

When Cancer Recurs

MEETING THE CHALLENGE



NATIONAL INSTITUTES OF HEALTH
National Cancer Institute

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health

Contents

- 1 Introduction
- 3 Why Cancer Can Recur
- 4 Where Cancer Can Recur
- 5 Diagnosing Recurrent Cancer
 - 6 Physical Exams
 - 6 Laboratory Tests
 - 6 Imaging
 - 7 X-Ray
 - 7 CT Scan
 - 7 MRI
 - 8 Nuclear Scan
 - 8 Ultrasonography
 - 8 Biopsy
- 9 Treatment Methods
 - 11 Surgery
 - 12 Radiation Therapy
 - 13 Chemotherapy
 - 14 Hormone Therapy
 - 15 Biological Therapy
 - 16 Bone Marrow Transplantation
 - 17 Supportive Therapy
 - 18 Nutritional Support
 - 18 Pain Management

21	New Cancer Treatments
	21 Clinical Trials
	22 Unconventional Cancer Treatments
24	Helping Yourself
	24 Gathering Information
	25 Taking Part in Your Treatment
	26 Managing Your Emotions
	28 Employment and Insurance Issues
30	Glossary
34	Resources
	34 Additional Reading
35	National Cancer Institute Information Services
	36 Telephone Service
	36 Electronic Services

Introduction

In the back of every cancer patient's mind is the possibility that the disease may return. Yet if it does, most patients think, "How can this be happening to me again?"

The shock is back. The fears are back—of telling your family and friends, of more treatment, and possibly of death. The anger is there, too. You've been told you have cancer again. You may feel that after all you've been through, it should have been enough. And the unanswered question is, "Will the treatment work this time?"

Even though you may feel some of the same things you felt when you were first diagnosed, now there is a difference. You've been through this before. You've faced cancer and its treatment and the changes that came to your life. You know that medical care and emotional support are available to you. Facing cancer again is difficult, but it's a challenge you can handle.

This booklet is about cancer that has returned—its diagnosis and treatment, suggestions for coping, and where to get help. The glossary at the end of the booklet explains some of the terms that you will read or may hear in talking with your treatment team.

As you read this booklet, remember that there are more than 100 different types of *cancer*.^{*} Each is different, and each person responds to treatment differently. No booklet can cover every situation for every person. For this reason, the information here is general, and some of it may not apply to you. Still, a lot of people have found ways to handle recurring cancer in similar ways, and their experiences may help you.

Many people who have faced the return of cancer will tell you that learning more about your illness and its treatment helps you take part in your care. Having a positive attitude toward treatment may help you control some of your emotional and physical reactions to it. Drawing on your own strengths and support from the people and resources around you can help you meet this challenge again.

Some of those resources are listed at the back of this booklet. Many of them are available from the National Cancer Institute's Cancer Information Service or the American Cancer Society (see p. 36).

**Italicized* words are defined in the glossary that begins on p. 30 of this booklet.

Why Cancer Can Recur

A cancer *recurrence* is the reappearance of disease that was thought to be cured or inactive (in remission). Cancer may recur after several weeks, several months, a few years, or many years.

Recurrent cancer starts from cancer cells that were not removed or destroyed by your original therapy. You may have had previous treatment that was meant to destroy the original cancer, as well as any cancer cells that may have moved to another part of your body. Sometimes, no matter what treatment is used, a small number of cancer cells survive, and it may take a while for them to grow into tumors that are large enough to be detected.

A cancer recurrence is not the same thing as a new cancer, even if it appears in a new place in your body. A recurrence has the same type of cancer cells as the original *tumor*—no matter where it is found. For example, if you had colon cancer and it recurs in your liver, it is not liver cancer; colon cancer cells have spread to the liver, and the disease is still colon cancer. (The spread of cancer cells to a new part of the body is called *metastasis*.) This point is important because there are different treatments for different types of cancer.

Although it's possible to develop a second, entirely new tumor that is not related to your original cancer, this situation is more unusual than a recurrence.

Where Cancer Can Recur

Not every cancer cell that breaks away from a tumor is able to grow elsewhere. Most are stopped by the body's natural defenses or destroyed by treatment. Cancers differ in their ability to recur and in the places where they are likely to show up.

Recurrent cancers are classified by location: local, regional, or distant.

- Local recurrence means that the cancer has come back in or very close to the same place as the original cancer. For instance, a woman who has had a mastectomy could later have a local recurrence of breast cancer in the area of her surgery. The term "local" also means that there is no sign of cancer in nearby lymph nodes or other tissues.

- A regional recurrence involves growth of a new tumor in *lymph nodes* or tissues near the original site but with no evidence of cancer at distant places in the body. A person who has had a melanoma removed from an arm, for instance, might have a regional recurrence in the lymph nodes under that arm.

- In distant recurrence, the original cancer has spread (metastasized) to organs or other tissues far from the site of origin. For example, a man who had prostate cancer could have a recurrence of that cancer in his bones. This man does *not* have bone cancer; he has prostate cancer that has spread to his bones.

Diagnosing Recurrent Cancer

Over the past several months or years, you may have had a number of tests and checkups. Most likely, your doctor told you to watch for changes in your body and to report any unusual symptoms. You may have noticed a weight change, bleeding, or pain (these changes don't always mean that you have cancer), or your doctor may have found signs of illness while examining you.

