancer of children), and retinoblastoma (an eye cancer of children). In these cases, the risk of developing cancer may be increased by other factors such as poor diet, hormone changes, and exposure to cancer-causing substances. These factors plus a family history of melanoma, breast, or colon cancer can put certain people at a slightly higher risk of getting cancer. However, just because someone in the family has cancer doesn't mean that someone else in the family will develop cancer. For example, 95% of women diagnosed with breast cancer do not have a family history of breast cancer.

Why Me?

Often one of the first questions most people ask after they have been diagnosed is, “What did I do?” or “Why me?” Since doctors cannot say for sure what causes cancer, many people have their own ideas about why they have the disease. Some people believe they are being punished for something they did or failed to do in the past. Some people think that if they had done something differently, they could have prevented the disease. Most people wonder if they caused the cancer themselves.

All of these thoughts or beliefs are common, but cancer is not a punishment for your past actions. It is much harder to cope with the disease if you blame yourself for getting it. The important thing is to focus on taking care of yourself now.

Am I Going to Die?

More than half of all the people diagnosed with cancer will be cured by today’s treatments. Each cancer is different. Some cancers are simple to treat. Others are more difficult. Progress has been made in effectively treating many forms of cancer. Many people recover completely, while others live for years with their cancer well controlled.

The fact is that most cancers can be treated. Remember that over half of the people who get cancer today will survive.

Even the people who are not cured often carry on with little change in their lives. Cancer for these people is an ongoing illness that might be compared to diabetes. When people with

diabetes watch their diets and take their medicine, they lead normal lives. Many people still believe that “cancer equals death.” But, the fact is that most cancers can be treated. Remember that over half of the people who get cancer today will survive. There are approximately nine million cancer survivors in America today. That number is growing because more people are living with cancer than are dying from it.

How Do I Cope?

At first, most people feel tremendous emotional upheaval after being diagnosed with cancer. They may experience many painful feelings such as disbelief, shock, fear, and anger. It is hard to absorb all of the information about the cancer with all the feelings that are going on. It takes time to accept and understand the diagnosis. Many cancer survivors say that being diagnosed with cancer gave them a chance to look at their lives and find strengths and abilities that they did not know they had. Many survivors say that the experience has actually improved the quality of their lives.

People cope with cancer just like people cope with many other problems in life – very differently. Over time, most people come to terms with the reality of living with a diagnosis of cancer. After the initial shock of diagnosis and the beginning of treatment, most people find that they are able to continue their normal lives. They learn to adapt and continue on with work, entertainment, and social relationships. Of course there are times when finding strength is hard and the situation feels overwhelming. When people need help coping, there are many resources to turn to.

As you try to find a way of coping that works for you, you may want to consider some of the following suggestions:

- **Build your knowledge base.** Some people find that learning as much as they can about their diagnoses and treatments gives them a sense of control over what happens. Along with your health care team, we can give you reliable information about cancer and put you in touch with other resources.
- **Express your feelings.** Many people discover that giving some kind of expression to their feelings helps them maintain a positive attitude about treatment. Some people feel that expressing sadness, fear, or anger is a sign of weakness. In fact, the opposite is often true; it is much more difficult to express complex, powerful emotions than it is to try to hide them. Hiding your feelings can also make it harder to find an effective way to cope with them. There are many ways to express your feelings; find one that is most comfortable for you. You might choose to talk with trusted friends or relatives, keep a private journal, or even express your feelings through painting or drawing.
- **Take care of yourself.** Take time to do something you enjoy every day. Prepare your favorite meal, spend time with an uplifting friend, watch a movie, meditate, listen to your favorite music, or do whatever you find most enjoyable.
- **Exercise.** If you feel up to it, and your doctor agrees that you're ready, start a mild exercise program such as walking, yoga, swimming, or stretching. Exercise can help you feel better about your body.
- **Reach out to others.** There will be times when finding strength is hard and the situation feels overwhelming. You may feel as if you can't do this all by yourself. If you are comfortable doing so, widen your circle of resources by reaching out to friends, family, or support organizations. These people can help you remember that you're not alone

on this journey. They will be there to share your fears, hopes, and personal accomplishments, every step of the way.

There is currently no research that proves a person's attitude will guarantee survival. Certainly, a positive attitude will affect the quality of your life, since people who feel positive and hopeful are happier than those who feel hopeless. But having a positive attitude does not mean that you and your loved ones should never feel sad, stressed, or unsure. What helps more is if you admit and deal with these painful feelings. Hiding feelings will actually keep you from being able to feel hopeful, positive, and more in control of your life. Also, those who believe that a positive attitude is the key to their survival may blame themselves if their disease returns. Cancer is a very complex disease, and people's attitudes don't cause or cure cancer.

People with cancer do not become hopelessly depressed. Just after learning they have cancer, they may go through a time of grief or mourning. This may seem like depression, but it really is not. People mourn for the loss of themselves as a healthy person and for the loss of certainty in their lives. This grieving time is not the same as clinical depression. It is often over soon, and it is a normal way to react when learning about a serious health concern.

People's attitudes don't cause or cure cancer.

When someone's emotional upset or sadness lasts over weeks or gets in the way of day-to-day things, they may have clinical depression. About one in four people with cancer will develop clinical depression, which causes greater worry and less ability to function and follow medical regimens. Talk with your doctor if you have concerns about depression.

