



Livestrong

Guidebook



Our Purpose

Living with cancer isn't easy, but it doesn't have to be so hard. It's the everyday cancer problems, like telling your loved ones or paying the bills. The problems that simply don't deserve to exist.

Settling for surviving isn't good enough. It's time to change how we help people live with cancer. Livestrong isn't just about hope. Our legacy is more than a wristband. We are listeners, collaborators, and practical problem solvers improving the everyday lives of anyone affected by cancer.

We are finding new solutions to old problems right now so we can fix them for good. We are dedicated to disruptive, energetic, and breakthrough ideas designed to ensure that each and every person with cancer doesn't just survive, they Livestrong.

Because if you're living with cancer, you deserve more than just hope for a better tomorrow. You deserve a better today.

People affected by cancer need more than just hope for a better tomorrow. You deserve the information, tools, and solutions for a better today.

When you hear the words “you have cancer,” you have started your cancer journey. This journey can be challenging and frightening, but know that we’re with you every step of the way. We believe that people affected by cancer need more than just hope for a better tomorrow, you deserve the information, tools, and solutions for a better today.

At Livestrong, we listen to people who are living with cancer to identify the most overlooked problems in cancer care. Then we work to find innovative solutions that can help people right now.

This guidebook is one of the solutions we have created to equip and empower you to face your diagnosis head-on.

This two-volume set is designed to help you navigate your cancer journey, from the moment you’re diagnosed, through treatment and beyond. This guidebook is filled with information and tools, and the planner and journal can help you keep track of important information and records, and also help you sort through your thoughts and feelings.

We created the Livestrong Guidebook to help you make informed decisions and ask the right questions. Use it and make it your own.

Here for you,
Your Livestrong Support Team



Livestrong GUIDEBOOK

A cancer diagnosis brings many unknowns. Most people affected by cancer are unsure about what to do first. They may not know how to get the best care for their own situation. The Livestrong Guidebook can help cancer patients, caregivers and their loved ones. It provides the information and tools that are needed to go through their cancer journey.

When cancer enters your life, you need knowledge, support and hope to help you face the challenges and changes the disease brings. Cancer affects each patient in physical and emotional ways. It also affects day-to-day issues such as insurance, finances and employment.

The Guidebook provides practical information to help you make decisions and find the best health care.

It covers the cancer journey from the time of diagnosis, through cancer treatment and after treatment. The Guidebook offers tools and resources that can empower you as you go through your unique experience with cancer.

The Livestrong Guidebook is organized as follows:

- Just Diagnosed
- During Treatment
- After Treatment
- Healthy Living
- Advanced Cancer



Also, see The Livestrong Guidebook Planner and Journal (Planner) for a calendar, worksheets and journal pages that specifically relate to the information in this book.

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About Livestrong

ABOUT LIVESTRONG

Livestrong provides free cancer support services to help people cope with the financial, emotional and practical challenges that accompany the disease. Founded in 1997, the Foundation is known for its powerful brand—Livestrong—and for its advocacy on behalf of survivors and their families. With its iconic yellow Livestrong wristband, the Foundation has be-

come a symbol of hope and inspiration around the world. Since its inception, the Foundation has raised more than \$500 million to support cancer survivors and served 5 million people affected by the disease. For more information, visit Livestrong.org.

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“You come full circle, and you incorporate your cancer experience into the rest of your life. What that means is you don’t ignore it, you don’t deny it, but it’s not the center of your life.”

—OCTAVIO Z.

Using the Livestrong Guidebook

The Livestrong Guidebook can help you from the moment cancer is diagnosed. It provides information and tools for survivors to use as they go through the cancer journey. The Guidebook can help you live life with cancer on your own terms.

Use the Guidebook to:

- Learn about cancer and treatment
- Find the best health care for your situation
- Know where to find help
- Learn what questions to ask
- Make health and life-planning decisions
- Understand insurance and financial issues

- Keep track of your cancer experience
- Find hope

HOW THE GUIDEBOOK IS ARRANGED

The Livestrong Guidebook is for all people affected by cancer. Because each situation is unique, some of the information may not apply to your condition. It is designed to be easy for you to find what you need. The pages that divide the sections in the Planner have pockets to hold your notes, medical reports, insurance forms and prescription records.



