



# After Diagnosis: A Guide for Patients and Families

Finding out you have cancer presents many changes for you and your loved ones. You probably have lots of questions:

- 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?

Simply having some answers can help you feel more in control and less worried about what lies ahead. Here, we offer answers to many of your questions about cancer and cancer treatment. We also tell you what you can expect from the people and services that are there to help you cope with cancer. To help you feel more prepared for visits with your health care team, we offer suggestions about questions you may want to ask them. We hope this information will help you and your family as you work through your fears and concerns about cancer and cancer treatment.

Please keep in mind that this information is not meant to replace the advice of your doctor or nurse. Talking with them is the best way to understand what is going on with your body and how treatment will work to control the disease.

## What is cancer?

Cancer is not just one disease. There are many types of cancer. Cancer can start in many different places in the body. It can start in the lungs, the breast, the colon, or even in the blood. Cancers are alike in some ways, but they are also different in the ways they grow and spread.

## How are cancers alike?

The cells in our bodies all have certain jobs to do. Normal cells divide in an orderly way. They die when they are worn out or damaged; then they are replaced with new cells. Cancer is a disease in which cells start to grow out of control. The cancer cells keep on growing and making new cells. They crowd out normal cells. This causes problems in the part of the body where the cancer started.

Cancer cells can also spread to other parts of the body. For example, cancer cells in the lung can travel to the bones and grow there. When cancer cells spread, it is called *metastasis*. When lung cancer spreads to the bones, it is still called lung cancer because that is where it started. It is not called bone cancer unless it started in the bones.

## How are cancers different?

Some cancers tend to grow and spread very quickly. Others grow more slowly. They also respond to treatment in different ways. Some types of cancer are best treated with surgery. Others do better with drugs called chemotherapy (often called simply “chemo”). Often 2 or more treatments are given to get the best results.

When someone has cancer, the doctor will want to find out what kind of cancer it is. People with cancer need treatment that is aimed at their type of cancer.

## What are tumors?

Most cancers form a lump that doctors call a tumor or a growth. Not all tumors (lumps) are cancer. Doctors have to take out a piece of the lump and look at it to find out if it is cancer. Lumps that are not cancer are called benign. Lumps that are cancer are called malignant.

There are also a few kinds of cancer, like leukemia (cancer of the blood), that do not form tumors. They grow in the blood or other cells of the body.

## Who gets cancer?

Almost 1.6 million people in the United States get cancer each year. Nearly half of all men and a little over one-third of all women in the United States will have cancer during their lifetimes. Cancer can happen at any age; but more than 3 out of every 4 cancers occur in people over the age of 55. People of all racial and ethnic groups can get cancer. Today, more than 11 million people are living with cancer or have survived the disease.

## What are the risk factors that can lead to cancer?

A risk factor is anything that affects your chance of getting a disease. Some risk factors can be changed (lifestyle choices) and others cannot. Risk factors that can't be changed

include your age, sex, and family health history. Lifestyle choices include things you do, such as use tobacco and drink alcohol, what you eat, and sun exposure. Other factors are linked to cancer-causing factors in the environment.

But risk factors don't tell us everything. Having a risk factor, or even many risk factors, does not mean that you will get the disease. And some people who get cancer may not have any known risk factors. Even if a person with cancer has a risk factor, it is often very hard to know what part that risk factor may have contributed to the cancer.

## **Can cancer be inherited?**

Though many people believe that cancer runs in families, cancer can't be passed on from parent to child the same way that height and eye color are. While some cancers do have genetic risk factors, most people with cancer have not inherited the disease, nor do they pass it on to their children.

People whose close blood relatives (parents, brothers, or sisters) have certain types of cancer may be at increased risk for those cancers. A person's risk for getting cancer is also strongly linked to age and lifestyle factors mentioned above.

## **Why me?**

The first question that comes up for many people who have been told they have cancer is, "What did I do wrong?" or "Why me?" Because doctors don't know for sure what causes cancer in each case, many people come up with 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. Most people wonder if they did something to cause the cancer. Some think that if they had done something differently, they could have prevented the disease.

If you are having these feelings, it's important to know that you're not alone. All of these thoughts and beliefs are common among cancer patients. But cancer is not a punishment for things you did or didn't do in the past. Don't blame yourself or look for ways you might somehow have prevented cancer. Cancer is not your fault, and it is almost never possible to find out its exact cause. Focus instead on taking good care of yourself now, both physically and emotionally.

## **Am I going to die?**

It is normal to think about dying if you have just been told you have cancer. You may feel better knowing that the outlook for many people diagnosed with cancer is very good. Many people still believe that "cancer equals death." But the fact is that most cancers can be treated. There are almost 12 million people living in the United States today who have or had cancer.

The survival rate among different cancers varies greatly, so it's important to look at how well treatment works for your type of cancer. While numbers provide an overall picture, keep in mind that every person is unique and statistics can't predict exactly what will happen in your case. Talk with your cancer care team if you have questions about your own chances of a cure, or how long you might survive your cancer. They know your situation best.

Sometimes people are found to have an aggressive or advanced cancer and are told that their future is not bright or that they might not be expected to live very long. This is very hard and is a lot to take in at once. The American Cancer Society has other publications that may be of help to you, such as *Advanced Cancer* or *Caring for the Patient With Cancer at Home: A Guide for Patients and Families*.