In either case, specific procedures and tests are used to find the exact cause of the problem and decide on the best treatment. These procedures and tests, which you may be familiar with from your original cancer, help your doctor answer these questions:

- Are the signs and symptoms caused by cancer or by some other medical problem?
- If cancer is present, is it a recurrence or is it a new type of cancer?
- Has the cancer spread to more than one place?

Because certain types of cancer tend to recur in certain parts of the body, your doctor is likely to check those places first. Information from physical exams and tests helps the doctor make an accurate diagnosis. If your cancer has recurred, an accurate diagnosis is the first step in determining the best course of treatment and getting the disease under control again.

Physical Exams

In addition to your routine physical exam, which includes feeling for lumps and swelling, your doctor may need to look inside your colon, stomach, bladder, breathing passages, or other organs for recurrent cancer. Special instruments are used for viewing different parts of the body. The names of most of these instruments end in “scope.” For example, a bronchoscope is used to view the air passages of a lung. In some cases, the doctor may even take a tissue sample (biopsy) through the scope and for viewing under a microscope.

Laboratory Tests

A number of laboratory tests are used to help diagnose recurrent cancer. For example, blood samples can be tested to check the levels of certain *tumor markers*, such as carcinoembryonic antigen (CEA), that may change when cancer recurs.

Other tests, such as the examination of a stool smear (*fecal occult blood test*), can detect internal bleeding that may be too slight for you to notice. If blood is found, a series of x-rays or another type of test is done to learn if the bleeding is caused by cancer or some other problem.

These are only a few examples of laboratory tests used to diagnose cancer and other health problems. Your doctor will select those that may be helpful in your case.

Imaging

To learn the location and size of suspected cancer, the doctor can use x-rays, computed tomography (CT) scans, magnetic resonance imaging (MRI), nuclear scanning, or ultrasonography. These tests are often done someplace other than your doctor’s office.

These tests may use radiation, computers, magnets, and other sophisticated equipment. If you have questions about how they’re used, their risks or ben-

efits, or what you should expect during the procedure, be sure to talk with your doctor, nurse, or technician about your concerns. It may be possible for you to see the equipment and how the test will be done in advance. Most CT and MRI equipment requires you to be in a tight space, sometimes for an hour or more. It also may be noisy. If you feel extremely uncomfortable in small spaces, discuss this with your doctor before your test is scheduled. The CT or MRI technician also may have suggestions.

X-Ray. Tumors can often be seen with a standard *x-ray*. Other tests use x-rays and a barium solution, dye, or air to give sharp pictures of organs such as the stomach, kidney, and colon that cannot be seen clearly with x-rays alone. An example of this kind of test is the “lower GI series” (barium enema followed by an x-ray of the gastrointestinal tract). Barium is a white, chalky substance that outlines the colon and rectum on the x-ray.

CT Scan (also called **CAT scan**, for computed axial tomography). In a *CT scan*, x-rays are taken from many directions and combined into one cross-sectional picture with the aid of a computer. The CT scan gives more detailed pictures than standard x-rays for certain body parts and often is used for tissues such as the liver and brain. In some cases, a special dye is injected into a vein before the scan to improve the details of the pictures.

MRI. Instead of x-rays, MRI uses radio waves and a powerful magnet to create detailed pictures of areas inside the body. Like a CT scan, MRI uses a computer to combine many images into a single picture. That picture may include organs, muscles, blood vessels, and other parts of the body that are hard to see with other equipment. For MRI, you’ll be asked to lie very still in a tunnel-like machine. Headphones are often available to help block the machine’s rather loud clicking sounds.

Biopsy

Nuclear Scan. *Nuclear scans* often are used to see areas inside the body. A special substance is swallowed or injected into the bloodstream. It contains a small amount of radioactivity, similar to the amount used in a chest x-ray, so it can be seen inside the body. A machine called a scanner then takes pictures of the areas of the body where the substance shows up. In the pictures, a cancer can appear as an area of more or less radioactivity than the tissue around it.

Ultrasonography. In *ultrasonography*, a microphone-like device sends sound waves that bounce off internal organs, like the brain or lung. A computer converts the echoes made by the sound waves into pictures called sonograms. The pictures are shown on a monitor like a TV screen. Tissues of different densities look different in the picture because they reflect sound waves differently. For example, a sonogram can often show whether a breast lump is a fluid-filled cyst or a recurrent cancer.

Biopsy is the removal of a tissue sample so it can be examined under a microscope to establish a precise diagnosis. Although an abnormal area of the body may be seen on physical exam or imaging, a biopsy is the only way to tell for sure whether the tissue contains cancer cells.

For some suspected cancers, the doctor uses a needle to withdraw fluid (aspirate) or remove small tissue samples (needle biopsy). A surgical biopsy, done under local or general anesthesia, removes the entire tumor or a piece of it.

Treatment Methods

Many of the same factors that affected treatment decisions for your original cancer will be taken into account in planning treatment for recurrent cancer. Some of those factors include the type, size, and location of the cancer, your general health, and other treatments you've had.

