



After Diagnosis: A Guide for Patients and Families

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

- Can it be cured?
- What are the best treatment options?
- Will treatment hurt or make me feel bad?
- How long will treatment take?
- Will I have to stay in a hospital?
- Will I be able to keep my job?
- How much will cancer treatment cost?

Here, we answer many 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 prepare for visits with your health care team, we offer ideas for questions you may want to ask. 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 is not meant to replace the advice of your doctor or nurse. Talking with them is the best way to understand what's going on with your body and how treatment will work.

What is cancer?

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

How are cancers alike?

The cells in our bodies all have their own jobs to do. Normal cells divide in a certain way. When they're worn out or damaged, they're replaced with new cells. Cancer is a disease in which cells aren't normal. Cancer cells keep on growing out of control, making new cells that don't die. These cells 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 and cause problems in those places. For instance, cancer cells in the lung can travel to the bones and grow there. When cancer cells spread, it's called *metastasis* (meh-TAS-tuh-sis). But when lung cancer cells start to grow in the bones, it's still called lung cancer. Cancers are named for where they start, not where they end up.

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 or radiation treatments. Often 2 or more treatments are used to get the best results. (We talk about this in the section called "Common types of cancer treatment.")

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

Who gets cancer?

Nearly half of all men and a little more than 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 are found in people older than 55. People of all racial and ethnic groups can get cancer.

Why me?

The first question that comes up for many people with cancer is, "What did I do wrong?" or "Why me?" Because doctors don't know for sure what causes cancer in most cases, many people come up with their own ideas about why they have it.

Some people believe they're being punished for something they did or didn't 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 it.

If you're having these thoughts, you're not alone. They are common among people with cancer. But cancer isn't a punishment for things you did or didn't do. Don't blame yourself. It's painful, and it rarely helps. It's almost never possible to know exactly what caused the cancer. Focus instead on taking good care of yourself now – both your body and your mind.

Did I cause my cancer?

We don't yet know what causes all cancers. We do know that there are certain things called "risk factors" that affect your chance of getting some diseases.

Some risk factors for cancer can be changed and others can't. Risk factors that can't be changed include your age, sex, and family history. Things that can be changed are things you do, such as whether you use tobacco or drink alcohol, what you eat, and how much sun you get. Other risk factors are linked to things in the environment that cause cancer.

But risk factors don't tell us everything. Having a risk factor, or even many risk factors, doesn't mean that you'll get cancer. And some people who get cancer may have few or no known risk factors. Even if a person with cancer has a risk factor, it's very hard to know what part that risk factor may have had in causing the cancer.

Can cancer be inherited?

Some cancers can run in families, but cancer isn't 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 didn't inherit it, nor do they pass it on to their children.

Am I going to die?

It's normal to think about dying if you've 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 = death." But the fact is that most cancers can be treated. There are more than 14 million people living in the United States today who have or had cancer.

The survival rate among different cancers varies greatly, so you'll want to look at how well treatment works for your type of cancer. Numbers can give you an overall picture, but keep in mind that every person is unique. Statistics can't predict exactly what will happen to you. 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 a fast-growing or widespread cancer and are told that they might not be expected to live very long. This is hard to hear and take in. The American Cancer Society has other information that may be helpful in these cases, such as *Advanced Cancer* or *Nearing the End of Life*. Call us to have free copies mailed to you, or visit www.cancer.org to read them online.

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's most important in their lives and 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. This can make it even harder to take in and understand all the medical information shared by the cancer care team. You'll likely need some time to absorb and understand what your diagnosis and treatment options mean for you and your loved ones.