Treatments for depression in people with cancer include medicines, counseling, a combination of both, and sometimes other special treatments. Treatment for depression not only helps people feel better but also helps them regain a sense of control and hope for the future.

How Do I Talk to People About My Diagnosis?

Your Family

You and your family can and should expect certain changes. Cancer affects the entire family, not just the person who has been diagnosed. People in your family may sometimes try to protect you or other family members from upsetting news or events. The wish to protect loved ones is understandable, but often protecting others is impossible. It may even use up energy. When you let family members know what is happening to you, they will be able to understand your challenges, provide support, and help you make informed decisions. They will also gain a greater sense of control when you give them information.

When someone has been diagnosed with cancer, family roles and routines may change. For example, your family may need to help with jobs you once handled alone. If changes need to be made in the family routine, everyone needs to talk about these changes. You may not be able to do all that you used to do. You may want to be independent, or you may be afraid that you will become a burden to your loved ones. Continue to do as much as you did before if there is no medical reason to stop. Allow the family to maintain a normal life while you are receiving treatment. It's healthy for the family to keep doing the things they always did (playing bridge, fishing, exercising, playing basketball, for example).

Dealing with Unexpected Feelings

Even in the most loving families, members sometimes feel resentment when one member is ill and cannot maintain the same responsibilities for awhile. This is especially true when the situation lasts for a long time. Family members may blame you for your illness. Realize that you may be a target for anger but that you are not the cause. It is common for family members to feel angry because their lives are changing. The best thing you can do for each other is to be honest about what you are feeling. People often have fears about the future. Once you share these feelings, most people find it easier to move forward. They feel free from the burden of unspoken fears and concerns.

Sometimes you and your loved ones will feel out of step with each other. For example, you may feel quite hopeful while your spouse is feeling scared, or the opposite may be true. This may be upsetting, but remember that people react differently to stressful situations. Everyone copes in a different way. Their experiences and personalities affect how they will react to problems. Some family members may become more absorbed in work, some may become over-involved by gathering every piece of information, while others may engage in activities outside the home. Talking about differences will help you respect and understand each other and work together. It is human nature to want to avoid situations and feelings that cause pain. However, ignoring painful feelings will only make things worse.

New Relationships

If you are single when you are diagnosed and recovering from cancer, you may be unsure how and when to tell a new romantic partner. Only you can know if and when you trust someone enough to share this part of you. Whether you tell

someone early in a relationship or later on is up to you. You may find it helps to practice what you will say with a friend before sharing with your new partner.

Talking with Children About Cancer

If there are young children in your family, you may wonder how they will cope with your cancer. How a child reacts very much depends on how the adults are handling the situation. Children understand through adults what is happening in their world. While we may know this, it can be very stressful, since adults can have very powerful feelings of their own. If children are not given an honest explanation, they will come up with their own conclusions. However, both adults and children can and do learn to cope with cancer and its treatments. When talking to children about cancer you should give them simple yet accurate information they will understand. It is best to share the information in small doses that are age appropriate. Be sure to give children the opportunity to ask and have their questions answered. You may also want to have a social worker or school psychologist talk with the child. They may know of support groups for children in your area.

Your Friends

The decision to discuss your cancer diagnosis with friends is yours alone. However, it is usually best to be honest with people close to you about your cancer. Keeping it a secret can cause you more stress at a time when you could use the support of others. At some point your friends will learn about your cancer. When they do, they are likely to feel hurt and left out if you do not tell them. Before you talk to others about your illness, consider your own feelings, your reasons for telling them, and your expectations of them. Be prepared for a wide variety of reactions. People often don't know what to say. They may act uncomfortable or feel awkward. They may feel sad and be

afraid of upsetting you. They may withdraw or distance themselves. People may react in hurtful ways because of their own fear or lack of information. Some people find it easier to talk, and still others may become overly considerate. Most likely, your friends will want to help you, so be prepared to tell them how they can help. Help may include such things as transportation to and from the clinic, buying groceries, or pet sitting.

Don't be afraid to educate people about what's happening with you. Explain what kind of cancer you have and the treatments you'll need. Tell them that cancer is not a death sentence, nor is it contagious. Find out what they think and how they feel, and try to answer their questions. Try to be direct with others and express your needs and feelings openly. It is generally more stressful to hide emotions than to express them. Sharing with other people can be helpful to both you and those close to you.

How Is Cancer Treated?

The number of treatment choices you have will depend on the type of cancer, the stage of the cancer, and other individual factors such as your age, health status, and personal needs. You and your cancer care team should discuss which treatment choices are best for you.

A cancer diagnosis almost always makes people feel they must get treatment as soon as possible. However, you have time to consider all the options available to you so you will be as well informed as possible.

The four major types of treatment for cancer are surgery, radiation, chemotherapy, and biologic therapies. You might also have heard about hormone therapy (such as tamoxifen) and bone marrow transplants.

What Is the Goal of My Cancer Treatment?