Book 1 is the Livestrong Guidebook. This book provides information that tells you what you will need to know to deal with cancer and treatment. It provides resources to find the best health care and get the help you need. There is also information for loved ones and caregivers.



Book 2 is the Livestrong Guidebook Planner and Journal. This book helps you plan and keep track of your cancer journey. The worksheets and planning pages support the activities described in Book 1. It can help you organize important information. It is also a place to take notes and journal your own thoughts and experiences.

Throughout the Guidebook, you will see at the end of each section a planner icon and sections of the Planner you may want to review.

The Guidebook set covers a great deal of information. It was designed to help you through all phases of the cancer journey. There is information to help you from the time cancer is diagnosed, through

treatment and after you have completed treatment. If you are newly diagnosed with cancer, you may be dealing with many emotions. All of the new information may seem overwhelming. It is important to take care of yourself. Allow yourself to go through the Guidebook information and worksheets slowly at first if that will be helpful. Continue when you are ready to learn more.

Using the Livestrong Guidebook

(continued)

COMMON TERMS USED IN THE LIVESTRONG GUIDEBOOK

The following terms are used often throughout the Guidebook:

Caregivers are friends, loved ones or others who provide daily support and care.

Health care providers are qualified medical professionals, institutions or agencies that provide health services to patients. Providers may include physicians, nurse practitioners and physician assistants.

Loved ones are family and others to whom you turn for support.

Patient navigation programs help patients, families and caregivers successfully get through the health care system.

Patient navigators work one-on-one with survivors to get quality health care. They help identify and reduce barriers. They may be nurses, social workers or community health workers.

Survivors include the person diagnosed with cancer, as well as loved ones, friends, caregivers and others who provide support.

Survivorship starts at diagnosis and continues through treatment and beyond. Survivorship issues include getting good health care, living a healthy lifestyle and dealing with the late effects of treatment.

GLOSSARY OF CANCER TERMS

The **National Cancer Institute (NCI)** maintains an excellent online Dictionary of Cancer Terms that includes the most current definitions for more than 4,000 terms related to cancer and medicine. Go to the NCI website, cancer.gov/dictionary, or contact

the NCI toll-free at 800.422.6237 to get answers to questions about cancer.

THE FOUNDATION'S ONLINE RESOURCES

The Foundation offers free online information, tools and support services for people affected by cancer. There are also materials for professionals who provide cancer support.

Resources and support programs include:

- Free one-on-one support available through the Foundation's navigation services by calling toll-free at 855.220.7777 or requesting support online at Livestrong.org/CancerSupport
- Free cancer information that addresses the physical, emotional and day-to-day concerns of living with cancer online at Livestrong.org/WeCanHelp
- Shared experiences to read or view online at Livestrong.org/Livestrong-Voices, as told by nearly 200 cancer survivors in their own words. Quotes from these shared stories are featured throughout the Guidebook.

The Foundation is grateful to all of the cancer survivors who have shared their personal experiences for the benefit of others.

EDUCATIONAL CONTENT DEVELOPMENT

The information in the Livestrong Guidebook relates to other Foundation educational materials and programs. Experts from specific topic areas work with us to develop and review these educational materials. These experts include physicians, nurse practitioners, physician assistants, nurses, social workers and cancer survivors.

At Livestrong.org/WeCanHelp you can find educational information about many topics related to the cancer journey:

- Brochures on cancer issues
- Shared experiences from cancer survivors
- Free one-on-one professional support with information on counseling needs, clinical trials and help finding or using local resources

DISCLAIMER

The Livestrong Guidebook can help you learn about how cancer might affect your life. It discusses changes and challenges that survivors might experience. The Guidebook can help you learn about important issues that you need to know.

The Guidebook is not intended, nor should it be interpreted, to provide expert medical, legal or financial advice. Always ask a trained professional for advice and specific recommendations for your situation.