Coping skills

People cope with cancer just like they cope with many other problems in life – each person does it in their own way. 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 your cancer and its treatment.** Some people find that learning about their cancer and its treatment gives them a sense of control over what's happening. Along with your cancer care team, we can answer your questions about cancer and help you find other resources. Call us at 1-800-227-2345 or visit us at www.cancer.org for more information.
- **Express your feelings.** Some people find that giving some kind of outlet to their feelings helps. Many people feel that expressing sadness, fear, or anger is a sign of weakness. In fact, the opposite is often true. It's much harder to express powerful emotions than it is to try to hide them. Hiding your feelings can also make it harder to find good ways to deal with them. There are many ways to express your feelings. Find one that fits you. You might try to talk with trusted friends or relatives, or keep a private journal. Some people express their feelings through music, painting, or drawing.
- **Take care of yourself.** Take time to do something you enjoy every day. Cook your favorite meal, spend time with a friend or loved one, watch a movie, meditate, listen to your favorite music, or do something else you really enjoy.
- **Exercise.** If you feel up to it, and your doctor agrees that it's OK, 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 things feel overwhelming. It's very hard for any one person to handle having cancer all alone. Try to widen your circle by reaching out to friends, family, or support organizations. These people can help you feel less alone. They'll be there to share your fears, hopes, and triumphs every step of the way.
- **Try to focus on what you can control, not what you can't.** Finding ways to be hopeful can improve the quality of your life, but it won't determine whether you'll beat cancer. Despite what you may hear, people's attitudes don't cause or cure cancer. It's normal to feel sad, stressed, or uncertain, and even to grieve over how your life has changed. When this happens, expressing those feelings can help you feel more in control rather than overwhelmed by your emotions. It also frees up energy for all the other things you need to handle.

For more on these topics, you can read *Attitudes and Cancer* and *Coping With Cancer in Everyday Life*. Read them online at www.cancer.org, or call us to have copies sent to you.

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 certainty in their lives. This sadness may seem like depression, but it's not the same. Grieving – feeling sadness, fear, anger, or going through crying spells – is a common reaction to learning you have cancer. It usually doesn't last a long time, and is a normal,

healthy response to such a profound change in a person's life. You can learn more in *Anxiety, Fear, and Depression*. Read it online at www.cancer.org, or call us for a free copy.

About 1 in 4 people with cancer becomes truly depressed. Depressed people often have very low energy, decreased drive to do things, and trouble making decisions. They also may feel useless or helpless. Depression can make it much harder to keep up with cancer treatment plans.

Signs of depression

You may be depressed if your time of grieving:

- Lasts for weeks and doesn't 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 are embarrassed or afraid to admit it if they're depressed. It may help to know that depression can be caused by the chemical changes that go along with cancer. It's not a sign of weakness, and it's no one's fault. Depression can be treated with medicines, counseling, or both. Treatment for depression can help you feel better and regain a sense of control and hope for the future. Talk to your doctor if you have concerns or questions about depression.

How do I talk to people about having cancer?

Here are some tips for talking with some of the key people in your life. You can find more in our other pieces: *Talking With Friends and Relatives About Your Cancer* and *Helping Children When a Family Member Has Cancer: Dealing With Diagnosis*. They can be read online, or call us to have free copies mailed to you.

Your family

Cancer often affects family roles and routines. Your family may need to help you with or even take over things 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. Working as a team helps to make everyone more comfortable with the changes that are part of your family life.

You might not be able to do all the things that you used to. You may be afraid that you'll become a burden to your loved ones. Talk with your cancer team about what you can do, and keep trying to do as much as you can. You and your family should also keep doing things you used to do together – like games or exercise. These are healthy and fun ways 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. But you can't protect someone all the time, and it uses up energy that could be used in better ways.

Some families try to protect the person with cancer from ever getting upset. This can cause tension and confusion as people try to act like everything is OK when it's not. If you think your family is doing this, you might gently let them know you'd rather hear from them about any stresses in the family rather than trying to make sense of all the conflicting messages you're getting. That might also free up more energy to take good care of themselves.

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

Dealing with unexpected feelings

You may find that you're taking out your anger and frustrations on the people you care about most. And even in the most loving families, members sometimes feel resentment or anger when one person is sick and can't do their part for a while. This is more often true when the changes last for a long time.

Though this kind of anger can confuse and upset family members, it's a common response to a major life change. The best thing you can do for each other is be honest about what you're 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 free all of you from the burden of unspoken fears and concerns.

Sometimes you and your loved ones will feel out of step with each other. For instance, you may feel quite hopeful while your spouse is feeling scared. Remember that people react differently to stressful situations. Some family members may become more absorbed in work or spend more time away from home. Others may stay home but remove themselves emotionally by spending time watching TV, reading, or playing video games. Still others may become overly involved in your treatment or personal life. Though it may be hard to do, talking about differences in your coping styles will help you respect and understand each other and, in the end, work together.