Cancer treatment is based on your unique situation. The type of cancer you have, the stage or extent of the disease, and your overall health are important factors to consider when treatment is planned. Not all types of treatment may be effective in your situation. Before starting treatment, ask about the goal of treatment. Will the treatment provide a cure or be palliative? The goal of palliative care is to make the patient comfortable while easing symptoms of the cancer. Sometimes the goal of the treatment may change once treatment has begun.

Remission is a period of time when the cancer is responding to treatment or is under control. In a complete remission, all the signs and symptoms of the disease disappear. It is also possible for a patient to have a partial remission in which the cancer shrinks but does not disappear. Remissions can last anywhere from several weeks to many years. Complete remissions may continue for years and be considered cures. If the disease returns, another remission often can occur with further treatment. A cancer that has recurred may respond to a different type of therapy, including a different drug regimen.

What Is Staging?

Staging is the process of finding out how far the cancer has spread. This is very important because the choice of treatment and the outlook for recovery depend on the stage of the cancer.

There is more than one system for staging. The TNM system is the one used most often. It gives three key pieces of information:

T describes the size of the tumor, and whether the cancer has spread to nearby tissues and organs.

N describes how far the cancer has spread to nearby lymph nodes.

M shows whether the cancer has spread (**metastasized**) to other organs of the body.

Letters or numbers after the T, N, and M give more details about each of these factors. To make this information somewhat clearer, the TNM descriptions can be grouped together into a simpler set of stages, labeled stage 0 through stage IV (0-4). In general, the lower the number, the less the cancer has spread. A higher number, such as stage IV (4), means a more serious cancer.

After looking at your test results, your doctor will tell you the stage of your cancer. Be sure to ask your doctor to explain your stage in a way you understand. This will help in making treatment decisions.

Surgery

Surgery is often the first treatment choice for many cancers. Many people with cancer have surgery. If the cancer appears localized (contained to one area), surgery may be used to remove it along with any surrounding tissue that might contain cancer cells. Sometimes it is difficult to tell how much surgery will be needed until the surgeon sees the extent of the cancer during the operation. Success of surgery depends on whether or not the tumor has spread to other areas. Today, surgery offers the greatest chance for cure for many types of cancer.

Other treatments, such as radiation therapy and chemotherapy, may be used along with surgery. They may be given before or after the surgery depending on the individual case.

Radiation Therapy

Like surgery, radiation therapy is used for cancers confined to one location (localized). Radiation therapy is used to destroy or damage cancer cells so that they cannot multiply. It can be used alone, or in addition to surgery or chemotherapy. More than half of all people with cancer have radiation treatment at some point.

Radiation therapy is given either through external high-energy rays or through internal implants. External radiation therapy is painless, like having an x-ray picture taken. It is usually given in an outpatient setting. Treatment typically lasts five days a week for five to eight weeks, depending on the size, location, and type of cancer being treated.

In some circumstances, radiation may be given through implants. These are small containers of radiation placed in or near the tumor while a person is under general or local anesthesia. They allow a person to receive a higher total dose of radiation to a smaller area and in a shorter amount of time than with external radiation.

Radiation implants are sometimes used for cancers of the prostate, head and neck, uterus, and cervix. Some implants can be placed in the body at an outpatient center, while some may require that the person stay in the hospital for a few days. Implants do not generally cause severe pain; however, there may be some discomfort if the implant is held in place by an applicator. Once an implant is removed, there is no radioactivity (radiation emitted) in the body.

Side Effects of Radiation Therapy

Side effects vary from patient to patient and depend on the part of the body being treated and the amount of radiation used. The most common side effects are fatigue, skin changes

in the area of treatment, and some loss of appetite. Other side effects usually are related to the treatment of specific areas, such as hair loss following radiation treatment to the head. Fortunately, most side effects will go away in time. In the meantime, your health care team will discuss with you ways to reduce the discomfort they cause.

For more information, you can get the booklet *Understanding Radiation Therapy: A Guide for Patients and Families* from your American Cancer Society.

Chemotherapy

While surgery and radiation therapy are used to treat localized cancers, chemotherapy is used to treat cancer cells that have spread, or metastasized, to other parts of the body. Depending on the type of cancer and its stage of development, chemotherapy can be used to cure cancer, to keep the cancer from spreading, to slow the cancer's growth, to kill cancer cells that may have spread to other parts of the body, or to relieve symptoms caused by cancer.

Chemotherapy is treatment with powerful anticancer drugs that are most often given by injection into a vein or by mouth. The drugs travel throughout the body in the bloodstream. Often, a combination of anticancer drugs is used because that has proven more effective than relying on a single drug.

Chemotherapy is given in cycles, each followed by a recovery period. Then another cycle of treatment is followed by a recovery period, and so on. The total course of chemotherapy is often about six months, usually ranging from three to nine months. After a cancer is removed by surgery, chemotherapy can significantly reduce the risk of cancer returning. The chances of cancer returning and the potential benefit of chemotherapy depend on the type of cancer and other individual factors.

Side Effects of Chemotherapy

Side effects of chemotherapy depend on the type of drugs, the amount taken, and the length of treatment. The most common are nausea and vomiting, short-term hair loss, increased chance of infections, and fatigue. Some side effects may be harder to cope with, while others may be mild. Most side effects can be controlled with medications, with supportive care measures, or by changing the treatment schedule. Because some side effects may require immediate medical attention, let your doctor know about any side effects you experience.

