

After Diagnosis:

A Guide for Patients and Families



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

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 cancer care team, we offer ideas for questions you may want to ask. Call us at **1-800-227-2345** or visit **www.cancer.org** for more information and support.

Please keep in mind that this is not meant to replace the advice of your health care provider. Talking with them is the best way to understand what's going on with your body and how treatment will work.

Contact us if you need help finding a health care provider or cancer treatment center. We have information that can help you with these decisions.

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What is cancer?

Cancer can happen at any age. People of all racial and ethnic groups can get cancer.

Cancer can start any place in the body. It starts when cells grow out of control and crowd out normal cells. This makes it hard for the body to work the way it should.

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).

What stage is the cancer?

Staging is the process of finding out how much cancer there is and how far it has spread. Knowing the stage of the cancer helps the doctor decide if more tests are needed. It also helps the doctor know the best treatment to offer and the expected response to treatment. Ask your doctor to explain the stage of your cancer and what it means for you.

What caused the cancer?

We don't yet know what causes all cancers. But 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, the sex you were born as, and your family history. Risk factors that can be

changed are things you do, such as if you use tobacco or drink alcohol, what you eat, and how much exercise or sun you get. Other risk factors are linked to things in the environment that may cause cancer.

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. Talk to your health care team about your risk factors for cancer and how to manage them.

How do I cope?

Taking in the news

At first, most people need some time to adjust to the fact that they have cancer. It's normal to have feelings of disbelief, fear, and anger or to be in shock. You may 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 in different ways. As you look for ways to cope that work 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.

- **Express your feelings.** It may help 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 cancer care team agrees that it's OK, try to continue your usual routine or start a mild exercise program such as walking, yoga, swimming, or stretching. Getting up and moving 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.
- **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 how your cancer may respond to treatment. While your attitude can be important to your overall health, it won't actually cause or cure cancer. It's normal to feel sad, stressed, or uncertain, and even to grieve over how your life has changed.
- **Talk to your cancer care team** if you think you may be anxious or depressed. Let your cancer care team know how you are handling things by reporting emotional concerns so they can help you manage them.

Making treatment decisions

Before getting any treatment, your doctor will first need to learn more about your cancer. The results of a biopsy, blood tests, physical exams, and imaging tests (x-rays or scans), along with any problems the cancer is causing, are 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.

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 and overall health
- Your personal choices

You are a key part of your cancer care team; you should talk about what treatment choices you feel are best for you. Don't be afraid to ask questions – as many as you need.

Getting a second opinion

One way to find out if a treatment is the best one for you is to get the opinion of at least one other health care provider before starting treatment. Your cancer care team shouldn't mind if you get a second opinion and can help refer you to another health care provider. It's good to find out if your insurance company covers a second opinion before you get one.

What is the goal of treatment?

Before starting treatment, ask about the goal of treatment. Is the purpose of the treatment to cure the cancer, to control its growth, or to manage the problems it's causing? This is a key part of the decision-making process. Sometimes the goal of treatment can change over time.

No matter what the treatment goal is, palliative care is a standard part of cancer care. Palliative care can be provided at any time during the cancer experience. It does not treat the cancer itself, but can be used before, during, or after treatment to help manage symptoms. Your cancer care team may work with a group of specialty care providers to manage your symptoms. Palliative care can help you feel good and help support you with the things you want and need to do.

How do I talk to people about having cancer?

Here are some tips for talking with some of the key people in your life. Contact us to learn more about dealing with these difficult, but needed conversations.

Your family and friends

It can be hard to talk about cancer, even with the people you love. Your loved ones may also have a hard time talking about cancer. It's not easy for them to know what to say to help you or make you feel better. Here are some tips to help you and your loved ones deal with cancer.

- Tell your family and friends about your cancer as soon as you feel up to it.
- When you talk to them, explain what kind of cancer you have and how it will be treated. Let them know that you've made the treatment decision along with your doctor.
- Tell the people who are closest to you how you feel. This may not be easy, but it can be a very important way to get the support you need when you need it most.
- If you have trouble talking about your feelings, you might find a support group or a mental health counselor to help you.
- If some people are not OK with talking about your feelings, don't be upset. Try talking to others who might listen.
- You may not be able to do things you were doing before you got cancer. If that's true, let your family and friends know.
- Allow friends and family to help you, and tell them what kind of help you need. It could be help around the house, or a ride to the doctor's office or hospital.
- It's best for your family and friends to keep doing the things they did before you had cancer, if possible. They should not feel guilty about this.