Talking with children about cancer

If there are young children in your family, you may be worried about how they'll respond to 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 want to protect the children from their fears and worries. Family members should decide ahead of time how best to talk to their children about cancer.

Keep in mind that if children aren't given honest answers, what they imagine may be worse and even more upsetting. Both adults and children can 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's 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 a chance to ask questions

and have their questions answered. You can read more in our piece *Helping Children When a Family Member Has Cancer: Dealing With Diagnosis*. You can read it online at www.cancer.org, or call us to have a free copy mailed to you.

If you'd like expert help, you could 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's outside of the family.

Romantic relationships

If you're single, you may be unsure how and when to share the news that you have cancer with a romantic partner. Trust yourself to be the judge of the best time to bring it up. You may find it helps to practice what you will say with a friend before talking with your partner. Do try to give your partner a chance to deal with it – don't assume they'll back away from your relationship because of the cancer. Whatever the reaction, you're not at fault for sharing the news at a "bad time."

Your friends and adult relatives

It's up to you to decide if and when you want to discuss your cancer diagnosis with friends and adult relatives. You may find that in the beginning you only want to tell your spouse or partner and a few close friends or family members. Over time you may want to share with a circle of friends and loved ones. Overall, it's usually best to be honest. Keeping cancer 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. Many times people don't know what to say, so they feel awkward and uncomfortable. They also may feel sad or be afraid they'll upset you. They may pull away from you but not explain that it's because they feel sad. Some may become overly polite and careful, and others might ask a lot of 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've never had cancer. You might feel upset to hear that, because you know it's not true. Or, someone may tell you a sad and discouraging story of another person with cancer who died. That's the last thing you want or need to hear! Sometimes people are just talking because they feel the need to respond, even though they don't know what to say. You can help them by telling them what you're OK talking about and what you're not. You could also tell them that you only need them to listen to you, and that 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. They probably want to help you any way they can, but they aren't 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, mow the grass, 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. Try to answer their questions. Be direct, and express your needs and feelings openly. It's usually more stressful to hide emotions than to express them. Sharing can help you and those close to you.

Making treatment decisions

The number and kinds of treatment choices you have will depend on all of these factors:

- The type of cancer you have
- The stage (extent) of the cancer
- Your age, overall health, 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 questions – as many as you need. Make sure you understand your options. Hearing that you have cancer almost always makes people feel like they have to start treatment as soon as possible. But you usually have plenty of time to think through all of your options so you can make the best possible choice.

How is cancer treated?

The major types of treatment for cancer are surgery, radiation, and chemotherapy (which are reviewed in the next section, "Common types of cancer treatment"). You might also have heard about hormone therapies, biologic therapies, targeted therapies, and stem cell transplants.

We have detailed information on all of these treatments, which may help you as you make decisions. We also have more about common treatment side effects and how to manage them. Read more at www.cancer.org, or call 1-800-227-2345 to learn more and have free information sent to you.

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. Knowing the exact type of cancer you have is important in deciding which treatments will work the best. The cancer's stage (how much cancer there is and where it is) will affect treatment options, too.

Your health, lifestyle, and personal preferences will also play a part in deciding which treatment plan is best for you. Some types of treatment might work better for you than others, so be sure you understand your options. Don't be afraid to ask questions. It's your right to know what treatments are most likely to help 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 problems it's causing? This is a key part of the decision-making process. Sometimes the goal of treatment can change over time.

What is remission?

Remission (re-MISH-un) is a period of time when the cancer is responding to treatment or is under control. Some people think that remission means the cancer has been cured, but that's not always the case.

Complete remission means that all the signs and symptoms go away and cancer cells can't be found with any of the tests used for that cancer. It's also possible to have a partial remission. That's when the cancer shrinks, but still causes symptoms or can be detected on tests.

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 might lead to another remission. A cancer that has recurred (come back) may respond to a different type of treatment, such as a different group of drugs or radiation versus surgery.

What is staging?