Fatigue is one of the most common side effects of radiation and chemotherapy. Like most other side effects, it will disappear once the treatment is complete. You can help yourself by getting enough rest, eating a well-balanced diet, drinking plenty of liquids, and planning your activities to include frequent rest periods.

Another concern people have is about hair loss. It is normal for people to feel distressed about hair loss. Some people experience hair loss during chemotherapy treatments (and sometimes with radiation treatment to the head) while others do not, even with the same drugs. Not all drugs cause hair loss. When it does occur, the hair almost always grows back after the treatments are finished. If hair loss does occur, it usually begins within two weeks of the start of therapy and gets worse one to two months after the start of therapy. Hair regrowth often begins even before therapy is completed. Most people are able to find suitable ways of managing the hair loss with special hats, scarves, and wigs.

People receiving chemotherapy sometimes become discouraged about the length of time their treatment is taking or the side effects they are having. If that happens to you, talk to your doctor. There are ways to reduce the side effects or make them

easier to manage. Keep in mind that the expected benefits of the treatment should outweigh any problems you might have.

For more information, you can get the booklet *Understanding Chemotherapy: A Guide for Patients and Families* from the American Cancer Society.

Biologic Therapies

There is a lot of evidence that suggests that the immune system plays a major role in the body's response to cancer. At least some forms of cancer occur when the body's natural defenses, the immune system, fail to destroy cancer cells or to prevent their growth. Biologic therapy is a promising new treatment for certain cancers. It is sometimes called immunotherapy, biotherapy, or biological response modifier therapy. Biologic therapies use the body's immune system to fight cancer or lessen the side effects of some cancer treatments.

Biologic therapies can act in several ways in cancer treatment. These include stopping or slowing cancer cell growth, acting indirectly to help healthy cells – particularly immune cells – control cancer, and helping to repair normal cells damaged by other forms of cancer treatment.

There are several kinds of biologic therapy now in use. You may hear terms such as interferons, interleukins, or tumor necrosis factor. More than one kind may be used, or biologic therapy may be combined with chemotherapy or radiation therapy.

Complementary and Alternative Therapy

You may hear terms such as questionable, unorthodox, unconventional, holistic, natural, or herbal used to describe these therapies. People use these words to mean different things. Standard or conventional treatment refers to

mainstream medical treatments that have been tested following a strict set of guidelines and found to be safe and effective. Alternative therapy refers to treatments that have not proven to be effective in treating a particular disease and are taken instead of conventional treatment. Examples of these include hydrogen peroxide therapy, hydrazine sulfate, and essiac tea.

Complementary therapy refers to supportive therapies that are used along with conventional treatments. Examples include relaxation training, acupuncture, and biofeedback. Complementary methods do not cure disease; rather they help control symptoms and improve well-being. Integrative therapy refers to the combination of mainstream and complementary methods.

Integrative medicine is safest and most effective when it is supervised by your doctor. Some herbal extracts (like echinacea, ginkgo, or valerian root) can actually be very potent or even dangerous, especially in combination with other medications. So be sure to talk to your doctor about any therapy you are considering. There are many complementary methods you can safely use along with standard treatment to relieve symptoms or side effects, to ease pain, and to help you enjoy life more. Complementary methods that some people have found helpful when used along with medical treatment include aromatherapy, art therapy, biofeedback, massage, meditation, music therapy, prayer, t'ai chi, and yoga. However, be wary of any method that claims it can cure cancer.

Clinical Trials

Clinical trials are carefully designed research studies in humans that test new ways to treat specific types of cancer. They often involve the evaluation of a new cancer drug or a new combination of existing drugs. Some clinical trials compare the best known standard therapy with a newer

therapy to see if one produces a better response and causes fewer side effects than the other. Investigational treatments are therapies being studied in a clinical trial.

A new treatment must withstand a demanding process in order for it to become an accepted standard treatment. It must go through preclinical testing in animals to determine safety and effectiveness before it can be tested in humans. Then, there is a strict three-stage evaluation process the new drug or treatment goes through in humans before it is accepted as standard treatment.

In the first phase, the treatment is given to a small number of people to answer questions about dosage. If testing goes well, phase II treatment is given to a larger group of people to answer questions about side effects and effectiveness. If the treatment appears effective, it then enters phase III testing. This phase compares the standard therapy for specific cancers to the new therapy and involves a much larger number of people.

Sometimes people are afraid to participate in clinical trials because they don't want to be "guinea pigs." However, by the time a new drug or treatment has reached the clinical trial stage, it has gone through much testing and review. People who take part in clinical trials are not denied any regular treatment and might actually benefit more from the treatment being evaluated.

No one involved in the study knows in advance whether the treatment will work and what unexpected side effects may occur. That is what the study is designed to discover. While most side effects will disappear in time, some can be permanent or even life threatening. Also, keep in mind that even standard treatments have side effects and that the disease you have can reduce the length or quality of your life.

Participation is completely voluntary. Your doctors and nurses will explain the study to you in detail and will give you a form to read and sign, indicating your understanding and your desire to take part. This is known as giving your “informed consent.” Even after signing the form and after the trial begins, you are free to leave the study at any time for any reason.