Your doctor may recommend surgery, radiation, anticancer drugs (chemotherapy), or a combination of these treatments. For certain cancers, such as those in the breast or reproductive organs, the doctor may suggest hormone therapy. In other cases, biological therapy may be considered. These kinds of treatments are discussed below.

Before you and your doctor agree on a treatment plan, you should understand why one treatment is recommended over others. Talk to your doctor about treatment goals, methods, and side effects. Compare the recommended treatment with other treatments. Do this by looking at the possible benefits, risks, side effects, and impact on the quality of your life. NOTE: If you're having radiation therapy or chemotherapy, be sure to check with your doctor before taking *any* medicines—even those you can buy without a doctor's prescription for colds or headaches. Some of these products can interfere or interact with your other treatments.

As with other important medical decisions, a second opinion about treatment for recurrent cancer is a good idea. Some insurance companies require a second opinion; others will pay for a second opinion at the patient's request. You can find another doctor to consult by asking your doctor or calling a local medical society, nearby hospital, or medical school. The Cancer Information Center (1-800-4-CANCER)

also can tell you about treatment facilities, including cancer centers and other programs supported by the National Cancer Institute (NCI).

You can take an active part in your treatment by asking questions and expressing your feelings. Questions that patients often ask are included throughout this section. You may want to add your own questions to discuss with your doctor, nurse, social worker, or other member of your health care team. Family members or others close to you may have questions, too.

Questions to ask about any recommended treatment:

- What is the goal of this treatment? Is it a cure, or will it shrink the tumor and relieve the symptoms only for a period of time?
- Why do you think this treatment is the best one for me?
- Is this the standard treatment for my type of cancer?
- Are there other treatments? What are they?
- Am I eligible for any clinical trials?
(See p. 21.)
- Where is the best place to receive treatment?
- What benefits can I expect from the treatment?
- Are there side effects with this treatment? What are they? Are they temporary or permanent?
- How can the side effects be treated or relieved?
- How safe is this treatment? What are the risks?
- How will I know if the treatment is working?
- Will I need to be in the hospital?
- What will happen if I don't have the treatment?
- Will I lose time from work or need help at home?
- What does my family need to know about the treatment? Can they help?

Surgery

- How long will I be on this treatment?
- How much will the treatment cost?
- How is this treatment similar to or different from my last treatment?

The remainder of this section describes the most common treatments, some of the newer methods now under study, and unconventional treatments that may not be familiar to you.

Surgery is local treatment to remove the cancer, and possibly tissue around it and nearby lymph nodes. Surgery often is used to treat cancer when it is first diagnosed, but it is used less often in recurrent cancer. Your doctor may recommend an operation to remove a recurrent cancer if it seems to be limited to a single or few spots on the skin or in the lung, liver, bone, brain, or lymph nodes. Surgery also may be suggested to alleviate symptoms. For many sites of recurrence, other methods such as radiation therapy, chemotherapy, biological therapy, or a combination of these have been shown to be more effective.

When cancer recurs in a weight-bearing bone such as the leg, the growing tumor can cause a fracture. In such a case, the doctor may suggest an operation to support the bone and prevent a break. This procedure can help relieve pain and keep the patient active during the wait for other forms of treatment to take effect and control the cancer.

Questions to ask about surgery:

- What type of anesthetic will be used?
- What side effects should I expect after surgery?
- How can the side effects be treated or relieved?
- How long will I have to restrict my activities after surgery?
- Is the surgery aiming to cure the cancer (curative) or relieve some of my symptoms (palliative)?

Radiation Therapy

Radiation therapy (also called radiotherapy) directs high-energy rays (tens of thousands of times the amount used to produce a chest x-ray) at a cancer site to stop cells from growing and dividing. Sometimes radiation therapy is used before surgery to shrink a cancerous tumor. After surgery, it may be used to stop the growth of any cancer cells that remain in a certain part of the body. In some cases, doctors use both radiation and anticancer drugs, in addition to or in place of surgery, to destroy a cancer and prevent it from returning.

Radiation affects both normal cells and cancer cells. Special equipment aims the radiation directly at tumors or target areas of the body, sparing as much normal tissue as possible. Like surgery, radiation therapy is a local treatment; it affects cells only in the treated area. Tiny marks, called pinpoint tattoos, are made on the body to help the technician direct treatment to the right place every time. Another type of radiation therapy uses implants that contain small amounts of a radioactive substance. This is called *internal radiation therapy*.

Radiation therapy is a commonly used treatment for cancer. The type of cancer, location, stage (extent of disease), previous radiation therapy, and other factors will determine whether this treatment is appropriate for you. Sites that may be treated with radiation include the brain, lung, and bone. When normal cells are affected by radiation therapy, most appear to recover.

Although radiation treatment can cause side effects, most are not serious. For example, fatigue and skin changes, such as redness or dryness, are common. The type of side effects you may experience depends on the part of the body that's being treated and the amount of radiation received. Side effects usually disappear within a few weeks after treatment ends, although some may last longer.

Radiation Therapy and You, a booklet available from NCI, answers many questions about the various forms of radiation therapy.