## How do I cope?

### Taking in the news

At first, most people need some time to adjust to the fact that they have cancer. They need time to think about what is most important in their lives and to get support from loved ones. For many, this is an emotionally hard time. Feelings such as disbelief, shock, fear, and anger are all normal. These feelings use up a lot of mental energy, which can make it hard to take in and understand all of the medical information shared by the health care team. You will likely need some time to absorb and understand what your diagnosis and treatment options mean to you and your loved ones, both physically and emotionally.

It may be helpful to know that many people with cancer say that being told they had cancer gave them a chance to re-think their lives and find strengths and abilities that they did not know they had. Some even say that the experience has improved the quality of their lives.

### Coping skills

People cope with cancer just like they cope with many other problems in life – each person does it in their own way. Cancer affects each person's body and lifestyle in a unique way, and every person has unique ways of coping with cancer. With time and practice, most people find ways to go on with their work, hobbies, and social relationships. They find new or different ways to live their lives to the fullest.

As you look for a way of coping that works for you, you may want to try some of these ideas:

- **Learn as much as you can about cancer and its treatment.** Some people find that learning about their diagnosis and treatment gives them a sense of control over what happens. Along with your health care team, we can answer your questions about cancer and put you in touch with other resources. Call your American Cancer Society at 1-800-227-2345.

- **Express your feelings.** Some people find that giving some kind of outlet to their feelings helps them keep a positive attitude about treatment. Many people feel that expressing sadness, fear, or anger is a sign of weakness. In fact, the opposite is often true. It is much harder to express powerful emotions than it is to try to hide them. Hiding your feelings can also make it tougher to find a positive way to deal with them. There are many ways to express your feelings other than talking. Find one that fits you. You might try to talk with trusted friends or relatives, keep a private journal, or even express your feelings through music, painting, or drawing.
- **Take care of yourself.** Take time to do something you enjoy every day. Prepare your favorite meal, spend time with a caring 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.
- **Reach out to others.** There may be times when finding strength is hard and the situation feels overwhelming. It is very hard for any one person to handle having cancer all alone. Try to widen your circle of resources by reaching out to friends, family, or support organizations. These people can help you not feel alone on this journey. They will be there to share your fears, hopes, and triumphs every step of the way.
- **Work to keep a positive attitude.** While a positive attitude doesn't guarantee that you will beat cancer, staying hopeful can improve the quality of your life as you make the cancer journey. Cancer is a complex disease, and people's attitudes don't cause or cure it. Keep in mind that having an upbeat attitude does not mean that you and your loved ones should never feel sad, stressed, or unsure. You will feel down at times. When you feel blue, talking about your feelings can help you feel more in control rather than overpowered by your emotions.

## Cancer and depression

Many people go through a time of grief and sadness when they first learn that they have cancer. They grieve the loss of health and the loss of certainty in their lives. This sadness may seem like depression, but it is not the same. Grieving – feeling sadness, fear, anger, or going through crying spells – is a normal, healthy reaction to learning of a serious health concern. It usually does not last a long time, and it is a normal response to a profound change in a person's life.

About 1 in 4 people with cancer becomes truly depressed. This can make it hard for them to follow their medical treatment plan because of very low energy, decreased drive to do things, trouble making decisions, and feeling useless or helpless. Talk to your doctor if you have concerns or questions about depression.

## Signs of depression

You may be depressed if your time of grieving:

- Lasts for weeks and does not seem to be getting any better
- Has you feeling worthless or hopeless
- Causes problems with your day-to-day activities (such as being too sad to leave the house or get out of bed)

## Getting help

Some people who may be depressed are embarrassed or afraid to admit it. It may be helpful to know that depression can be caused by the chemical changes that take place in your body when you have cancer. It is not a sign of weakness, nor is it anyone's fault. Depression can be treated with medicines, counseling, or a combination of both. Treatment for depression can help you feel better and regain a sense of control and hope for the future.

## How do I talk to people about my diagnosis?

### Your family

A cancer diagnosis often affects family roles and routines. For example, your family may need to help you with jobs you once handled alone. You and your loved ones should talk about what changes need to be made to your family routines. This way, you can make decisions as a team and work together to make everyone as comfortable as possible with the changes that are now part of your family life.

You may not be able to do all that you used to do. You may be afraid that you will become a burden to your loved ones. But if there is no medical reason to do less than you did before, continue to do as much as you can. You and your family should also continue doing things you used to do together – like playing games, hobbies, or exercising. Doing so will be a healthy and fun way to keep working as a team.

### “Protecting” versus sharing

Cancer affects the whole family, not just the person who has it. People in your family may sometimes try to “protect” you or other family members from upsetting news or events. This happens even in families where the children are grown adults. But you can't protect someone all the time, and it uses up energy that could be used in better ways. If your family seems to be trying to protect you from becoming upset, you might gently tell them that a better use of their energy would be to support you and take good care of themselves.

When you let your family members know how you feel, both emotionally and physically, they will be able to better understand what you are going through, give you support, and help you make informed decisions.