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The National Cancer Institute (NCI) funds most clinical trials through cancer centers or networks made up of research institutions, university and community hospitals, and clinics associated with them. Ask your oncologist to find out about any clinical study that may benefit you. You can get more information about clinical trials studying your type of cancer by calling NCI’s Cancer Information Service at 1-800-4-CANCER, visiting their Web site at www.cancer.gov/clinical_trials/, or calling the American Cancer Society at 1-800-ACS-2345.

To find out more about clinical trials, talk to your cancer care team. Among the questions you should ask are:

- What is the purpose of the clinical trial?
- What does the study involve? What kinds of tests and treatments? (Find out what is done and how it is done.)
- What is likely to happen in my case with, or without, this new research treatment? (What may the cancer do and what may the treatment do?)

- What are other choices and their advantages and disadvantages? (Are there standard treatments for my case, and how does the study compare with them?)
- How could the study affect my daily life?
- What side effects should I expect? What can be done about them?
- How long will the study last? Will it require an extra time commitment on my part?
- Will I have to be hospitalized? If so, how often and for how long?
- Will I have any costs? Will any of the treatment be free?
- If I am harmed as a result of the research, what treatment will I be entitled to?
- What type of long-term follow-up care is part of the study?

How Is Treatment Planned?

You may be concerned that extra appointments for tests and consulting with doctors will take up time that could be spent treating your cancer. How long is too long? Different types of cancer grow at different rates. Certain types of leukemias and lymphomas tend to grow more quickly. However, most cancers do not grow very quickly, so there is time to gather information about your cancer, consult with specialists, and make a decision about which treatment option is best for you. Talk with your cancer care team if you are concerned that treatment is not beginning right away.

The type of treatment you receive will depend on several factors. The type of cancer (including the location and cell type), the stage or extent of your cancer, and your overall health are the most important factors your cancer care team will consider when deciding on your treatment options. Other

factors that will be considered include your personal situation (including your ability to travel and participate in treatment), the effectiveness of each treatment in your situation, as well as possible side effects and risks of each type of treatment.

Gathering information about your cancer is the first step your cancer care team will take. A biopsy and other laboratory tests, physical examination, signs and symptoms, and imaging tests are used to determine the best treatment in your situation. Your doctor will use all of this information to select treatment options and make recommendations for treatment. He or she may consult with other specialists and with other health care professionals to help plan your treatment. You may also wish to get a second opinion at another treatment center. Often getting the opinions of more than one expert may help you feel more comfortable in selecting the best treatment option for you.

What Should I Ask My Doctor?

Your relationship with your doctor is a critical part of your care. Ideally you will have one doctor who coordinates all your care. This doctor should be someone you feel listens to your concerns and answers your questions thoughtfully and thoroughly. Your doctor will explain your diagnosis, health status, and treatment progress. There are also nurses working with your doctor who have specialized knowledge and skills to assist you with your treatment or any side effects you may have. In many cases, the nurse can answer your questions directly and will help you get the answers you need from other members of the health care team.

Like all successful relationships, your relationship with your doctor is a two-way street. It is your responsibility to ask questions and become educated about your treatment and health. Doctors differ in how much information they give to people with cancer and their families. Likewise, people who are

newly diagnosed also differ in the amount of information they need or want. It is up to you to tell your doctor if he or she is giving you too much or too little information. Doctors do not know what information you need unless you tell them. They will take their cues from you, so it is important to work on communicating with your doctor.

Your relationship with your doctor is a critical part of your care.

Make sure that all your questions, no matter how small, have been answered. It may take more than one visit to discuss all of your concerns since new questions may come to mind. It may be hard to remember everything your doctor says in your meetings. Some people find it helpful to take notes, bring a family member or friend, tape-record the conversations, and/or bring a prepared list of questions.

You have the right to a second opinion about your diagnosis and the recommended treatment. Asking for a second opinion does not mean that you don't like or trust your doctor. Doctors understand you need to feel that every possibility for the best treatment is being explored. You can also ask your doctor if he or she has consulted with other specialists at the treatment center.

Your doctor will discuss your treatment plan with you. The following are examples of questions to ask during the discussion:

- What type of cancer do I have? What is the stage or extent of my cancer?
- What is my prognosis (or outlook for the future), as you view it?

- What treatment do you recommend and why?
- What is the goal of treatment – cure or control of my symptoms?
- What are the possible risks or side effects of treatment?
- What are the pros and cons of my treatment?
- Are there other treatments for me to consider?
- How often will I need to come in for treatment or tests?
- How long will my treatments last?
- What if I miss a treatment?
- Will my life change? Will I need to make changes in my work, family life, and leisure time?
- What are the names of the drugs I will take? What are they for?
- What other drugs or treatments may I have to take?
- How will you know that my treatment is working?
- Why do I need a blood test and how often?
- If other specialists take part in my care, who will coordinate my entire treatment program?
- What symptoms or problems should I report right away?
- If I do not feel sick, does that mean the treatment is not working?
- What are the chances that my cancer may recur (come back) with the treatment programs we have discussed?
- What can I do to be ready for treatment?
- Will I still be able to have children after treatment?
- Are there any special foods I should or should not eat?
- Can I drink alcoholic beverages?

- What costs will I have?
- What is the best time to call you if I have a question?

Will I Have Pain?