WAYS TO GET INVOLVED

You may want to help in the fight against cancer. Join the Foundation in our mission to inspire and empower people affected by cancer. Take steps such as:

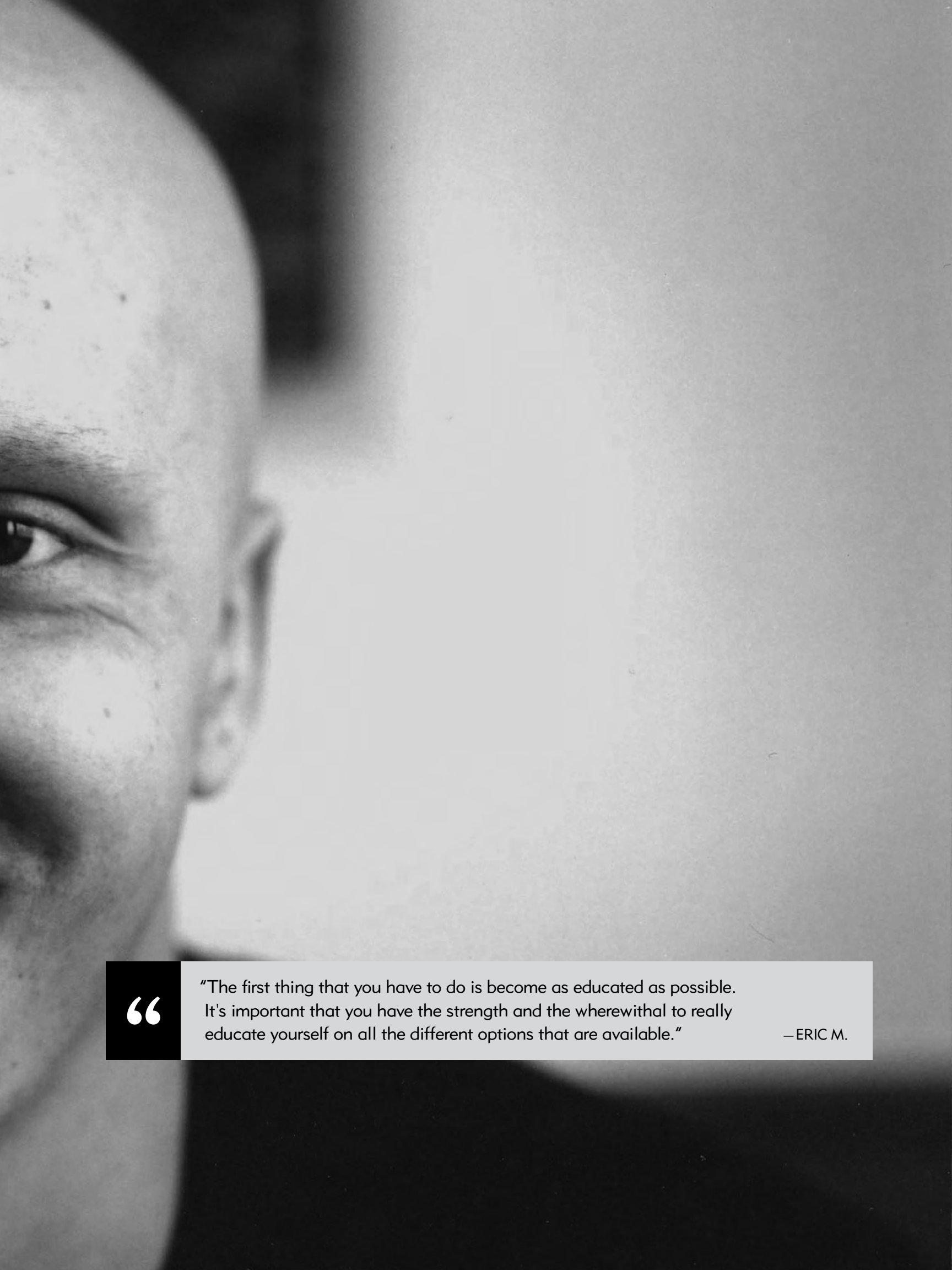
- Telling loved ones, friends and health care professionals about free Foundation resources and programs
- Sharing the word about the Foundation through online sources such as blogs, chat groups, Facebook, Twitter and YouTube

- Participating in events to raise funds and awareness to help others, such as Team Livestrong events
- Becoming a Livestrong Leader in the fight against cancer in your community
- Learning about specific concerns of young adults affected by cancer by viewing the Moving Forward Video Series at Cancer.net/MovingForward and visiting the Young Adult Alliance Online Resource Page
- Telling teachers and parents about the Livestrong at School online (K–12) curriculum to help children whose lives have been affected by cancer
- Staying connected with the Foundation by joining us on Facebook, Twitter and Instagram
- Contributing to help fund Foundation programs and cancer support services

ORDER THE LIVESTRONG GUIDEBOOK

You may order a Livestrong Guidebook and learn about other cancer support information and services by calling the Foundation's navigation services at 855.220.7777.