Staging is the process of finding out how much cancer there is and how far it has spread. Staging the cancer is a key step in making treatment choices. It also gives your cancer care team a better idea of your chances for recovery. The staging process takes time, but it's how you and your cancer care team learn which treatments are likely to work best before you start treatment.

A staging system is a way for your cancer care team to sum up the extent of the cancer. The TNM system is the one used most often. It gives 3 key pieces of information:

- **T** usually describes the size of the main **tumor** and whether it 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 parts 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 parts of the body.

Once the TNM descriptions have been found, they are grouped together into a simpler set of stages, in most cancers stage 0 through stage IV (0-4). As a rule, the lower the number, the less the cancer has spread. A 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 have about what the stage of your cancer means and how it affects your treatment options. Contact us if you need help understanding the stage of your cancer.

Common types of cancer treatment

Surgery

Many people with cancer have surgery, especially if the cancer seems 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's hard to tell how much surgery is 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. Surgery offers the greatest chance of a cure for many types of cancer. It may also be used to treat problems caused by cancer, such as taking out a tumor that's blocking the intestine.

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 (RAY-dee-A-shun) therapy is used mostly to treat localized cancers – those contained in one area. Radiation destroys cancer cells or damages them so they can't grow. It can be used alone or along with surgery or chemotherapy. More than half of all people with cancer get radiation at some point.

How is radiation given?

Radiation is given 2 ways: either high-energy rays are aimed from a machine (external radiation) or implants are put into the body near the tumor.

External radiation: Getting external radiation is painless, much like having an x-ray taken. It's 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 implants: In some cases, radiation may be given through implants placed inside the body. Another name for radiation given as an implant is brachytherapy (BRAY-kee-**THAIR**-uh-pee).

This type of radiation uses small containers of radiation that are placed in or near the tumor. Implants 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. Some implants can be put in at an outpatient center, while others may require that the person stay in the hospital for a few days. Implants are sometimes put in while a person is in a deep sleep, which is called general anesthesia (AN-es-**THEE**-zhuh). Other implants only require that the area be made numb (local anesthesia). Implants can be permanent or temporary.

Side effects of radiation therapy

Side effects vary from patient to patient. The most common side effects are feeling tired, 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 after radiation treatment to the head. Most side effects go away in time, but some might last or might not show up until years later. Be sure to talk to your cancer care team about any problems you have – there are often ways to help.

Chemotherapy

Chemotherapy (pronounced KEY-mo-**THAIR**-uh-pee, but most people call it “chemo”) is treatment with strong drugs that are most often given by mouth or by injection. In most cases, more than one chemo drug is used. Unlike radiation therapy or surgery, chemo drugs can treat cancers that have spread throughout the body because they travel through the bloodstream. It’s given for different reasons, depending on the type of cancer and its stage.

Chemo can be used to:

- Cure the cancer.
- Keep it from spreading.
- Kill cancer cells that may have already spread.
- Slow the cancer’s growth.
- Relieve symptoms caused by cancer.
- Shrink a tumor before surgery is done to remove it.
- Lower the risk of cancer coming back after surgery.

Talk with your doctor or your cancer care team to find out the purpose of your chemo.

How is chemo given?

Chemo is given in cycles, each followed by a rest period. A cycle might be one dose followed by days or weeks without treatment. The rest period gives the body’s normal cells time to recover. Chemo cycles are set up in other ways, too. Some drugs work best when they’re given a few days in a row, or every other day, followed by a time of rest.

If more than 1 drug is used, the treatment plan will show how often and 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. Sometimes the plan may be more flexible. This lets the doctor space the cycles based on how the treatment affects the cancer and your overall health.

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, greater chance of infections, and tiredness. Chemo drugs can have other side effects. Be sure to ask your doctor or nurse what to watch for based on the drugs you’re getting.

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 them. It’s

important to tell your cancer care team about any side effects you have because some, like fever and infection, may need to be treated right away.

People getting chemo sometimes become discouraged about the length of time the treatment takes or the side effects they're having. If this happens to you, talk to your doctor. There are often 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 have because of it.