Pain is one of the reasons people fear cancer so much. Having cancer does not mean you will have pain. Much progress has been made in pain control. Some cancers cause no physical pain at all. Even people with advanced cancers do not always have pain; however, if pain does occur, there are many ways to relieve or reduce it. In addition to medicines, there are other techniques to manage pain, such as imagery, biofeedback, relaxation, distraction, surgery, and nerve blocks. A combination of pain control methods can be used.

*Much progress has been made in pain control.
Some cancers cause no physical pain at all.
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have pain.*

Some people are reluctant to take medication for pain because they are afraid they will become addicted. Research has shown that people with cancer can take pain medications as long as needed, if used properly, without becoming addicted. People also worry that if they take their medications continuously, they will become “immune” to that dosage and need higher and higher doses until no dosage will work. In reality, increasing the dosage for most prescribed medications increases their effectiveness. You can get more information about pain control by calling your American Cancer Society.

Will I Be Able to Work During Treatment?

The answer to this question depends on the type of treatment, stage of cancer, your health status, and type of work you do. What you can and cannot do will depend on how you feel. Some people with cancer are able to go to work or enjoy leisure activities while they receive treatment. Others find that they need more rest than usual and, therefore, cannot do as much. Your doctor may suggest that you limit some activities.

Many people are able to continue working while they are receiving treatment. It may be possible to schedule your treatments late in the day or right before the weekend so they interfere with work as little as possible. If your treatment makes you very tired, you might want to think about adjusting your work schedule for a while. Speak with your employer about your needs and wishes at this time. You may be able to agree on a part-time schedule, or perhaps you can do some of your work at home. Under federal and state laws, some employers may be required to allow you to work a flexible schedule to meet your treatment needs.

Will I Be Able to Exercise During Treatment?

Your exercise routine during cancer treatment will depend on your physical condition, including the stage and type of your cancer, the type of treatment you will receive, the side effects you experience as a result of treatment, and your general health before you were diagnosed. Exercise, with adequate periods of rest built into your day, can be helpful for a number of reasons. It can boost your energy level, relieve stress, decrease anxiety and depression, and stimulate your appetite. You can also make a choice to exercise alone or with a group of friends.

Particularly if you enjoyed regular exercise before your diagnosis, exercise during cancer treatment may help you feel like some areas of your life are still “normal.” If you have surgery as part of your cancer treatment, movement after surgery is especially important to prevent complications and maintain range of motion in your joints and muscles. Be sure to speak with your doctor to help you determine activities and a schedule that are appropriate for you.

How Will Cancer Affect My Sex Life?

Sexual feelings and attitudes vary greatly among people under ordinary circumstances. This is also true during illness. Some people experience little or no change in their sexual desire and energy level. Others find that their sexual interest declines because of the physical and emotional stresses of having cancer and getting treatment. These stresses may include worries about changes in appearance; anxiety about health, family, or finances; or side effects, including fatigue and hormonal changes. However, some people find that they feel even closer to their partners and have an increased desire for sexual activity.

Sexual problems may occur for a number of reasons. Some common concerns are stress, fatigue, and low desire, as well as body image issues. Surgery for cancers in the pelvic or abdominal areas may affect sexual functioning. Vaginal dryness, erectile dysfunction (inability to have an erection), or painful intercourse may occur as a result of the side effects of some treatments.

If you were comfortable with and enjoyed an active sex life before starting therapy, chances are you will still find pleasure in physical intimacy during your treatment. You may find that being close takes on a new meaning and you relate differently.

Hugging, touching, holding, and cuddling may become more important, while sexual intercourse may become less important. You and your partner will continue to decide together what makes you happy and fulfilled.

A healthy sex life depends on many factors. Some people with cancer need to cope with changes in appearance or side effects, while others may need to work through negative thoughts or depression. There are several things that are important to consider. First of all, the most important part in resuming sexual activity with a partner is good communication. A partner's concerns or fears also can affect the sexual relationship. It is normal to have fears and concerns, and it is helpful to discuss them openly. Some may worry that having sex will harm the person who has cancer. Others may fear that they might "catch" the cancer or be affected by the radiation or chemotherapy. Talking about these things can clear up many misunderstandings. It will also help you find out what different things you can do to make your sex life enjoyable.

A healthy sex life also can be difficult to focus on when there are so many physical and emotional factors involved. Get as much information from your doctor and other resources as possible so that you have a full understanding of what you can and cannot do before, during, and after treatment. For more information, you may order the booklets *Sexuality and Cancer: For the Man Who Has Cancer and His Partner* and *Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner* from the American Cancer Society. (See page 40.)

Fertility

Women may find that their menstrual periods become irregular or stop after chemotherapy or radiation treatment. This does not mean that they are unable to become pregnant, so birth control may still be needed during treatment. In men,

the treatments may reduce or damage sperm cells. In many cases, fertility is restored after treatment is complete.

Whether you are a man or a woman, a discussion of fertility issues with your doctor will help you make treatment decisions that are best for you.

How Will I Pay for All of This?

The cost of treatment varies with the type of treatment, how long and how often it is given, and whether you are treated at home or in a clinic, office, or hospital. Most health plans, including Medicare Part B, cover at least part of the cost of many treatments. In many states, Medicaid may help pay for certain treatments. Before you begin treatment, find out whether your insurance company or Medicare will pay for your care.