Questions to ask about radiation therapy:

- What benefits can I expect from this therapy?
- What type of radiation therapy will I be getting?
- How long do the treatments take? How many will I need? How often?
- Can I schedule treatments at a certain time of day?
- What if I have to miss a treatment?
- What risks are involved?
- What side effects should I expect? What can I do about them? How long do they usually last?
- Who will give me the treatments? Where are they given?
- Will I need a special diet?
- Will my activities be limited?
- Will I miss work or need help at home?

Chemotherapy

Chemotherapy is the use of anticancer drugs to treat cancer. It may consist of a single drug or a combination of drugs. Chemotherapy may be used alone or in combination with radiation therapy, surgery, or biological therapy.

Anticancer drugs may be given by mouth or by injection into a vein or muscle. Because anticancer drugs can reach and destroy cancer cells in nearly every part of the body (called *systemic treatment*), chemotherapy is the primary treatment for many kinds of recurrent cancers that have spread beyond a single site or region.

Chemotherapy can affect any rapidly growing cells in the body—normal as well as cancer cells. The normal cells most likely to be affected are the

Hormone Therapy

blood-producing cells in the bone marrow, cells lining the mouth, digestive tract, reproductive organs, and hair follicles. Again, many normal cells are able to replace themselves.

Every person reacts differently to chemotherapy. Some people have few or no side effects; others say their side effects are less severe than they expected; still others have a more difficult time. Ask your doctor, nurse, or pharmacist about side effects that could occur with the anticancer drugs prescribed for you. They can give you suggestions to help with problems that may occur. Although most side effects gradually go away between treatments or after treatment ends, the fatigue that some patients feel during chemotherapy sometimes lingers for a while.

The NCI booklet *Chemotherapy and You* provides more information about this type of cancer treatment.

Hormone therapy (also called endocrine therapy) is the treatment of disease by blocking hormones or changing the way they work. Some cancers use *hormones* in the body to grow. *Hormone therapy* can prevent cancer cells from getting or using the hormones they use. Like chemotherapy, hormone therapy may be given by mouth or by injection and is a systemic treatment. Sometimes surgery is suggested to remove organs that make the hormones. Radiation therapy and chemotherapy can also stop the body from producing the hormones that cancer cells need to grow.

Hormone therapy is often used to treat breast, uterine, and prostate cancers. It is also being studied in the treatment of other cancers, such as melanoma, uterine cancer, and certain leukemias. It can cause a number of side effects, depending on the type of drug or surgical procedure used. Patients may have

nausea, swelling, or weight gain. Breast cancer patients taking the anti-estrogen drug tamoxifen may have some symptoms of menopause.

Questions to ask about chemotherapy and hormone therapy:

- What do you expect the drugs to do for me?
- Which drugs will I be getting? How is each one given?
- Where are the treatments given?
- How long do the treatments take? How many will I need?
- What happens if I miss a dose?
- What risks are involved?
- What side effects should I expect? What can I do about them? How long do they usually last?
- Will I need a special diet or other restrictions?
- Can I take other medicines during treatment?
- Can I drink alcoholic beverages during treatment?
- Can my treatment be delayed if I don't feel up to it?
- Will I miss work or need help at home?

Biological Therapy

Biological therapy (also called immunotherapy and biotherapy) is a promising new area of cancer treatment. It uses both natural and manufactured substances, called biological response modifiers (BRMs), to boost the body's own immune (defense) system to fight cancer or reduce side effects from treatment. Researchers are studying biological therapies to learn how BRMs work best and against which cancers. BRMs that are being used in cancer treatment include interferons, interleukins, tumor necrosis factor, colony-stimulating factors, monoclonal antibodies, and cancer vaccines.

Bone Marrow Transplantation

Questions to ask about biological therapy:

- Exactly what kind of therapy will I receive?
How is it given?
- Has this type of therapy already been shown to work against my type of cancer?
- Will I need to change my diet?
- Will I miss work or need help at home?
- What side effects should I expect? What can be done about them? How long do they usually last?
- Where will I have to go for treatment?
- Who will be the doctor responsible for my care?
- How long will the treatment last?
- Will I have to be in the hospital?
- How much will the treatment cost? Will my insurance pay for it?

Some cancers and cancer treatments can damage or destroy bone marrow, the soft, spongy material found inside bones. In some cases, high doses of chemotherapy or radiation therapy are needed to treat cancer. These treatments can destroy bone marrow, whose main job is to produce blood cells. *Bone marrow transplantation* (BMT) is a procedure that replaces damaged or destroyed marrow with healthy marrow. In BMT, healthy marrow is removed from a bone with a needle. The patient later receives the marrow by injection into a vein. Cells with the potential to re-form all the normal blood cells also circulate in the bloodstream. These are called stem cells. They can be separated from the blood by a machine, stored, and returned to the patient after treatment.

There are three categories of BMT, depending on where the marrow comes from: the patient (autolo-

gous transplantation), an identical twin (syngeneic transplantation), or another person (allogeneic transplantation). Numerous factors determine what type of transplant a patient receives. These include the type of cancer and the availability of a suitable donor. (See NCI's Research Report, *Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation*, available from the CIS.)