## Dealing with unexpected feelings

Even in the most loving families, members sometimes feel resentment or anger when one person is sick and cannot keep up with their responsibilities for a while. This is often true when the situation lasts for a long time. Whether they express it or not, family members may feel angry with you because their lives are changed by your illness. While you may be the target for such anger, keep in mind that the situation is not your fault. Try to remember the anger is not aimed at you personally.

Though this kind of anger can be confusing and upsetting for everyone, it is a common response to a major life change. The best thing you can do for each other is be honest about what you are feeling. Fears about the future and feelings of guilt, frustration, and confusion are often less upsetting when you share them with others in a calm, honest manner. Doing so can also help all of you feel free from the burden of unspoken fears and concerns. Together, you can begin to build hope for the future together.

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 can be upsetting, but remember, people react differently to stressful situations. Some family members may become more absorbed in work; some may become overly involved in your treatment or personal life, while others may remove themselves from the situation and become involved in activities outside the home. Though it may be difficult, talking about differences in your coping styles will help you respect and understand each other and, in the end, work together.

## New relationships

If you are single and have cancer, you may be unsure how and when to share this news with a romantic partner. As you get to know the person, it may become easier to know when the time is right to talk. Trust yourself to be the judge of the best time to share this part of your life. You may want to tell someone early in a relationship, or you may wish to wait until later. Remember that this decision is yours to make. Whatever the reaction, you are not at fault for sharing the news at a “bad time.” You may find it helps to practice what you will say with a friend before talking with your new partner.

## Talking with children about cancer

If there are young children in your family, you may be worried about how they will respond to your cancer. How a child reacts to upsetting news often depends on how the adults are handling it. Many times adults have their own strong, private feelings about a cancer diagnosis, and they may want to protect the children from their fears and worries. Family members should decide ahead of time how best to talk to the children about cancer.

If children are not given honest answers, what they imagine may be worse and even more upsetting. Both adults and children learn to cope with cancer and its treatments. When talking to children about cancer, you should give them truthful information that they can understand. It is best to share small amounts of information over time and keep the answers suitable to their age and level of understanding. Be sure to give children the chance to ask questions and have their questions answered.

If you would like expert help, you might have a social worker or school counselor talk with your child, too. They may know of support groups for children in your area. They can also give the child a source of support that is outside of the family.

## Your friends and adult relatives

The decision to discuss your diagnosis with friends and adult relatives is a private one. You may find that in the beginning you only want to tell your spouse or partner and 1 or 2 friends or family members. Over time you can increase the circle of friends and loved ones you tell about your cancer. Overall, it is usually best to be honest about your cancer. Keeping it a secret can lead to more stress at a time when you need the support of others. Remember, too, that your friends will most likely learn about your cancer at some point. If and when they do, they may feel hurt if you haven't told them. This can sometimes make it harder for them to be supportive in the future.

Before you talk to others about your illness, think through your own feelings, your reasons for telling them, and what you expect of them. People react differently to upsetting news, so try to be ready for this. Many times people don't know what to say, and this makes them feel awkward and uncomfortable. They also may feel sad or be afraid of upsetting you. They may withdraw or distance themselves but not explain that it's because they feel sad. Some may become overly polite and careful or ask too many personal questions.

Sometimes people don't mean to, but they react in hurtful ways because of their own fear or lack of information. For example, someone may say, "I know just how you feel," when they have never had cancer. This may upset you, because you know that this is not true. Or, someone may begin to tell you a sad and discouraging story of another person with cancer who died. This is the last thing you want or need to hear! Sometimes people are just talking because they feel the need to respond, but they don't know what to say. You can help them by telling them that you only need them to listen to you and you don't need them to say anything other than that they care and are there for you.

Most likely your friends' hearts are in the right places, and they want to help you any way they can, but they are not sure how to be helpful. Be ready to tell them how they might help. You might ask them to do things like drive you to and from the clinic, do your grocery shopping, take your children to school or sports activities, or pet sit for you.

Once people have had time to adjust to the news, try to help them understand what's happening with you. Explain what kind of cancer you have and the treatments you'll need. Give them a clear and honest picture of what your life is like right now. Tell them that cancer is not a death sentence and they cannot "catch it" from you. Find out what

they think and how they feel. Try to answer their questions. Be direct with others and express your needs and feelings openly. It is usually more stressful to hide emotions than to express them. Sharing can be helpful both to you and to those close to you.

## **Making treatment decisions**

The number and kinds of treatment choices you have will depend on the type of cancer, the stage of the cancer, and other factors, such as your age, current health status, and personal needs. You are a key part of your cancer care team – you should talk about what treatment choices are best for you. Don't be afraid to ask as many questions as you like. Make sure you understand your options. A cancer diagnosis almost always makes people feel they must get treatment as soon as possible. But you usually have plenty of time to think through all the options available so you can make the best possible choice.

### **How is cancer treated?**

The 4 major types of treatment for cancer are surgery, radiation, chemotherapy, and biologic therapies. You might also have heard about hormone therapies, such as tamoxifen, and transplant options, such as those done with bone marrow.