Other drugs used to treat cancer

Some newer cancer treatments use drugs that are different from what most people think of as chemo. Examples of these drugs are biologic therapies and targeted therapies.

Biologic (BY-o-LA-jick) **therapies** are sometimes called immunotherapy (IM-yuh-no-**THER**-uh-pee). These treatments use the body's immune system to fight cancer or lessen the side effects of some cancer treatments. Different biologic therapies act in different ways. They can stop or slow down cancer cell growth, help healthy immune cells control cancer, or help repair normal cells damaged by other forms of cancer treatment.

Targeted therapies are drugs that target the specific gene changes that help cancer cells grow. They attack the cancer cells' inner workings – the parts that make them different from normal, healthy cells.

These drugs tend to have different side effects from standard chemo drugs. They are often given along with standard chemo and/or other cancer treatments.

Complementary and alternative therapy

When you have cancer, you are likely to hear about other ways to treat it or relieve symptoms. These other ways are different from the mainstream (standard) medical treatments used by your cancer care team. They can include vitamins, herbs, special diets, or methods such as acupuncture or massage – among many others.

Not everyone describes complementary and alternative therapies 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* treatments are those used *instead of* standard medical treatment.

Complementary methods most often are used to help you feel better. Some examples are meditation to reduce stress, acupuncture to relieve pain, or peppermint tea to ease nausea. There are many others. Though some of these methods have been studied and are known to help, others have not been tested. Many of those that have been tested have not been proven to be helpful, and a few have even been found harmful.

Alternative treatments are those that are used instead of standard medical care. These treatments have not been proven safe, and clinical trials have not proven that they work. Some of these methods may even be harmful. Most of the time, the biggest danger is that you can lose the chance to benefit from standard treatment. Delays or interruptions in your medical treatments may give the cancer more time to grow and make it less likely that treatment will help.

Sometimes people suggest that their method can cure cancer without having serious side effects, and it's normal to want to believe them. But the truth is that most alternative treatments have not

been tested in scientific studies. So far, the alternative treatments that have been studied have not been proven to work in treating cancer.

Contact us at 1-800-227-2345 to learn more about complementary and alternative methods in general and to find out about the specific methods you are looking at. You can also visit the “Complementary and Alternative Medicine” page of www.cancer.org for more information.

Clinical trials

You may have had to make a lot of decisions since you’ve been told you have cancer. One of the most important decisions you’ll make is working with your cancer care team to choose which treatment is best for you. You may have heard about clinical trials being done for your type of cancer. Or maybe someone on your cancer care team has mentioned a clinical trial to you.

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’s 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 and sometimes fewer side effects than today’s treatments. If that happens, the new treatment usually goes on to become tomorrow’s standard treatment.

To find out more about clinical trials for your type of cancer, ask your cancer care team if your clinic or hospital offers clinical trials. The American Cancer Society also offers a clinical trials matching service, which can help you find a clinical trial that’s right for you. You can reach this service at www.cancer.org/clinicaltrials or at 1-800-303-5691.

Taking part in a clinical trial doesn’t keep you from getting any other medical care you need. You are free to leave the study at any time, for any reason. You can get a lot more information on clinical trials in our document called *Clinical Trials: What You Need to Know*. You can read it on www.cancer.org or call us to have it sent to you.

How is treatment planned?

Planning cancer treatment takes time. Most people want to start treatment right away. They worry that extra time needed to do tests or other things takes 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 faster than solid tumors, so treatment for these cancers might need to be started within a couple of days. But most cancers don’t grow very quickly, which leaves plenty of time to get information about your cancer, see specialists, and make decisions about which treatment is best for you. Keep in mind that the information gathered during this time is key to planning the best treatment for you. If you’re worried because treatment isn’t starting right away, discuss your concerns with your cancer care team to be sure that any delays won’t cause problems.

How does the doctor know how to treat my cancer?

The type of treatment you get will depend on a lot of things. The type of cancer (including where it is and the cell type), the stage (extent) of the cancer, and your overall health are the most important ones. Other things to think about are your personal situation (including how well you can travel and take part in treatment), how well each treatment will likely work in your case, and 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 (x-rays or scans), and any problems the cancer is causing, are all used to decide which treatment options might be best for you. Your doctor may also talk with other experts to get their opinions. Your doctor will then discuss the goal of treatment and the pros and cons of each treatment option with you.