Talking with children about cancer

If there are children in your family, you may be worried about how to talk with them about cancer and how they'll respond to the news. Family members should decide ahead of time when and how best to talk 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.

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.

Common types of cancer treatment

The most common treatments for cancer are surgery, radiation therapy, chemotherapy, and targeted or immunotherapy. Many times, more than one type of cancer treatment is used to get the best possible results. For instance, radiation therapy and/or chemotherapy may be used along with surgery.

Surgery

Many people with cancer have surgery, but it is not used for all types of cancer. Surgery can be used 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.

Surgery works best when the tumor has not spread to other areas. Depending on the type and stage of cancer, surgery may offer the greatest chance for a cure. It may also be used to treat problems caused by cancer, such as taking out a tumor that's blocking the intestine.

Radiation therapy

Radiation (RAY-dee-**A**-shun) therapy uses strong beams of energy to destroy cancer cells or damages them so they can't grow. Radiation therapy can be given in different ways:

- **External radiation** (or external beam radiation): uses a machine that directs high-energy rays from outside the body into the tumor. Most people get external radiation therapy over many weeks.
- **Internal radiation:** Internal radiation is also called brachytherapy. A radioactive source is put inside the body into or near the tumor.
- **Systemic radiation:** Radioactive drugs given by mouth or put into a vein are used to treat certain types of cancer. These drugs then travel throughout the body.

The kind of radiation you might get depends on the type and stage of cancer you have and where it is. In some cases, more than one type of treatment is used.

Chemotherapy

Chemotherapy (pronounced KEY-mo-**THAIR**-uh-pee, sometimes called “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. Chemo drugs can help treat certain cancers that have spread to other parts of the body because they travel through the bloodstream. The goal of treatment with chemo can be different, depending on the type of cancer and its stage.

Chemo can be used to:

- Cure the cancer.
- Keep it from spreading.
- 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 cancer care team to find out the purpose of your chemo.

Targeted therapy and immunotherapy

Some cancer treatments use drugs that are different from what most people think of as chemo. Examples of these drugs

are biologic therapies that are known as targeted therapy or immunotherapy.

Immunotherapy (IM-yuh-no-**THER**-uh-pee) is treatment that uses certain parts of the body's immune system to help treat cancer. It may boost the immune system or use man-made immune system proteins to attack cancer cells.

Targeted therapies are drugs that target certain gene changes or proteins that may help cancer cells grow. They attack a specific part of the cancer cell that is different from a normal, healthy cell.

Side effects of treatment

It's important to know that side effects from treatment can be different for each person. No matter what, ask your cancer care team about what side effects you may have from your treatment. If you have any side effects, be sure to talk to them about it; there are often ways to help.

Complementary and alternative therapy

When you have cancer, you are likely to hear about other ways to treat it or relieve symptoms. They can include vitamins, herbs, diets, and other things.

Complementary therapy is used along with standard treatment. There are many complementary methods that have been shown to be safe and can help relieve symptoms or side effects, ease stress or pain, and help you enjoy life more. You can work with your cancer care team to choose therapies that won't interfere with your cancer treatment. Examples may include acupuncture, meditation, aromatherapy, and yoga.

Alternative therapy refers to treatments that are used *instead of* the standard medical treatments used by your cancer care team. These treatments have not been proven safe, and clinical trials have not proven that they work. Some of these methods may even be harmful. If you consider using one of these therapies instead of a treatment recommended by your doctor, you may lose the chance to benefit from the standard treatment. Delays or interruptions in standard cancer treatment may give the cancer more time to grow and make it less likely that standard treatment will help.

Talk to your cancer care team about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

Clinical trials

Clinical trials are research studies that are done to test new drugs or new ways to give treatments in people. In the US, these are carefully controlled studies that have led to how we treat cancer and find new ways to treat it.