If you are looking at insurance options, be aware of differences in coverage.

Check to see if you qualify for state or local benefits such as Medicaid if you are in a low-income bracket or are unemployed. If you are currently employed and are considering leaving your job, find out about conversion options through your current plan. Conversion options may allow you to switch from your employer's insurance plan to an individual plan with similar coverage. Many group plans have a clause for conversion to individual plans, although premiums may be considerably higher. These individual plans usually must be applied for within 30 days of leaving your job.

If you are looking at insurance options, be aware of differences in coverage. Ask about choice of doctors, protections against

cancellations, and increases in premiums (what you pay for insurance). Determine what the plan really covers, especially in the event of catastrophic illness (generally defined as an illness that prevents you from working). What are the deductibles? Sometimes higher deductibles go with better comprehensive coverage.

Most managed care plans should pay for a clinical trial if a patient's doctor recommends the treatment and if the clinical trial is approved by a trustworthy agency. They typically have case managers or other staff with whom your doctor can argue for the need for drugs not typically covered.

Health maintenance organizations (HMOs) commonly provide preventive care and routine doctor visits; however, access to state-of-the-art cancer care is sometimes difficult to obtain. Learning about your health insurance will help you be prepared. Patients who understand their insurance are more likely to be successful in getting the coverage they need. Sometimes it is necessary to go outside the plan for the cancer care that is best for you.

People who have a dispute with their health plan have several options. Always keep records and document all aspects of care and interaction with health plan staff and clinicians. The doctor is a patient's ally and advocate. In cases of denied care, it is the doctor who may go to the proper manager within the health plan, such as a medical director, to provide additional information about a patient's case.

For people not insured, there are several options to consider in seeking coverage, such as an independent insurance broker who may be able to help you locate a reasonable benefit package. Determine whether you can apply for group insurance through professional organizations (such as those for retired persons, teachers, social workers, or realtors).

What Resources Are Available?

There are many places where you can get assistance. Your hospital is one of the first sources that can help you get the support you need. Hospital support services are an important part of your care. Support services that may be available include nursing services, social services, nutritional services, rehabilitation services, or spiritual services.

Some people worry that asking for emotional support is a sign of weakness, as if they are somehow expected to be strong and handle the situation on their own. However, solitude and strength are not the same thing; you don't have to be alone to be strong. Emotional support is crucial at every stage of the cancer journey, and it can come from many places. In addition to your family and friends, consider contacting sources of support such as health professionals, support groups, and your place of worship. Asking for support is one way you can take control of your situation. Talking with family and friends can bring comfort and reassurance.

Cancer can be an awkward thing to talk about, and sometimes people may worry that they will upset you by bringing up the topic or talking about your illness. You may need to take the first step. Individual or group counseling or support groups can help you cope with the stresses your illness brings in your everyday life. Many people with cancer find it easier to talk with people who are going through experiences like theirs. Support groups can also provide important practical information about your cancer and its treatment. Community agencies can sometimes relieve the demands cancer places on families and friends.

Most importantly, a person with cancer is never alone. There are people who care and who are ready to help.

Resource List

American Cancer Society Publications

Pamphlets (single copies are free)

Breast Cancer Treatment Guidelines for Patients (9405)

Cancer Facts and Figures (5008) current year

Caring for the Patient with Cancer at Home (4656)

Nutrition for the Person with Cancer (9410)

Prostate Cancer Treatment Guidelines for Patients (9402)

Sexuality & Cancer: For the Man Who Has Cancer & His Partner (4658)

Sexuality & Cancer: For the Woman Who Has Cancer & Her Partner (4657)

Understanding Chemotherapy: A Guide for Patients and Families (9458)

Understanding Radiation Therapy: A Guide for Patients and Families (9459)

In addition to pamphlets, information is also available by calling day or night – 1-800-ACS-2345.

Books

Cancer in the Family: Helping Children Cope with a Parent's Illness. Sue P. Heiney, Joan F. Hermann, Katherine V. Bruss, and Joy L. Fincannon. Atlanta, GA: 2002.

Caregiving: A Step-by-Step Resource for Caring for the Person with Cancer at Home. Peter S. Houts and Julia A. Bucher. Atlanta, GA: 2000.

Colorectal Cancer: A Thorough and Compassionate Resource for Patients and Their Families. Bernard Levin. New York: Villard Books, 1999.

Coming to Terms with Cancer: A Glossary of Cancer-Related Terms. Edward H. Laughlin. Atlanta, GA: 2002.

Complementary and Alternative Cancer Methods Handbook. Atlanta, GA: 2002.

Consumer Guide to Cancer Drugs. Gail M. Wilkes, Terri B. Ades, and Irwin Krakoff. Boston: Jones and Bartlett, 2000.

Informed Decisions, Second Edition. The Complete Book of Cancer Diagnosis, Treatment, and Recovery. Harmon J. Eyre, Diane Partie Lange, and Lois B. Morris. Atlanta, GA: 2002.

Prostate Cancer: A Thorough and Compassionate Resource for Patients and Their Families. David G. Bostwick, Gregory T. MacLennan, and Thayne R. Larson. New York: Villard Books, 1999.