Getting a second opinion

One way to find out if a suggested treatment is the best one for you is to get the opinion of at least one other doctor before starting treatment. Your doctor shouldn't mind if you get a second opinion and can help refer you to another doctor. A few insurance companies even require a second opinion, but you'll want to find out if your insurance company covers it before you get one.

Once you've decided who you will see for your second opinion, ask that your medical records, original scans, and all test results be shared with the new doctor. That way you won't have to repeat them. You may need to sign a release of information form to have the records sent. Or you may want to take copies of your medical records to the new doctor yourself.

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 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 goals, and your progress throughout treatment.

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

Like all good relationships, your relationship with your doctor is a 2-way street. It's 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 people with cancer and their families. And people who are newly diagnosed also differ in the amount of information they need or want. If your doctor is giving you too much or too little information, let them know. Feel free to ask your doctor questions and let them know what you need.

These are examples of questions you may want to ask:

- What kind of cancer do I have? Where is it?
- Do I need any other tests before we decide on treatment?

- How often do you treat this type of cancer?
- What treatment do you suggest and why?
- What's the goal of treatment – to cure or to control my symptoms?
- What are the possible risks or side effects of treatment?
- Will I be able to have children after treatment?
- What are the pros and cons of the treatment you recommend?
- Are there other treatments I should consider?
- How often will I need to come in for treatment or tests?
- How long will treatment last?
- What if I miss a treatment?
- What kind of changes will I need to make in my work, family life, sex life, and leisure time?
- What are the names of the drugs I'll take? What are they for?
- What other drugs or treatments will I need?
- How will we know if the 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 don't feel sick, does that mean the treatment isn't working?
- What's my outlook for the future (prognosis), as you see it?
- What are the chances that the cancer may come back (recur) with the treatment plans we've discussed? What would we do if that happens?
- What can I do to be ready for treatment?
- Are there any special foods I should or shouldn't eat?
- Is it OK to drink alcohol during treatment?
- How much will treatment cost? Will my insurance pay for it?
- What's the best time to call you if I have a question?
- How do I reach you after hours or on weekends and holidays?
- Should I think about taking part in a clinical trial?

Make sure that all of your concerns and questions, no matter how small, have been answered. It may take more than one visit to discuss all of your concerns, and new questions may come up. It

can be hard to remember everything your doctor talks about. Some people find it helps 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.

You can also ask the doctor or nurse to write all of this down for you:

- Your exact diagnosis and stage
- The names of the drugs you'll be taking and what each is for
- A list of any problems you should call the doctor about right away
- The names and contact numbers of specialists you'll be seeing

This is information you'll want to keep. Bring it to each visit and ask them to update the information as things change.

Will I be able to work during treatment?

The answer to this question depends on the type of treatment you get, the type of cancer, your overall 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 everyday activities while getting treatment. Others find that they need more rest than usual and can't do as much. Your doctor may suggest that you limit some of your activities.

You may be able to schedule your treatments late in the day or right before the weekend so that they affect your work as little as possible. If your treatment makes you very tired, you might have to change your work schedule for a while. 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. They might also have to help you in other ways if you can still do the main duties of your job. Call us for more on this or see the section on www.cancer.org called "Working During and After Treatment."

Will I be able to exercise during treatment?

Your activity level during cancer treatment will depend on your overall fitness and health before the cancer was found and on how treatment is affecting you. Your doctor can tell you if you can exercise and what kind of exercise is OK. Exercise, with rest breaks built into your day, can be very helpful. It can help boost your energy level, relieve stress, decrease anxiety and depression, and make you hungry.

If you enjoyed regular exercise before cancer, keeping up your exercise routine during treatment may help you feel like some areas of your life are still "normal." If you have surgery as part of your treatment, your doctor may recommend changes to help prevent problems and keep full use of 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, even when they're not sick. Some people have little or no change in their sexual desire and energy level during cancer treatment. Others find that they have less interest in sex because of the physical and emotional demands of cancer and treatment.

