

A photograph showing a younger woman with brown hair and a blue button-down shirt leaning over an older woman with blonde hair and a white button-down shirt. The younger woman's hand is resting on the older woman's shoulder in a comforting gesture. Both women have their eyes closed.

After Diagnosis

A Guide for People
With Cancer and
Their Loved Ones



**American
Cancer
Society®**

Every cancer. Every life.™

Finding out you or your loved one has cancer can cause many feelings. This brochure will give you information to help you better deal with the diagnosis, make decisions about treatment, and talk to friends, family, and children about your cancer.

This booklet is written from the perspective of the person with cancer. But caregivers, family members, and other loved ones are likely to also find it helpful.

What does it mean to have cancer?

When you find out that you or your loved one has cancer, it may take time to adjust to the news. You may feel afraid, angry, or have trouble believing it's true.

Having cancer is different for each person. Your experience can be affected by:

- The type of cancer you have
- Whether the cancer has stayed where it started or spread to other parts of your body
- How your type of cancer is usually treated
- How old you are
- Whether you have other medical problems

Your experience can also be affected by the responsibilities you have. Do you go to work or school? Are you the main caregiver for children or another adult? Do you provide income needed by your family or yourself?

Each person has their own way of coping when they find out they have cancer. As you look for ways to cope, it may help to:

- **Learn about your cancer and its treatment.** Some people find that learning as much as they can gives them a sense of control over what's happening.

- **Bring someone with you to appointments.** They can help you remember the questions you want to ask and what your cancer care team tells you. They can also take notes for you.
- **Ask where you can find more information about your cancer and treatment options.** You can look at this information when you have more time. It can also help you remember what your doctor or cancer care team tells you.

Making treatment decisions

One of the biggest decisions you will need to make is about treatment. The number and kinds of treatment choices you have will depend on:

- The type and stage of your cancer
- Tests to learn more about your cancer
- Your overall health and any medical problems you have
- Your personal choices



Your cancer care team should explain your options and answer all your questions before you decide which treatment choice is best for you. Be sure you understand what you can expect with each treatment before choosing one.

What is the goal of treatment?

Ask your cancer care team what the goal of treatment is for you. Are they trying to cure your 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.

What are my treatment options?

To get the best possible results, many people with cancer will have more than one type of treatment. For example, radiation therapy and/or chemotherapy may be used along with surgery.

Surgery

Many people with cancer have surgery. Surgery can be used for treatment if the cancer seems to be contained in one area (localized). Surgery may be used to remove some or all of the cancer along with any nearby tissue that might have cancer cells.

Surgery may also be used to treat problems caused by cancer, such as taking out a tumor that's blocking the intestine. If surgery is recommended for you, ask your doctor to explain the goal of the surgery.

Radiation therapy

Radiation therapy uses strong beams of energy to destroy or damage cancer cells so they can't grow. Radiation therapy can be given in different ways:

- **External radiation (or external beam radiation):** A machine directs high-energy rays from outside your body into the tumor.
- **Internal radiation (brachytherapy):** A radioactive source is put inside your body, usually into or near the tumor.
- **Systemic radiation:** Radioactive medicines are given by mouth or put into a vein. These medicines then travel through your body to find certain types of cancer cells.

The kind of radiation you get depends on the type and stage of your cancer and where it is. In some cases, more than one type is used. Ask your cancer care team about the type of radiation prescribed for you, how it might affect your body, and any safety precautions that may be needed.

Chemotherapy

Chemotherapy or “chemo” is treatment with strong medicines that can kill cancer cells. Chemo is used to treat many types of cancer, but not everyone who has cancer will get chemo. 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. (This means the cancer goes away and doesn't come back.)
- Shrink tumors and/or stop the cancer from growing and spreading.
- Relieve symptoms caused by cancer.
- Shrink a tumor before surgery to make it easier to remove.
- Lower the risk of cancer coming back after surgery or radiation.

Talk with your cancer care team to find out the goal of your chemo, what side effects you might have, and if you need to follow any safety precautions during treatment.

Targeted medicine therapy

Targeted medicines find and attack specific parts of cancer cells.

They work in a different way than chemo. Chemo attacks cancer cells, but it can also damage normal, healthy cells. Targeted medicines usually attack cancer cells without damaging normal, healthy cells. But these medicines can still cause side effects, so ask your cancer care team what to expect.

Immunotherapy

Immunotherapy uses certain parts of your immune system to help treat cancer. Some immunotherapy drugs help the immune system work harder so it can find cancer cells and stop them

from growing and spreading. Other types can change how the immune system works so it is better able to attack cancer cells. Ask your cancer care team how the type of immunotherapy you get might affect your body.