### **What treatment will be best for me?**

Your cancer treatment will be based on your situation. Certain types of cancer respond better to certain types of treatment, so knowing the type of cancer you have is an important step toward knowing what treatments will work the best. The cancer's stage (how widespread it is) will also determine the best course of treatment. Your health, lifestyle, and personal preferences will also play a part in deciding what treatment options will be best for you. Not all types of treatment will work in your situation, so be sure that you understand your options. Don't be afraid to ask questions. It is your right to know what treatments are most likely to help you and what their side effects may be.

### **What is the goal of my treatment?**

Before starting treatment, ask about the goal of treatment. Is the purpose of the treatment to cure the cancer, control it, or treat symptoms? Sometimes the goal of treatment can change over time.

### **What is remission?**

Some people think that remission means the cancer has been cured, but this is not always the case. 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 go away and cancer cells cannot be detected by any of the tests available for that cancer. It is also possible to have a partial remission. This is when the cancer shrinks but does not completely disappear. Remissions can last anywhere from many weeks to many years. Complete remissions may go on for years and over time be considered cures. If the

cancer returns, more treatment can lead to another remission. A cancer that has recurred (come back) may respond to a different type of treatment, such as a different drug combination or radiation versus surgery.

## What is staging?

Staging is the process of finding out how far the cancer has spread. Staging the cancer is a key step in learning your treatment choices. It will also give your health care team a better idea of the outlook for your recovery. But staging can take time, and people are often eager to begin treatment right away. Do not worry that the staging process is taking up treatment time. Keep in mind that by staging the cancer, you and your health care team will know what treatments are likely to be the best before starting the treatment.

There is more than 1 system for staging cancer. The TNM system is the one used most often. It gives 3 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. For instance, a tumor staged as T1, N0, M0 is a tumor that is very small, has not spread to the lymph nodes, and has not spread to distant organs of the body.

Once the TNM descriptions have been found, they can be grouped together into a simpler set of stages, stages 0 through stage IV (0-4). As a rule, the lower the number, the less the cancer has spread. A higher number, such as stage IV (4), means a more serious, widespread cancer.

After looking at your test results, your doctor will tell you the stage of your cancer. Be sure to ask your doctor any questions you might have about what the stage of your cancer means and how it affects your treatment options.

## Surgery

Many people with cancer have surgery. If the cancer appears to be contained in one area (localized), surgery may be used to remove it along with any nearby tissue that might contain cancer cells. Sometimes it is hard to tell how much surgery will be needed until the surgeon sees the extent of the cancer during the operation. Surgery is most successful when the tumor has not spread to other areas. Today, surgery offers the greatest chance of 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.

## Radiation therapy

Like surgery, radiation treatment is used for localized cancers. Radiation destroys or damages cancer cells so they cannot grow. It can be used alone or along with surgery or chemotherapy. More than half of all people with cancer have radiation treatment at some point.

Radiation therapy is given 2 ways: either through external high-energy rays or through implants put in the body near the tumor.

### **External radiation**

Getting external radiation therapy is painless, much like having an x-ray taken. It is usually done in an outpatient setting, and the treatments take very little time. Treatment is most often given 5 days a week for 5 to 8 weeks, depending on the size, place, and type of cancer being treated.

### **Radiation seed implants (called brachytherapy)**

In some cases, radiation may be given through implants, sometimes called “seeds.” These are small containers of radiation placed in or near the tumor while a person is in a deep sleep (under general anesthesia) or with the area numbed (local anesthesia). They allow a person to get 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 put in place at an outpatient center, while others may require that the person stay in the hospital for a few days. The placement can be permanent or temporary.

### **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. Most side effects go away in time. But be sure to talk to your health care team about any discomfort you are feeling as there are often ways to help.

## Chemotherapy

While surgery and radiation therapy are used to treat localized cancers, chemotherapy (often called just “chemo”) is used to treat cancer cells that have spread to other parts of the body. Depending on the type of cancer and its stage, chemo 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.

## **What is chemo?**

Chemo is treatment with strong drugs that are most often given by mouth or by injection. Unlike radiation therapy or surgery, chemo drugs can treat cancers that have spread throughout the body because they travel through the bloodstream. Most often, a combination of chemo drugs is used instead of just 1 drug.

## **How is chemo given?**

Chemo is given in cycles, each followed by a rest period. A cycle may involve one dose followed by several days or weeks without treatment. This gives the normal cells in the body time to recover from the drug's side effects. Doses may also be given several days in a row, or every other day for several days, followed by a period of rest. Some drugs work best when given non-stop over several days.

Different drugs work best on different schedules. If more than 1 drug is used, the treatment plan will show how often and exactly when each drug should be given. The number of cycles you get may be planned before treatment starts (based on the type and stage of cancer) or may be flexible, in order to see how the treatment affects the cancer and your health.

After a cancer is removed by surgery, chemo can reduce the risk of cancer returning. Chemo can also be given before surgery to shrink a tumor before it is removed.

## **Side effects of chemo**

Side effects of chemo depend on the type of drugs, the amounts taken, and the length of the treatment. The most common side effects are nausea and vomiting, short-term hair loss, increased chance of infections, and fatigue. Many of these side effects can be uncomfortable or upsetting. But most side effects can be controlled with medicines, supportive care, or by changing the treatment schedule. If you have side effects, ask your doctor or nurse about ways to help ease or prevent them. Also, some side effects may need to be treated right away.