Questions to ask about bone marrow transplantation:

- Why is BMT appropriate for me?
- Will the BMT extend my life or improve my quality of life?
- Can my own marrow be used, or will I need someone else's?
- What risks are involved?
- What side effects should I expect? What can I do about them? How long do they usually last?
- Will I need a special diet?
- Will my activities be limited?
- Will I miss work or need help at home?
- Where will I have to go for treatment?
- Who will be the doctor responsible for my care?
- Will I have to be in the hospital?
- How much will the treatment cost? Will my insurance pay for it?

Supportive Therapy

When you were first treated for cancer, you may have had physical therapy or used the services of a psychological counselor or social worker. You may want to consider seeking those kinds of help again. Two other types of supportive therapy that also could be important to you are nutritional support and pain management.

Nutritional Support

Nutrition should be considered an important part of your treatment plan. Radiation therapy and chemotherapy destroy normal cells as well as cancer cells. Good nutrition is needed to replenish those normal cells. Studies have shown that patients who eat well may be able to cope better with the cancer and its treatment. Dieting during treatment is not advised because it deprives the body of needed calories and nutrients. It's a good idea to discuss your nutritional plans with your doctor, a dietitian, or both.

Eating well means choosing foods that have the protein, calories, and other nutrients you need to keep your body working normally. If you're having problems eating and digesting because of the treatment or the cancer, you may need nutritional supplements, or you may find it easier to eat several small meals throughout the day rather than large meals at your regular breakfast, lunch, and dinner times.

You can find many suggestions for healthy ways to eat during treatment in the NCI booklet ***Eating Hints for Cancer Patients. Chemotherapy and You*** and ***Radiation Therapy and You***, also available from NCI, discuss specific nutrition problems associated with those treatments.

If eating enough to stay at your normal weight continues to be a problem in spite of your efforts, ask to speak with a dietitian at the hospital where you had your treatment about planning your diet. For severe nutrition problems, special treatments can be given at home or in the hospital.

Pain Management

Having cancer doesn't always mean having pain. But if pain does occur, there are many ways to relieve or reduce it. Cancer pain almost always can be relieved or controlled. **You have a right to ask those caring for you to help you control your pain as much as possible.**

The best way to manage pain is to treat its cause. When it is clear that a tumor is the direct cause of pain, the pain can sometimes be treated by removing the tumor or decreasing its size. To do this, your doctor may recommend surgery, radiation therapy, or chemotherapy. If removing or shrinking the size of the tumor is not possible, or when the cause of pain is unknown, other pain relief methods are used.

Most pain can be controlled by oral pain medicines. Your doctor may recommend over-the-counter (nonprescription) pain medicines for mild pain, or may give you a prescription pain medicine for moderate to severe pain. Many patients try to avoid using pain medicine because they're afraid of becoming "addicted." This rarely happens in cancer treatment. If you have concerns, talk with your doctor or nurse. Pain is most effectively relieved when pain medication is taken on a regular schedule, and if it's taken when the pain first begins. **Tell your doctor or nurse if the pain medication is not effective.**

When describing pain to your doctor, be as specific as you can. To recommend the best pain treatment for you, your doctor will want to know the following things:

- Where *exactly* is your pain? Does it ever move from one spot to another?
- How does the pain feel (dull, sharp, burning, etc.)?
- How often does it occur?
- How long does it last?
- Does it start at a specific time of day (morning, afternoon, evening)?
- Does anything (lying down, sitting, eating, etc.) seem to relieve the pain or make it worse?

Narcotic pain medications usually have some sedative effects, which disappear after a few days. This type of medication also can cause constipation. Your doctor may prescribe a laxative or stool softener to be taken with your medicine.

Because pain can be worse when you're frightened or worried, you may find some relief by using relaxation exercises or meditation. These activities, which usually involve deep, rhythmic breathing and quiet concentration, can be done almost anywhere.

A number of nonmedical ways to reduce pain have been gaining attention in recent years. Hypnosis and *biofeedback* have been helpful for some people with serious illness. If you want to learn about them, ask your doctor or nurse to refer you to a health professional who is trained to teach these methods. Three booklets on handling pain—***Questions and Answers About Pain Control***, ***Managing Cancer Pain***, and ***Getting Relief From Cancer Pain***—are available from NCI's Cancer Information Service (CIS). ***Questions and Answers About Pain Control*** is also available from the American Cancer Society (ACS). To get copies, call the CIS at 1-800-4-CANCER, the ACS at 1-800-ACS-2345, or contact your local ACS office listed in the telephone directory.

New Cancer Treatments

Clinical Trials

Clinical trials are studies of new methods for treating disease that are used under strict scientific conditions. These methods have been tested on animals and have shown promise for treating humans. Doctors test the value of new treatments with the help of cancer patients who take part in these studies.

Patients who take part in clinical trials may be the first to benefit from improved treatment methods. They also can make an important contribution to medical care because the results of the studies may help many people. Patients participate in clinical trials only if they so choose and are free to leave the trial at any time. More information about these studies is available from the Cancer Information Service. NCI's booklet *Taking Part in Cancer Treatment Studies: What Patients Need to Know*, also provide information.

Right now, cancer clinical trials are studying several new treatments. If proven effective, these treatments could become the standard treatments of the future.