Hormone therapy

Some cancers depend on hormones to grow. Treatments that block the effect of hormones might help slow or stop the growth of these cancers. These are used most often to treat breast and prostate cancer.

Clinical trials

Clinical trials are research studies that test new treatments in people. Many cancer clinical trials test a new treatment and compare it to a standard treatment. Standard treatments are those currently being used to treat a type of cancer.

If you would like to know more about clinical trials, talk to your cancer care team. Ask if clinical trial might be an option for you. You can also call the American Cancer Society at **1-800-227-2345** to find out more about clinical trials and the ACS ACTS™ clinical trial matching service.

Side effects of treatment

Side effects from treatment can be different for each person. Ask your cancer care team what side effects you may have from your treatment. Also ask what you can do to prevent or manage these side effects.

Be sure to tell your cancer care team when you have side effects. There are often ways your team can help you manage them.

Palliative care as part of cancer treatment

No matter what treatment you get, palliative care can be a helpful part of your cancer care. Palliative care focuses on improving your quality of life. It helps you cope with the physical, emotional, spiritual, and social impact cancer has on your life.

Palliative care can be used before, during, or after treatment. If you get palliative care, your cancer care team will work with a group of specially trained health care providers to manage your symptoms or side effects. Palliative care can help you feel better and support you with the things you want and need to do.

Getting a second opinion

You might wonder if another doctor could offer you other treatment options for your cancer. If so, you might want to get a second opinion to help you feel more certain about your treatment plan.

Your cancer care team shouldn't mind if you get a second opinion and can help refer you to another cancer doctor. It's good to find out if your insurance company covers a second opinion before you get one.

What if I decide not to get treated, or want to delay my treatment?

Not everyone diagnosed with cancer decides to get treatment or to be treated right away. That is always a choice, but make sure you understand why you are thinking about not getting treatment or delaying it.

It's normal to feel anxious and overwhelmed by the amount of information you've been given. Make sure you get answers to all your questions, so you understand what is likely to happen if you put off treatment or decide not to get treatment.

Complementary, integrative, and alternative therapy

When you have cancer, you are likely to hear about other ways to treat it or relieve your symptoms.

Complementary or integrative therapy is used *along with* standard treatment. There are many complementary methods that have been shown to be safe and can help relieve symptoms of cancer or side effects of cancer treatment. But talk with your doctor or cancer care team before using any of these. Examples include acupuncture, meditation, aromatherapy, and yoga.

Alternative therapy refers to treatments that are used *instead of* the cancer treatments suggested by your doctor and cancer care team. Many of these treatments *have not* been proven safe and effective through research studies. Some might even be harmful.

Examples include special diets, certain supplements and herbs, or high doses of vitamins.

If you consider using an alternative therapy 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 could give the cancer more time to grow and make it less likely that standard treatment will help.

Talk to your cancer care team about any complementary, integrative, or alternative therapy you're thinking about using.

Coping with your cancer diagnosis

You may wonder how cancer will affect your life and the lives of those around you. You might have both physical and emotional changes that impact the way you feel and how you live.

These changes may affect your daily life, but there are ways to cope:

- **Express your feelings.** It may help to talk with trusted friends or relatives, or to keep a journal. Some people like to express their feelings through music, painting, or drawing.
- **Take care of yourself.** Make time to do something you enjoy every day.
- **Stay physically active.** If you feel up to it, and if your cancer care team agrees that it's OK, find an activity you enjoy. Even a short walk can help lower stress.

- **Reach out to others for support.** You might reach out to friends, family, spiritual leaders, or support organizations.
- **Talk to your cancer care team** about any concerns, or if you think you might be anxious or depressed. Let them know how you are coping so they can help you manage your emotions.
- **Think about counseling or joining a cancer support group.** There are many in-person and virtual options.

How do I talk to people about having cancer?

Your family and friends

It can be hard to talk about cancer, even with your loved ones. They may also have a hard time talking about cancer. Here are some tips to help you and your loved ones cope:

- Talk to your family and friends about your cancer as soon as you feel up to it.
- 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 cancer care team.
- Tell the people who are closest to you how you feel. This may not be easy, but it can help you get the support you need.
- Some people may struggle with hearing about your feelings. Try not to let this upset you. Talk to others who are more comfortable listening to you.

Some people will ask you how they can help. Others will wonder what they can do for you but don't know how to ask.

Make a list of things you think you might need help with so family and friends can pick something they're able to do for you. Maybe they can make a meal, go to the store, babysit, walk your dog, or give you a ride to treatment. Think of what might give you time to rest, relax, or take a walk.



Talking with children about cancer

If you have children, you may be worried about how to talk with them about cancer. They will likely be upset but can usually sense that something is wrong. Think about the following when you talk with them:

- Being honest and open can help children feel less confused and afraid.