People getting 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 because of it.

## **Biologic therapies**

The immune system, the body's natural defense system, plays a major role in the body's response to cancer. Some forms of cancer occur when the immune system doesn't destroy cancer cells or prevent their growth. Biologic therapy is an effective treatment for certain cancers. It is sometimes called immunotherapy or biological response modifier therapy.

Biologic treatments use the body's immune system to fight cancer or to lessen the side effects of some cancer treatments.

Biologic therapies can act in several ways. They can stop or slow down cancer cell growth, help healthy immune cells control cancer, and help to repair normal cells damaged by other forms of cancer treatment.

There are several kinds of biologic therapy now in use. More than 1 kind of biologic therapy may be used, or biologic therapy may be combined with chemo or radiation to treat cancer.

## Complementary and alternative therapy

When you have cancer, you are likely to hear about ways to treat your cancer or relieve symptoms that are different from mainstream (standard) medical treatment. These methods can include vitamins, herbs, and special diets, or methods such as acupuncture or massage – among many others.

Not everyone uses these terms the same way, so it can be confusing. The American Cancer Society uses complementary to refer to medicines or treatments that are used *along with* your regular medical care. Alternative medicine is a treatment used *instead of* standard medical treatment.

**Complementary methods:** Complementary treatment methods, for the most part, are not presented as cures for cancer. Most often they are used to help you feel better. Some methods that can be used in a complementary way are meditation to reduce stress, acupuncture to relieve pain, or peppermint tea to relieve nausea. There are others. Some of these methods are known to help, and others have not been tested. Some have been proven not to be helpful. A few have even been found harmful.

**Alternative treatments:** Alternative treatments are those that are used instead of standard medical care. These treatments have not been proven safe and effective in clinical trials. Some of these methods may even be harmful. The biggest danger in most cases is that you may lose the chance to benefit from standard treatment. Delays or interruptions in your standard medical treatment may give the cancer more time to grow.

It is easy to see why people with cancer may think about alternative methods. You want to do all you can to fight the cancer. Sometimes standard treatments such as chemotherapy can be hard to take, or they may no longer be working.

Sometimes people suggest that their method can cure your cancer without having serious side effects, and it's normal to want to believe them. But the truth is that most of these treatments have not been tested and have not been proven to be effective for treating cancer.

As you think about your options, you should talk to your doctor or nurse about any method you are thinking about using. You can also contact the American Cancer Society at 1-800-227-2345 to learn more about complementary or alternative methods.

## Clinical trials

Clinical trials are carefully controlled research studies that are done with patients. These studies test whether a new treatment is safe and how well it works. Clinical trials may also test new ways to find or prevent a disease. These studies have led to many new ways to prevent, diagnose, and treat cancer.

A clinical trial is only done when there is good reason to believe that the treatment, test, or procedure being studied may be better than the one used now. Treatments used in clinical trials are often found to have real benefits. If that happens, they may go on to become tomorrow's standard treatment.

Taking part in a clinical trial does not keep you from getting any other medical care you may need. You are free to leave the study at any time, for any reason. To find out more about clinical trials for your type of cancer, talk to your cancer care team. The American Cancer Society also offers a clinical trials matching service, which will help you find a clinical trial that is right for you. You can reach this service at 1-800-303-5691 or through our Web site at [www.cancer.org/clinicaltrials](http://www.cancer.org/clinicaltrials).

## How is treatment planned?

Planning cancer treatment takes time. Most people want to start treatment right away. They worry that extra time taken to do tests or other things will take up precious time that could be spent treating the cancer.

## How long is too long to wait before treatment?

Different types of cancer grow at different rates. Certain types of leukemias and lymphomas tend to grow more quickly than solid tumors. But most cancers do not grow very quickly, so there is usually plenty of time to get information about your cancer, see specialists, and make decisions about what treatment option is best for you. Keep in mind that the information gathered during this time is key to planning the best treatment plan for you. If you are worried that treatment is not starting right away, discuss your concerns with your cancer care team and be sure that any delays will not cause more problems.

## How does my doctor know how to treat my cancer?

The type of treatment you get will depend on a lot of information. 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 issues. Other things to think about are your personal situation (including how well you can travel and take part in treatment), the effectiveness of each treatment in your case, as well as the possible side effects and risks of each type of treatment.

Your doctor will first gather information about your cancer. A biopsy and other lab tests, physical exams, imaging tests, and your signs and symptoms, are all used to decide on the best treatment for you. Your doctor will use all of this information to choose treatment

options and make recommendations for treatment. Your doctor may talk with other experts to help plan your treatment.

## What should I ask my doctor?

Your relationship with your doctor is a key part of your care. You will likely have one doctor who coordinates all of your care. This doctor should be someone that you feel comfortable with and someone who listens to your concerns and answers all of your questions. Your doctor will explain your diagnosis, your health condition, your treatment options, and your progress throughout treatment.

There will also be nurses with special training and skills who will be working with your doctor. These nurses are there to help you with your treatment or any side effects you may have. In many cases, the nurse can answer your questions. Nurses can also help you get the answers you need from other members of your health care team.