Questions to ask about clinical trials:

- What trials are available for my type of cancer?
- What is the purpose of these trials?
- Who is sponsoring the study?
- How are the study data and patient safety being checked?
- Where will the information from the study go?
- What benefits can I expect from the treatment?
- Is there scientific evidence that the treatment can help?

Unconventional Cancer Treatments

- What are the known or potential risks?
- What are the possible side effects?
- Will I have to get the new treatment from a different doctor?
- Will my insurance cover the costs of treatment?
- Will I have to travel to get the treatment?
How often?

Unconventional cancer treatments are those that have not been shown to be effective in accepted scientific studies. Some unconventional treatments you may have heard about use various diets, vitamins, and herb mixtures.

Certain clues can help you know whether a new treatment approach is part of a clinical trial or is an unconventional method. One way is to look at how results of the treatment are reported. Findings from clinical trials usually are reported first in medical and scientific journals or at scientific conferences and later may be reported on TV and in newspapers and magazines directed to the general public. Today, a lot of clinical trials information is also available on the Internet. Unconventional methods generally rely on reports by patients, don't discuss scientific data, and keep details of the treatment secret. They often make ambitious claims about results and minimal side effects, especially for advanced cancers. Using unconventional treatments actually may be harmful. They may cause dangerous reactions or may delay or interfere with treatments proven to be effective and thus may reduce a patient's chances for cure or control of cancer. If you're thinking of using an unconventional treatment method, be sure to discuss it with your doctor. Be wary of cure claims from profitable companies that cannot produce sound scientific data on the efficacy of their products.

As you think about your treatment options, consider the following list of suggested questions carefully.

Questions to ask about unconventional treatments:

- What benefits can I expect from the treatment?
- Is there scientific evidence that the treatment can help?
- How many patients have received this treatment?
- How many patients have had successful results? May I speak with one of them?
- Have other researchers had the same results using the same techniques?
- What are the known or potential risks?
- What are the possible side effects?
- How much will the complete treatment cost?
- Will my insurance cover the costs of treatment?
- Will I have to travel to get the treatment? How often?

Helping Yourself

You may remember that much of the fear and anxiety that you felt the first time cancer appeared in your life was “fear of the unknown.” You can help yourself again by gathering information, taking part in your treatment as actively as possible, and finding the support you need to deal with your feelings.

Gathering Information

Learn as much as you can about what’s happening to you. If you have questions, ask your doctor, nurse, and other members of your treatment team. Your pharmacist is a good person to talk to if you have questions about your medicines. Your nurse can discuss ways to handle the side effects of your treatment. If you don’t understand the answer to a question, ask again.

Some patients hesitate to ask their doctors about their treatment options. They may think that doctors don’t like to have their recommendations questioned. Most doctors, however, believe that the best patient is an informed patient. They understand that coping with treatment is easier when patients understand as much as possible, and they encourage patients to discuss their concerns.

Here are some ideas that other people have found helpful:

- Write down your questions about possible treatments or anything else related to treatment. When you see your doctor, bring the questions with you so you don’t forget something you wanted to ask. (You can bring this booklet, which includes some of those questions and space in the back to write answers.)

Taking Part in Your Treatment

- Ask a friend or relative to go with you. This can be an emotional time, and you may not be able to focus on what the doctor says. It can be easier for someone else to write down information and help you remember later what was discussed. Or use a tape recorder instead of notes.

- Speak openly with the doctor about your needs, expectations, wishes, and concerns, to get the most useful advice. And don't be embarrassed to ask the doctor to repeat or explain something or spell unfamiliar words.

Taking an active part in your care can help you have a sense of control and well-being. You can be involved in many ways. One is to follow your doctor's recommendations about caring for yourself, such as staying on a special diet.

Another way you can help is to keep your doctor informed. Report honestly how you feel, and if problems arise, describe them as specifically as possible. Don't ever hesitate to report symptoms to your doctor or to ask advice about what to do about them. Although many health-related signs and symptoms may not seem important to you, they could provide valuable information to your doctor. Make sure you know what signs you should look for, and if any of them appears, tell your doctor promptly.

Take care of yourself. Some things you can do to keep up your strength are to:

- *Eat well.* Ask about nutrition recommendations for cancer patients. They can be very different from usual suggestions about healthy eating. (See NCI's booklet *Eating Hints for Cancer Patients*, available from the CIS.) Learn when your appetite is best and try to eat well at that time.

Managing Your Emotions

- *Get extra rest.* Your body will use a lot of extra energy during treatment. Get more sleep at night, and take naps whenever you feel the need.

- *Adjust activities.* Try to stay active, but don't demand too much of yourself. Ask other people to take over some of your tasks if necessary. If your energy level is low, do the things that are most important to you and cut back on the others. Talk to your doctor if you have questions about doing specific activities.

The diagnosis of cancer, whether for the first time or when it recurs, can threaten anyone's sense of well-being. Some people feel shock and denial when they first find out that cancer has returned. Many had put their experiences with cancer completely behind them, and the new diagnosis hits them as hard as it did the first time—or even harder. Others are not surprised, as if they had been expecting it all along.