Women and Cancer: A Thorough and Compassionate Resource for Patients and Their Families. Carolyn D. Runowicz, Jeanne A. Petrek, and Ted S. Gansler. New York: Villard Books, 1999.

Online Cancer Information

The information offered by Web sites, message boards, and online support groups can be very helpful, but it varies widely in quality and accuracy. Some people may find online support groups helpful. It may be comforting to chat with other people facing similar situations. Chat rooms, however, are not the best source for locating information, especially if they are not monitored by trained experts. Any online information you receive should be discussed with your health care team to determine if it applies to your particular situation.

The **American Cancer Society** (www.cancer.org) Web site contains information on specific types of cancer, cancer statistics, news updates, patient and family information, diet, home health care, managing medical costs, program events, and other links.

The **National Cancer Institute** (NCI) (www.cancer.gov) is part of the government-supported National Institutes of Health. It is the government's principal agency for cancer research, training, and information sharing. NCI provides information on cancer research, diagnosis, treatments, comprehensive cancer centers, clinical trials, and community clinical oncology programs.

National Coalition for Cancer Survivorship (NCCS) (www.cansearch.org) is a network of independent organizations working in the area of cancer survivorship and support. NCCS serves as an information clearinghouse and an advocacy group.

Oncolink (www.oncolink.com), sponsored by the University of Pennsylvania Cancer Center, contains detailed descriptions of a variety of cancers and cancer information, news developments, survivors' stories, and answers to frequently asked questions.

American Cancer Society

The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer, through research, education, advocacy, and service. The Society offers up-to-date cancer information, educational programs, services, and referrals. Check your local telephone directory for your nearest Society office or call 1-800-ACS-2345. The programs described may be available in your community and are free.

1-800-ACS-2345

Trained cancer information specialists are available 24 hours a day, seven days a week to answer questions about cancer, link callers with resources in their communities, and give information on local events. This unique service provides needed information and support through the warmth of a live phone call. Spanish-speaking information specialists are available, and callers who speak languages other than English or Spanish can also be assisted.

www.cancer.org

This user-friendly site includes a cancer resource center with in-depth information on every major type of cancer, as well as an email service to answer your cancer questions. Visitors can order Society publications, read articles on the latest cancer news, and find other helpful cancer resources in their areas. The site also includes a directory of medical resources and tools for managing day-to-day tasks and keeping track of appointments. Select content is available in Spanish.

Cancer Survivors NetworkSM

Created by and for cancer survivors and their families, this “virtual” community offers anonymity and accessibility to survivors, caregivers, and all those touched by cancer. It is a welcoming, safe place for people to find hope and inspiration from others who have “been there.” Services include radio talk show conversation and interviews, individual stories, personal Web pages, discussion forums, an Expression Gallery, and more – available online at www.cancer.org or by phone at 1-877-333-4673 (HOPE).

I Can Cope[®]

I Can Cope is an educational program provided in a supportive environment for adults with cancer and their families. A series of classes discusses such topics as the disease, coping with daily health problems, expressing feelings, living with limitations, relieving pain, money matters, and local resources. Through lectures, group discussions, and practical hints, the course helps people with cancer regain a sense of hope and control over their lives.

Look Good...Feel Better

This program is for women going through chemotherapy or radiation treatment for cancer. It teaches skills to improve and enhance appearance through the use of cosmetics, wigs, turbans, and scarves. The program also focuses on beauty techniques that can help a woman restore her self-image. There is also a program for teens.

Man to Man[®]

The Man to Man program is designed for men and their families who have prostate cancer concerns. The purpose of the program is to provide accurate information about diagnosis, treatment options, living with side effects of

treatment, and other related issues in a supportive atmosphere. Men and their partners are able to ask questions and share common experiences and feelings with the assistance of experts and the mutual aid of the group. This program also promotes awareness of prostate cancer as a major health care concern for all men. It is believed that men and their partners can greatly benefit from the program and that participation immediately following diagnosis is especially important to help reduce anxiety and facilitate a healthy adjustment. There is also a bulletin board on the American Cancer Society Web site where medical questions about prostate cancer can be posted and medical experts respond.

Reach to Recovery®

Reach to Recovery volunteers are breast cancer survivors who have adjusted well to their own diagnosis and treatment. The program carefully matches a trained volunteer with a woman facing the emotional and physical challenges related to the diagnosis, treatment, and effects of her breast cancer. The patient may request a Reach to Recovery visit at any point in her breast cancer experience, including early support at the time of diagnosis. Visits can also be arranged for women considering breast reconstruction or for a woman experiencing a recurrence.

To schedule a Reach to Recovery visit, contact your American Cancer Society office listed in the telephone directory or call 1-800-ACS-2345. A visit can also be requested by the patient or by her doctor, nurse, family member, or friend. Although personal visits are recommended, the visit can also take place over the telephone if necessary. The Reach to Recovery visitor often makes a follow-up visit or phone call to the patient to answer any questions or to offer additional support if needed. Long-term support, however, is not part of the program.



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99-(Rev. 9/02)-200M-No. 9440.00-HCP

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No matter who you are, we can help. Contact us anytime, day or night, for information and support.



1.800.ACS.2345
www.cancer.org

Hope.Progress.Answers.®