Like all good relationships, your relationship with your doctor is a 2-way street. It is your job to ask questions, learn about your treatment, and become an active part of your cancer care team. Doctors may differ in how much information they give to people with cancer and their families. And people who are newly diagnosed also may differ in the amount of information they need or want. If your doctor is giving you too much or too little information, let him know. Feel free to ask your doctor questions and let him know what you need.

The following are examples of questions you may want to ask:

- What type of cancer do I have? What is the stage or extent of my cancer?
- What is my outlook for the future (prognosis), as you see it?
- What treatment do you suggest and why?
- What is the goal of treatment – to cure or to control 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?
- What kind of changes will I need to make 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 might I have?

- How will you know whether my treatment is working?
- Why do I need blood tests, and how often will I need them?
- If other specialists take part in my care, who will be in charge of my treatment plan?
- 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 come back (recur) with the treatment plans 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?
- How much will treatment cost? Will my insurance pay for it?
- What is the best time to call you if I have a question?
- Should I think about entering a clinical trial?

Make sure that all your concerns and questions, no matter how small, have been answered. It may take more than 1 visit to discuss all of your concerns, and new questions may come to mind. It might be hard to remember all your doctor talks about. Some people find it helpful to take notes, bring a family member or friend, record the conversations, and/or bring a list of questions and write down the doctor's answers.

Remember that you have the right to a second opinion about your diagnosis and 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 all options for the best treatment are being explored. You can also ask whether your doctor has talked with other specialists at the treatment center.

## **Will I have pain?**

Pain is one of the reasons people fear cancer so much. They are afraid that if they have pain, it will not be relieved. Having cancer does not mean that you will have pain. To some people's surprise, some cancers cause no physical pain at all. Even people with advanced cancers do not always have pain. But if pain does occur, there are many ways to relieve or reduce it. Along with medicines, there are other ways to help manage pain, such as imagery (mental exercises designed to allow the mind to influence the body), biofeedback (a treatment method that uses monitoring devices to help people consciously control certain physical processes such as heart rate, blood pressure, temperature,

sweating, and muscle tension), relaxation, distraction, surgery, and nerve blocks. A combination of pain control methods can be used if needed.

Some people don't want to take medicines for pain because they are afraid they will become addicted to them. Research has shown that addiction is not an issue for people with cancer who use pain medications as prescribed by their doctor. People also worry that if they take their medicines around the clock, they will become "immune" to that dose and need higher and higher doses until no dose will work. But increasing the dose when needed increases the success of most prescribed pain medicines.

For more information about pain and pain control, call the American Cancer Society's toll-free number at 1-800-227-2345, or visit our Web site at [www.cancer.org](http://www.cancer.org).

## **Will I be able to work during treatment?**

The answer to this question depends on the type of treatment you are getting, the stage of your cancer, your health, and the kind of work you do. How much work you can do and whether you need to limit how much you do both depend on how you feel during treatment. Some people with cancer are able to go to work and go on with much of their normal every day activities while they get treatment. Others find that they need more rest than usual and cannot do as much. Your doctor may suggest that you limit some of your activities.

Many people are able to keep working while they are getting treatment. You may be able to schedule your treatments late in the day or right before the weekend so that they interfere with work as little as possible. If your treatment makes you very tired, you might want to think about changing your work schedule for a while. Talk with your employer about your needs and wishes. You may be able to agree on a part-time schedule, or maybe 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 and your general health before the cancer was found. Your doctor will be able to tell you if you can exercise and what kind of exercise is OK. Exercise, with periods of rest built into your day, can be helpful for many reasons. It can boost your energy level, relieve stress, decrease anxiety and depression, and make you hungry. You can exercise alone, or you may find it easier and more fun to exercise with a group of friends.

If you enjoyed regular exercise before cancer, keeping up your exercise routine while having 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, your doctor may recommend changes to prevent problems and maintain range of motion in your joints and muscles. Your doctor or a physical therapist can help you come up with a schedule and activities that are right for you.

# How will cancer affect my sex life?

Sexual feelings and attitudes vary greatly among people under any circumstances. This is also true during illness. Some people have little or no change in their sexual desire and energy level because of cancer. Others find that their interest declines because of the physical and emotional stresses of having cancer and getting treatment. Stress may include concerns about changes in appearance; worry about health, family, or money; or the result of treatment side effects, including fatigue and hormone changes.

Some people find that they feel even closer to their partners during this time and have an increased desire for sex. Even though pregnancy may be possible during cancer treatment, it may not be wise because some treatments could cause birth defects. Many doctors tell men and women to use birth control throughout their treatment.

If your sexual desire and energy levels change during treatment, keep in mind that this is normal and can happen for a number of reasons. Some common reasons are stress, fatigue, and other treatment side effects. Body image issues may also play a part. If you have had surgery for a cancer in the pelvic or stomach areas, it may make sex difficult or painful for a time. Some women have vaginal dryness, and some men have problems with erections (erectile dysfunction) as a side effect of some treatments. If possible, discuss these concerns with your cancer care team and your partner.

If you were comfortable with and enjoyed a healthy sex life before starting treatment, chances are you will still find pleasure in physical intimacy during your treatment. You may find that intimacy takes on a new meaning and you relate differently. Hugging, touching, holding, and cuddling may become more important, while sex may become less important.