If your sexual desire and energy levels change during treatment, keep in mind that this happens to a lot of people. It can be caused by stress, feeling tired, and other treatment side effects. How you feel about your body may also play a part.

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

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 reliable sources as you can so that you understand what you can and can't do before, during, and after treatment. Talk with your partner about their concerns and what you feel OK with – which can change from week to week. For more information, read the booklets *Sexuality for the Man With Cancer* or *Sexuality for the Woman With Cancer* at www.cancer.org, or order free copies by calling us at 1-800-227-2345.

Fertility

Even though pregnancy is sometimes possible during cancer treatment, it's not wise – some treatments can cause birth defects. Doctors often tell men and women to use birth control throughout treatment, and even for a few weeks or months after treatment is done.

Women may find that their periods become irregular or stop while getting treatment. This doesn't mean that they can't get pregnant, so birth control is still needed.

In men, the treatments may reduce or damage sperm cells. Even so, men often become fertile again after treatment is done.

Whether or not you plan to have children, it's 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.

You can also learn more about how different cancer treatments can affect fertility and what your options are if you want to have children later. Read *Fertility and Men With Cancer* or *Fertility and Women With Cancer* online at www.cancer.org, or call us for a free copy.

How will I pay for all of this?

How much will it cost?

The cost of treatment depends on the type of treatment, how long it lasts, how often it's given, and whether you're treated at home, in a clinic, in the doctor's office, or in the hospital. Most health

plans, including Medicare, cover at least part of the cost of many treatments. In some states, Medicaid might help pay for certain treatments, even if you don't normally get Medicaid. Before you start treatment, find out whether your insurance will pay for your care. Also, find out what part of the cost, if any, you will have to pay. Talk with your cancer care team social worker about this.

Health insurance

Getting or keeping health insurance

If you're in a low-income bracket or aren't working, check to see if you can get state or local health benefits, such as Medicaid. If you're employed and are thinking about leaving your job, find out about COBRA options through your employer's insurance plan. (Call us or read *What Is COBRA?* at www.cancer.org for more on this.) If your employer has been paying part of your health premiums, your cost under COBRA may be much higher than before.

Before you accept COBRA, compare your COBRA costs and coverage with similar health plans in your state health insurance marketplace. Keep in mind that if you lose your health insurance because you quit or lost your job, you don't have to wait for the open enrollment period in your state marketplace – you'll have a 60-day special enrollment period. (If you lose your health insurance because your spouse lost their job, through divorce, or a number of other reasons, you may still be allowed the 60-day special enrollment.)

Remember that you can't be turned down for marketplace insurance plans because you have cancer. Visit healthcare.gov/marketplace to find out about special enrollment periods, compare plans, learn about help with premiums, and even find out if you qualify for Medicaid. Or you can reach your state marketplace on the phone by calling toll-free 1-800-318-2596.

Learning the ins and outs of your plan

Learning about your health insurance plan will help you be ready for the cost of treatment. This can also prepare you to talk with all the people who will work with your health insurance plan to get payment for your care. Ask for a Summary of Plan Benefits from your insurance administrator at work or from your insurance company.

Patients who understand their insurance and know how to talk with their insurance company are more likely to get their medical needs covered. And knowing what your health insurance will cover ahead of time can give you some peace of mind as you make treatment decisions.

Sometimes health plans won't cover certain things, and will deny payment for them. There are actions you can take to help get health claims paid. Always keep records of your care and all interactions with health insurance staff and your cancer care team. If your plan denies coverage for some treatment or care, ask your doctor how to get help dealing with your health plan.

We have a lot of information on health insurance and financial assistance. You can read it on www.cancer.org, or call us for answers to your questions.

If you don't have health insurance, it's very important to get it. Talk to a social worker or call us at 1-800-227-2345 to find out more about your options.

What other resources do I have?

Your cancer care team will be your first source of information and support, but there are many places where you can get more help when you need it. Hospital- or clinic-based support services are an important part of your care. These might include nurse or social work services, financial aid, nutritional advice, rehab, or spiritual help.

Some people worry that asking for 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, look to other sources of support, such as your cancer 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 worry that they’ll upset you by bringing up the topic or talking about it. You may need to take the first step.