Starting cancer treatment again can place demands on your spirit as well as your body. Your attitudes and actions really can make a difference. Remember that you've coped with this situation before. Keeping your treatment goals in mind may help you keep your spirits up during therapy. As you go through treatment, you're bound to feel better about yourself on some days than on others. When a bad day comes along, try to remember that there have been good days, and there will be more. Feeling low today doesn't mean you'll feel that way tomorrow or that you're giving up. At these times, try distracting yourself with a book, a hobby, or plans for a new garden. Many people say it helps to have something to look forward to—even simple things like a drive, a visit from a friend, or a telephone call.

Sometimes, however, you may feel overcome by fear, anxiety, anger, or depression, and you may just want to cry. That's okay, too. These emotions are common ways to cope with a difficult situation like

recurrent cancer. Feel free to express these feelings if they occur. None of these reactions is wrong, and letting them out can help you deal with them.

During your treatment, you may need to rely more on the people closest to you, but this may be difficult at first. You may not want to accept help, and some people may have trouble giving it. Many people don't understand cancer, and some may avoid you because they're afraid of your illness. Others may worry that they'll upset you by saying the wrong thing. You may have to make the first move. Try to be open in talking with others about your illness, your treatment, your needs, and your feelings. Once people know that you can discuss these things, they may be more willing to open up and help. By sharing your feelings, you and your loved ones will be better able to help each other through a difficult time. Another NCI booklet, *Taking Time*, offers useful advice for cancer patients and their families.

Sometimes it's easier to talk to someone other than your family or your friends. Try talking to your doctor, nurse, social worker, or a member of the clergy with whom you feel comfortable. You may want to consider a counselor trained to help cancer patients deal with their feelings. These counselors understand the special problems that go along with serious illness as well as the various ways of coping that others have found useful. If you think this kind of professional support could help you, ask your doctor or nurse for the name of an appropriate counselor, such as an oncology social worker or psychologist.

Many people also find that hospital-sponsored or other support groups, where they can meet others who have been through similar experiences, are helpful places to express their thoughts and feelings. Your hospital, as well as the Cancer Information Service and American Cancer Society, can help you find local support groups.

Employment and Insurance Issues

Although feeling stressed by the continuing changes in your life is normal, too much stress can harm your health and make you feel like you're losing control. You may not be able to remove all the stress around you, but you can try to limit it. Relaxation techniques help you reduce stress and cope better with your illness. Rhythmic breathing, imagery, and distraction are among the techniques that are easy to learn and use whenever you need them. If you're interested, ask your doctor or nurse to refer you to someone trained to teach these techniques. The local library and bookstore also have useful books on relieving stress.

If you have a job, you may want to return to work as soon as you can. You even may find it possible to continue to work during the time you are receiving treatment. This depends on the kind of treatment you are getting, what side effects you have, and how you feel about working.

Sometimes cancer patients find that they are treated differently on the job because of their medical condition. If this happens to you, be aware of your rights. Your employer may be violating laws that protect you from unfair practices.

Although as many as 1 million cancer patients in the United States experience some form of employment discrimination, this practice is illegal. The Americans with Disabilities Act, which went into effect in 1992, bans discrimination by both private and public employers against qualified workers who have disabilities or histories of disability. The Federal Rehabilitation Act of 1973 states that Federal employers or companies receiving Federal funds cannot discriminate against handicapped workers, including cancer patients. In addition to Federal protection, you may be eligible for protec-

tion under state laws. Find out the legal facts on equal opportunity by contacting your local department of employment services.

You need to understand fully your insurance rights not only as a cancer patient but as an employee of your company. Carefully read your health insurance policy. If you have any questions, contact your state insurance commission or department. This agency determines what types of insurance policies must be offered and when rates may be raised. Social workers and financial counselors in your hospital also may be sources of information.

If you have trouble learning what your rights are, or if you have any questions about employment issues, contact the National Coalition for Cancer Survivorship at (301) 650-8868. It can help you find local agencies that respond to problems cancer survivors face regarding their rights. You can also find practical information about cancer survivor issues in *Facing Forward: A Guide for Cancer Survivors*, available free from the CIS (1-800-4-CANCER).

If you don't feel able to return to work, you may want to find out about disability options. Social Security offers a disability program for people who qualify. (The toll-free number is 1-800-772-1213.) Your employer also may have disability programs.

Glossary

Biofeedback: A technique to monitor certain body functions, such as heart rate or blood pressure, to gain some control over them.

Biological (bye-uh-LOJ-i-kul) therapy: Treatment that uses the body's immune (defense) system to fight cancer or reduce side effects that some cancer treatments may cause. Also called immunotherapy.

Biopsy (BYE-op-see): The removal of a sample of tissue, which is then examined under a microscope to check for cancer cells.

Bone marrow transplantation (trans-plan-TAY-shun): A procedure in which doctors replace marrow damaged or destroyed by cancer or treatment with high doses of anticancer drugs or radiation. The replacement marrow may be taken from the patient before treatment (autologous; aw-TAHL-uh-gus) or may be donated from an identical twin (syngeneic; sin-jih-NEE-ik) or by another person (allogeneic; al-uh-jih-NEE-ik).

Cancer: A term for diseases in which abnormal cells divide without control. Cancer cells can invade nearby tissues and can spread through the bloodstream and lymphatic system to other parts of the body.