Good communication is the key to staying sexually active or resuming your sex life with your partner. Your partner's concerns or fears are normal, and they can have an impact on your sex life. Some partners may worry that physical closeness will hurt the person who has cancer. Others may fear that they might "catch" the cancer or be affected by the radiation or chemotherapy. Catching cancer is not possible, but talking about issues like these can clear up many problems. It will also help you find out what different things you can do to make the sexual contact something you can both enjoy.

A healthy sex life can be hard to maintain when there are so many physical and emotional factors involved. Get as much information from your doctor and other resources as you can so that you understand what you can and cannot do before, during, and after treatment. For more information, you may order the free booklets *Sexuality for the Man With Cancer* and *Sexuality for the Woman With Cancer* by calling your American Cancer Society at 1-800-227-2345.

## Fertility

After chemotherapy or radiation treatment, women may find that their periods become irregular or stop. This does not mean that they cannot get pregnant, so birth control is still

needed during treatment. In men, the treatments may reduce or damage sperm cells. But in many cases, men are again fertile after treatment is done.

Whether or not you plan to have children, it is normal to worry about how treatment will affect your fertility. Talk to your doctor before treatment starts about any questions or concerns you have about fertility and cancer treatment. This will help you make the treatment decisions that are best for you.

## How will I pay for all this?

### How much will it cost?

The cost of treatment depends on the type of treatment, how long it lasts, how often it is given, and whether you are treated at home, in a clinic, in the doctor's office, or in the 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 start treatment, find out whether your insurance company or Medicare will pay for your care. Also, find out what part of the cost, if any, you will have to pay.

### Health insurance

If you are in a low-income bracket or are not working, check to see if you can get state or local benefits, such as Medicaid. If you are employed and are thinking about leaving your job, find out about conversion options through your current insurance plan. Conversion options may allow you to switch from your employer's insurance plan to an individual plan with similar coverage. Many group plans allow for conversion to individual plans, but the cost may be much higher. You usually must apply for individual plans like this within 30 to 60 days of leaving your job.

If you are looking at insurance options, look closely at the differences in coverage between plans. Ask about your choice of doctors, as well as protections against cancellations and increases in what you pay for insurance (premiums). Figure out what the plan really covers, especially in the event of an illness that prevents you from working (a catastrophic illness). What are the amounts you must pay yourself (deductibles)? Remember that many health insurance plans have different deductible amounts for different services. Sometimes higher deductibles go with better comprehensive coverage.

Most managed care plans should pay for you to be in a clinical trial if your doctor recommends the treatment and if the clinical trial is approved by a trustworthy agency. These plans also often have case managers or other people with whom your doctor can speak about the need for drugs not usually covered. Health maintenance organizations (HMOs) often pay for preventive care and routine doctor visits; but access to state-of-the-art cancer care can sometimes be hard to get through these organizations.

Learning about your health insurance will help you be ready for the cost of treatment and for talking with all the people who handle your health insurance plan. Patients who understand their insurance and know how to communicate with the insurance company

are more likely to get the coverage they need. You may have to go outside the plan for the cancer care that is best for you. Knowing what your health insurance will cover ahead of time can give you some peace of mind as you make treatment decisions.

There are actions people who have a dispute with their health plan can take. Always keep records of your care and your interactions with health insurance staff and your health care team. Your doctor can usually help you. In cases of denied care, your doctor may have to give more information about your case to the health plan.

If you do not have health insurance, there are several options to look into when trying to get coverage. For instance, an independent insurance broker may be able to help you find a benefits package you can afford. You might also be able to apply for group insurance through professional organizations (such as those for retired persons, teachers, social workers, or real estate agents). Talk to a social worker or call the American Cancer Society at 1-800-227-2345 to find out more about insurance options.

## **What other resources do I have?**

Your health care team will be your first source of support, but there are many places where you can get more help when you need it. Hospital support services are an important part of your care. These might include nursing services, nutritional advice, rehabilitation, or spiritual help.

Some people worry that asking for emotional support is a sign of weakness. They may feel that they need to “be strong” and handle things on their own. You don’t have to be alone to be strong. Emotional support is needed at every stage of the cancer journey, and it can come from many places. Along with your family and friends, consider other sources of support, such as your health care team, support groups, and your place of worship. Asking for support is one way you can stay in control of your situation. Talking about what’s going on and how you feel can bring comfort and reassurance.

It can be awkward to talk about cancer, 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 stress of your illness. Many people with cancer find it easier to talk with people who are going through experiences like theirs. Support groups can also give you useful information about your cancer and its treatment. If you are not able to get to a group near you, there are online support groups like the American Cancer Society Cancer Survivors Network<sup>®</sup>. This is a free, online support network for cancer survivors from all across the country. You can access it at [csn.cancer.org](http://csn.cancer.org). Community agencies can sometimes help with the demands cancer places on families and friends. All of these resources may also be helpful for people who are supporting loved ones with cancer.

A person with cancer is never alone. There are people who care and who are ready to help. For more information about cancer or other topics addressed here, contact us at 1-800-227-2345 or online at [www.cancer.org](http://www.cancer.org).

## To learn more

The American Cancer Society programs listed below may be offered in your area. Check your local phone book for your nearest Society office or call 1-800-227-2345.