If you would like to know more about clinical trials, start by asking your health care provider about where and what type of clinical trials may be available. It's important to know details about any clinical trial you may consider to know if it's right for you. You'll also need to know what other treatment options you may have, and what is involved in getting into, staying in, and leaving a clinical trial.

For more information on clinical trials, you can also call us at **1-800-227-2345** and speak with our caring, trained staff.

Questions for your cancer care team

It's your job to ask questions, learn about your treatment, and be an active part of your cancer care team.

Here are some 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?
- What treatment options do you suggest and why? What are the pros and cons of the treatment options you recommend?
- Should I think about taking part in a clinical trial?
- How much will treatment cost? Will my insurance pay for it?
- What's the goal of treatment – to cure my cancer or to control my symptoms?



- How long will my treatment last?
- What are the names of the drugs I'll take or treatments I will receive and what are they for?
- What are the possible risks or side effects of treatment?
- Why do I need blood tests, and how often will I need them?
- How will we know if the treatment is working?
- What kind of changes will I need to make in my work, family life, sex life, exercise, and leisure time?
- Will I be able to work during treatment?
- Are there foods I should or shouldn't eat, and can I drink alcohol during my treatment?
- If other specialists take part in my care, who will be in charge of my treatment plan?
- Will I be able to have children after treatment?
- What's my outlook for the future (prognosis), as you see it?
- What are the chances that the cancer may come back with the treatment plans we've discussed? What would we do if that happens?
- How can I contact my cancer care team if I have a question or concern?

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 health care provider 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 health care provider's answers.

You can also ask the cancer care team 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 cancer care team 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. In addition to knowing the best phone number to call for questions, ask about a patient portal that your health care provider may have where you can find more information and communicate if needed.

To learn more

American Cancer Society programs and services

The American Cancer Society programs and services listed here may be offered in your area. Check a local directory for your nearest American Cancer Society office or call **1-800-227-2345**.



Lodging during treatment

Our Hope Lodge® program provides a free, nurturing home away from home for cancer patients and their caregivers when they have to travel far from home for treatment. In some areas where we don't have a Hope Lodge community or it is full, our Hotel Partners Program lets patients and caregivers stay for free or at reduced rates in hotels close to where they get treatment.

Transportation to treatment

One of the biggest roadblocks to cancer care can be the lack of transportation. That's why the American Cancer Society started the Road to Recovery® program. It is at the very heart of our work of removing barriers to quality healthy care by providing patients transportation to treatment through volunteer drivers, partners, or community organizations.

Finding hope and inspiration

The American Cancer Society Cancer Survivors Network® provides a safe online connection where cancer patients can find others with similar experiences and interests. At <http://csn.cancer.org>, members can participate on discussion boards, join the chat room, and build their own support network from among the members.

Caregiver Resource Guide

The *American Cancer Society Caregiver Resource Guide* is a tool for people who are caring for someone with cancer. It can help you: learn how to care for yourself as a caregiver, better understand what your loved one is going through, develop skills for coping and caring, and take steps to help protect your health and well-being. You can find this information at <https://www.cancer.org/treatment/caregivers.html>.

Breast cancer support

The American Cancer Society Reach To Recovery® program connects breast cancer patients with trained volunteers who have had similar diagnoses and treatment plans to provide peer-to-peer support on everything from practical and emotional issues to helping them cope with their disease.

Mastectomy and hair-loss products

The American Cancer Society “*tlc*” *Tender Loving Care*® publication offers affordable hair loss and mastectomy products for women coming with cancer, as well as advice on how to use them. Products include wigs, hairpieces, hats, turbans, and breast forms, as well as mastectomy bras, camisoles, and swimwear. Call **1-800-850-9445**, or visit the “*tlc*”™ website at tlc.direct.org to order products or catalogs.



Learning you have cancer can lead to many changes for you and the people you love. You may have a lot of questions, and it can be hard to know where to start.

We hope this booklet helps you learn about cancer and its treatment and helps you find resources to guide you through your cancer journey.

For the latest cancer information, day-to-day help, and support, visit your American Cancer Society website at **www.cancer.org** or call us at **1-800-227-2345**.



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