Chemotherapy (kee-mo-THAIR-uh-pee): Treatment with anticancer drugs.

Clinical trials: Carefully designed research studies that involve patients and have been approved by an Institutional Review Board. Each study is designed to answer specific scientific questions and to find better ways to prevent or treat cancer or improve care.

CT (an abbreviation for computed tomography)

scan: A series of detailed pictures of areas inside the body; the pictures are created by a computer linked to an x-ray machine. Also called computed axial tomography (CAT) scan.

Fecal occult (FEE-kul o-KULT) blood test: A test to check for hidden blood in stools.

Gastrointestinal (GAS-tro-in-TES-ti-nul) tract:

The part of the digestive tract where the body processes and uses food and eliminates waste. It includes the esophagus, stomach, liver, small and large intestines, and rectum.

Hormone therapy: Treatment that prevents certain cancer cells from getting the hormones they need to grow.

Hormones: Chemicals that are produced by glands in the body and circulate in the bloodstream. Hormones control the way certain cells or organs act.

Institution Review Board (IRB): A group of scientists, doctors, clergy, and consumers at each health care facility at which a clinical trial takes place. IRBs are designed to protect patients who take part in clinical trials. They must approve the protocols (action plans) for all clinical trials funded by the Federal Government. They check to see that the study is well designed, does not involve undue risks, and includes safeguards for participants.

Local treatment: Therapy that can affect cancer cells only in the treated area.

Lymph (limf) nodes: Small, bean-shaped organs located along the channels of the lymphatic system. Bacteria or cancer cells that enter the lymphatic system may be found in the nodes. Also called lymph glands.

Metastasis (meh-TAS-ta-sis): The spread of cancer from one part of the body to another. Cells that have metastasized are like those in the original (primary) tumor.

MRI: An abbreviation for magnetic resonance imaging, a procedure that uses a magnet linked to a computer to create pictures of areas inside the body.

Nuclear (NOO-klee-ur) scans: Pictures of the inside of the body taken after material “labeled” with radioactivity is swallowed or injected into the bloodstream.

Radiation (ray-dee-AY-shun) therapy: Treatment with high-energy rays to kill cancer cells.

Recurrence (rih-KUR-unse): The reappearance of cancer.

Remission (rih-MISH-un): The disappearance of the signs and symptoms of cancer. When this happens, the disease is said to be “in remission.” A remission can be temporary or permanent.

Stage: The extent of a cancer, especially whether the disease has spread from the original site to other parts of the body. There are different staging systems for different cancers.

Surgery: An operation.

Systemic (sis-TEM-ic) therapy: Treatment that reaches and affects cells all over the body by traveling through the bloodstream.

Tumor (TOO-mur): An abnormal mass of tissue.

Tumor marker: A substance in blood or other body fluids that may suggest that a person has cancer.

Ultrasonography (ul-tra-son-OG-ra-fee): A test in which sound waves (called ultrasound) are bounced off tissues and the echoes are converted into a picture (sonogram).

Unconventional cancer treatments: Approaches that use substances or methods of treating cancer that have not been shown to be effective by accepted scientific methods, such as carefully designed clinical trials.

X-ray: High-energy radiation used in low doses to diagnose diseases and in high doses to treat cancer.

Resources

Information about cancer is available from the sources listed below. You may wish to check for additional information at your local library or bookstore and from support groups in your community.

Additional Reading

Cancer patients, their families and friends, and others may find the following booklets useful. They are available by calling 1-800-4-CANCER (1-800-422-6237) or online at

<https://cissecure.nci.nih.gov/ncipubs>:

■ ***Advanced Cancer: Living Each Day***. Contains information intended to help patients facing death from cancer live their remaining days as well as they can.

■ ***Chemotherapy and You: A Guide to Self-Help During Treatment***. Explains chemotherapy and addresses problems and concerns of patients undergoing this treatment. Available in Spanish.

■ ***Eating Hints for Cancer Patients***. Provides information and recipes to help patients meet their need for good nutrition during treatment. Available in Spanish.

■ ***Radiation Therapy and You: A Guide to Self-Help During Treatment***. Explains radiation therapy and addresses concerns of patients receiving radiation treatment. Available in Spanish.

■ ***Taking Time: Support for People With Cancer and the People Who Care About Them***. Discusses the emotional side of cancer—how to deal with the disease and learn to talk with friends, family members, and others about cancer.

National Cancer Institute Information Services

You may want more information for yourself, your family, and your doctor. The following National Cancer Institute (NCI) services are available to help you.

Telephone Service

Telephone

CANCER INFORMATION SERVICE (CIS)

Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment.

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Electronic Services

Internet

<http://cancer.gov>

NCI's primary Web site. Contains information about the Institute and its programs, cancer issues, and clinical trials.

Notes

This booklet was written and published by the National Cancer Institute, 31 Center Drive, MSC 2580, Bethesda, MD 20892-2580. NCI, the largest component of the National Institutes of Health, coordinates a national research program on cancer cause and prevention, detection and diagnosis, and treatment. In addition, NCI's mission includes dissemination of information about cancer to patients, the public, and health professionals.



NIH Publication No. 97-1136
Revised April 1997
Reprinted June 1997