- Use words they will understand.
- Find a balance between too much and too little information.
- Explain the physical changes they might see.
- Explain cancer is a serious illness.
- Let them ask questions and express their feelings.
- Reassure them that they didn't do anything to cause the cancer.

It's best to share small amounts of information over time and adjust your answers to the child's age and level of understanding. If you'd like expert help, you could ask a social worker or school counselor to help you talk with your child. They may also know of support groups for children in your area.

Questions for your cancer care team

If you've been told you have cancer, you may have a lot of questions. Your doctor or cancer care team is the best place to start. Here are some questions you might ask them:

When you're told you have cancer

- What kind of cancer do I have? Where is it?
- Do you know the stage of the cancer? What does that stage mean for me?
- Do I need other tests before we decide on treatment?

- Can biomarker or molecular testing be done for my type of cancer?
- Should I think about genetic counseling and testing for myself or my family?

Deciding on a treatment plan

- What treatment options do you suggest? Why?
- What's the goal of treatment? Do you think it could cure my cancer?
- What are the risks and benefits of the treatment options?
- How soon do I need to start treatment?
- What will happen if I decide not to get treatment right now?
- Should I get a second opinion? How would I do that?
- Is there a clinical trial that might be right for me?
- Will I be able to have children after treatment? Are there things that can be done to protect my ability to have children in the future?

Insurance and money concerns

- Who can help me figure out what my insurance covers and what I will have to pay myself?
- What financial support can I get to help pay for daily needs or medical costs insurance doesn't cover?
- What can I do if I don't have health insurance?

- What can I do if I can't afford the treatments I need?
- Is there a financial counselor or patient navigator I can talk with?

Getting ready for treatment

- What will my treatment be like? How long will it last?
- Where will I go for treatment? Who will do my treatments?
- Will I be able to go to work or school, spend time with my family, and do my daily activities during treatment?
- What can I do to get ready for treatment?
- What side effects could I have from these treatments?
- Will I need to take any special precautions while I'm getting treated?
- Do I need to change what I eat during treatment?
- Will I be able to exercise? What kind of exercise can I do, and how often?
- How will we know if the treatment is working?
- What would we do if the treatment doesn't work?
- Can you suggest a mental health professional I can see if I start to feel anxious, depressed, or distressed?
- Will I need help at home? If so, who can help me figure out how to get the help I'll need?

If you choose to delay or not get treated

- What type of follow-up will I need? Will I continue to see my cancer care team or only my primary care provider?
- Who can help me manage my symptoms and cope with my cancer? Would it help for me to see a palliative care team or doctor?
- How much longer do you think I will live? Would hospice be a good option for me?

Keeping track of your cancer treatment information

It may take more than one visit to ask all your questions and discuss all of your concerns.

It can be hard to remember everything your cancer care team talks about. It might help to:

- Bring a list of questions.
- Take notes.
- Bring a family member or friend to help you remember what's said.
- Record the conversations. (Be sure to ask permission before doing this.)

Many doctors and cancer care teams can give you a visit summary that has the information they shared with you.

Ask them to make sure this includes:

- The type and stage of your cancer
- Types of treatments that are recommended
- A list of 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 if your cancer care team has an online patient portal where you can find more information and communicate if needed.

To learn more

American Cancer Society programs and services

The American Cancer Society offers many programs and services that you might find helpful. You can find out more about them at cancer.org/support-programs-and-services or by calling us at **1-800-227-2345**.

Lodging during treatment

Our Hope Lodge® program provides free housing for people with cancer and their caregivers when they have to travel for treatment.

If your treatment facility doesn't have a Hope Lodge community nearby, the American Cancer Society partners with hotels in many locations.

Rides to treatment

Our Road To Recovery® program provides free transportation to cancer-related medical appointments.

Help navigating your cancer journey

The ACS CARES™ mobile app helps the person with cancer and their loved ones find the information and resources they need to navigate the cancer journey. Visit cancer.org/acscares to learn more.

Connecting cancer survivors

The American Cancer Society Cancer Survivors Network® provides a safe online connection where people with cancer can find others with similar experiences and interests. At csn.cancer.org, people with cancer, survivors, and caregivers support each other, ask questions, and share practical tips.

Support for caregivers

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. Visit cancer.org/caregiverguide to find out more about this guide.



Learning you or your loved one has cancer can lead to many changes. You may have a lot of questions, but it can be hard to know where to start.

This booklet will tell you about:

- Making treatment decisions
- Coping with the cancer diagnosis
- Programs and services that can help you and your loved ones deal with your cancer diagnosis and treatment

This booklet also includes a list of questions you can ask your cancer care team to help you find out what you need to know about your cancer.



For more information and answers, visit the American Cancer Society website at **cancer.org** or call us at **1-800-227-2345**. We're here when you need us.



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