### **Cancer Survivors Network<sup>SM</sup>**

The American Cancer Society Cancer Survivors Network is a free online community created by and for people with cancer and their families. This online community is a welcoming, safe place for people to find hope and inspiration from others who have “been there.” Services include discussion boards, chat rooms, and personal Web space to tell your story, blog, post images, exchange private messages with members, and much more. Check it out at <http://csn.cancer.org>.

### **Hope Lodge<sup>®</sup>**

The American Cancer Society Hope Lodge Network offers people with cancer and their families a free, temporary place to stay when their best hope for quality care may be far from home. By not having to worry about where to stay or how to pay for lodging, Hope Lodge guests can focus on getting well. And Hope Lodge offers much more than just free lodging. It provides a nurturing, home-like environment where patients and caregivers can retreat to private rooms or connect with others who are going through similar experiences. The Society can tell you if there are other resources offering free or low-cost housing in cities where a Hope Lodge is not available.

### **I Can Cope<sup>®</sup>**

This is a free educational program for adults with cancer and their families. Doctors, nurses, social workers, and other experts teach classes on different topics, such as cancer treatments, dealing with side effects, eating healthy, sharing concerns, finding resources, and more. I Can Cope classes are also offered online at <http://cancer.org/onlineclasses>.

### **Look Good...Feel Better<sup>®</sup>**

Some cancer treatments can change the way you look. At a Look Good...Feel Better session, you can learn ways to help with side effects like hair loss and skin changes. There are also programs for men and teens. This free program is offered jointly by the American Cancer Society, the Personal Care Products Council Foundation, and the Professional Beauty Association | National Cosmetology Association. For more information, call 1-800-395-LOOK (1-800-395-5665) or your local American Cancer Society office.

### **Man To Man<sup>®</sup>**

The American Cancer Society Man To Man program provides free prostate cancer education and support for men newly diagnosed with prostate cancer, men currently in

treatment, and for the growing number of survivors. Program offerings vary by location. Some programs offer regular group meetings or one-on-one calls with a prostate cancer survivor.

### **Reach To Recovery®**

If you have breast cancer, you may want to talk to someone who knows what you're feeling – someone who has “been there.” The American Cancer Society can help through our free Reach To Recovery program. We can match you with a volunteer who will talk with you about coping with your breast cancer diagnosis and treatment. Every volunteer is trained and is a breast cancer survivor. They know what it is like to hear the words “You have breast cancer.”

### **Road To Recovery®**

Every day, thousands of cancer patients need a ride to treatment, but some may not have a way to get there. If finding a ride is a problem for you, we may be able to help. The American Cancer Society Road To Recovery program provides rides to and from treatment for people with cancer who do not have a ride or are unable to drive themselves. Volunteer drivers donate their time and the use of their cars so that patients can get the lifesaving treatments they need.

### **“tlc”™ magalog**

The “tlc” magalog is the American Cancer Society's catalog and magazine for women. It offers helpful articles and a line of products made for women fighting cancer. Products include wigs, hairpieces, breast forms, bras, hats, turbans, swimwear, and accessories. You can order by phone at 1-800-850-9445 or online at [www.tlccatalog.org](http://www.tlccatalog.org). All proceeds from product sales go back into the American Cancer Society's programs and services for patients and survivors.

## **More information from your American Cancer Society**

The following information may also be helpful to you. These materials may be ordered from our toll-free number, 1-800-227-2345.

A Message of Hope: Coping With Cancer in Everyday Life (also available in Spanish)

Advanced Cancer (also available in Spanish)

Americans With Disabilities Act: Information for People Facing Cancer

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also available in Spanish)

Choosing a Doctor and a Hospital (also available in Spanish)

Fertility and Cancer

Helping Children When a Family Member Has Cancer: Dealing With Diagnosis (also available in Spanish)

Health Insurance and Financial Assistance for the Cancer Patient (also available in Spanish)

In Treatment: Financial Guidance for Cancer Survivors and Their Families

Nutrition for the Person with Cancer: A Guide for Patients and Families (also available in Spanish)

Sexuality for the Man With Cancer (also available in Spanish)

Sexuality for the Woman With Cancer (also available in Spanish)

Talking With Your Doctor (also available in Spanish)

Understanding Chemotherapy: A Guide for Patients and Families (also available in Spanish)

Understanding Radiation Therapy: A Guide for Patients and Families (also available in Spanish)

## **Books**

The following books are available from the American Cancer Society. Call us at 1-800-227-2345 to ask about costs or to place your order.

*Because Someone I Love Has Cancer: Kids Activity Book*

*Cancer in the Family*

*Caregiving: A Step-by-Step Approach for Caring for the Person With Cancer at Home*

*Couples Confronting Cancer*

*I Can Survive!*

*What Helped Get Me Through: Cancer Patients Share Wisdom and Hope*

*What to Eat During Cancer Treatment* (cook book)

No matter who you are, we can help. Contact us anytime, day or night, for cancer information and support. Call us at 1-800-227-2345, or visit [www.cancer.org](http://www.cancer.org).

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For additional assistance please contact your American Cancer Society  
1 · 800 · ACS-2345 or [www.cancer.org](http://www.cancer.org)