Individual or group counseling and support groups can help you cope. Many people with cancer find it easier to talk with people who are, like them, going through cancer. Support groups can also give you useful information about your cancer and its treatment. If you’re not able to get to a group near you, there are online support groups like the American Cancer Society Cancer Survivors Network[®]. This is a free online support community created by and for people with cancer and their families. Visit <http://csn.cancer.org> to sign up. Community agencies can sometimes help with the many demands cancer places on families and friends. All of these resources may also help those who are supporting and caring for 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 any of the other topics addressed here, find us at www.cancer.org or call us at 1-800-227-2345.

To learn more

American Cancer Society programs

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.

Finding hope and inspiration

The American Cancer Society Cancer Survivors Network is a free online community created by and for people with cancer and their families. You can get and give support, connect with others, find resources, and tell your own story through personal expressions like music and art. Visit <http://csn.cancer.org> to find out more.

Lodging during treatment

The American Cancer Society Hope Lodge[®] program provides free overnight lodging to cancer patients and their caregivers who have to travel away from home for treatment. Not having to

worry about where to stay or how to pay for it allows patients to focus on the most important thing: getting well. And Hope Lodge communities offer much more than just free lodging. They provide 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 also partners with local hotels across the country to provide rooms for cancer patients who aren't able to travel back and forth from home to the hospital while receiving treatment.

Cancer education classes

I Can Cope[®] classes are available free online for people facing cancer and their families and friends. The program is made up of self-paced classes that can be taken anytime, day or night. Visit cancer.org/icancope to use this resource.

Transportation to treatment

Having cancer is hard. Finding a ride to treatment shouldn't be. The American Cancer Society Road To Recovery[®] program provides free rides to cancer patients to and from treatments. Trained volunteer drivers donate their time and the use of their personal vehicles to help patients get to the treatments they need.

Breast cancer support

The American Cancer Society Reach To Recovery[®] program matches trained volunteer breast cancer survivors to people facing or living with breast cancer. Our volunteers give cancer patients and their family members a chance to ask questions, talk about their fears and concerns, and express their feelings. Our Reach To Recovery volunteers have been there, and they offer understanding, support, and hope.

Help for women with appearance-related side effects of treatment

Look Good Feel Better[®] workshops help women with cancer manage the appearance-related side effects of treatment. Trained volunteer beauty professionals teach simple techniques on skin care, makeup, and nail care, and give practical tips on hair loss, wigs, and head coverings. Each registered program participant receives a complimentary beauty kit to use during the workshop and take home. The program is a collaboration of the American Cancer Society, the Personal Care Products Council Foundation, and the Professional Beauty Association. For more information, visit lookgoodfeelbetter.org or call 1-800-395-LOOK (1-800-395-5665).

Mastectomy and hair-loss products

The "tlc"[™] catalog is the American Cancer Society's publication that offers affordable hair loss and mastectomy products, as well as advice on how to use these products, for women fighting cancer. Products include wigs, hairpieces, breast forms, bras, hats, turbans, swimwear, and accessories. You can order at www.tlcdirect.org or by calling 1-800-850-9445. 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 can be read at www.cancer.org or ordered from our toll-free number, 1-800-227-2345.

Dealing with the medical system

Choosing a Doctor and a Hospital (also in Spanish)

Talking With Your Doctor (also in Spanish)

Health Professionals Associated With Cancer Care

More on treatment

A Guide to Cancer Surgery (also in Spanish)

A Guide to Chemotherapy (also in Spanish)

Understanding Radiation Therapy (also in Spanish)

Stem Cell Transplant (Peripheral Blood, Bone Marrow, and Cord Blood Transplants) (also in Spanish)

Coping with cancer

Coping With Cancer in Everyday Life (also in Spanish)

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

Caring for the Patient With Cancer at Home (also in Spanish)

Nutrition for the Person With Cancer (also in Spanish)

We have many other sources of information, including books. If you don't see what you're looking for here, please contact us. We're available anytime, day or night, to help you with cancer information, answers, and support at www.cancer.org or 1-800-227-2345.

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For additional assistance please contact your American Cancer Society
1-800-227-2345 or www.cancer.org