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“The first thing that you have to do is become as educated as possible. It's important that you have the strength and the wherewithal to really educate yourself on all the different options that are available.”

—ERIC M.



Just Diagnosed: **GETTING STARTED**

This section includes information that is helpful to those who are trying to deal with the emotions, questions and concerns that come with a cancer diagnosis. It includes information about:

- > The Cancer Diagnosis
- > Your Feelings About Cancer
- > Dealing With Emotions
- > Telling Others
- > Starting to Deal With Cancer
- > Developing Your Support System
- > Personal Beliefs and the Cancer Journey

The Cancer Diagnosis

A cancer diagnosis comes as a shock to most people. It is the beginning of a personal journey for each person and for his or her loved ones. Each individual has a unique set of beliefs, values and ways of coping. You will find the ways that work best for you.

“

“Survivorship begins the moment that you are diagnosed. ... It has changed the person I am. It has made me a stronger, much better person.” —CHRIS C.

You are likely to learn and grow as you go through the cancer experience. Many people are surprised to find a new inner strength and courage. Healing can happen on physical, emotional and spiritual levels. This can even result in a renewed outlook on life.

DEFINING CANCER

The **National Cancer Institute (NCI)** defines cancer as a group of more than 100 related but separate diseases. All cancers begin in the body's cells. The body is made up of many types of cells. Normal cells grow and divide to produce more cells as older cells die off. This keeps the body healthy. However, sometimes something goes wrong with the body's process of producing cells.

If the genetic material (DNA) of a cell is damaged or changed, the abnormal cells are able to invade other tissues. These cancer cells can spread through the blood and lymph systems to other parts of the body.

Cancer is generally categorized by where the disease begins in the body and not by where it has spread. For example, lung cancer begins in the lung.

In some types of cancer, new cells form when the body does not need them or old cells do not die when they should. The extra cells form a mass of tissue called a growth or tumor.

Not all tumors are cancerous. They can be benign or malignant. The cells in benign tumors do not spread to other parts of the body. Most importantly, benign tumors are rarely a threat to life.

Malignant tumors are cancer. Cells in malignant tumors are abnormal and divide without control or order. Cancer cells invade and destroy the tissue

around them. They may metastasize or spread to nearby tissues and other parts of the body. Cancer cells spread through the blood and lymph systems.

Not all types of cancers are tumors. Leukemia is a cancer of the bone marrow and blood. In the case of leukemia, cancer may be described as an accumulation or uncontrolled growth of blood cells.

The NCI defines the main categories of cancer as follows:

Carcinoma begins in the skin or tissues that line or cover internal organs.

Sarcoma begins in bone, cartilage, fat, muscle, blood vessels or other connective or supportive tissue.

Leukemia starts in blood-forming tissue, such as the bone marrow, and causes abnormal blood cells to be produced.

Lymphoma and myeloma begin in the cells of the immune system.

Central nervous system cancers begin in the tissues of the brain and spinal cord.

CANCER CAUSES

The causes of all types of cancer are not yet known. Research shows that certain factors can change normal genes into those that allow the growth of cancer. These factors include tobacco use, dietary choices and too much exposure to ultraviolet light, chemicals or certain substances.

The risk of developing certain types of cancer might also be inherited. If there is a history of specific types of cancer in your family, such as breast or colon cancers, talk with your health care provider. Discuss a referral to test for your genetic risk. However, keep in mind that even if a genetic risk exists, cancer may never actually develop.

It is not your fault if you get cancer. There are many myths about what causes cancer. Wrong beliefs that are shared by others can be hurtful and confusing. For example, it is not true that someone who has the disease can spread cancer. An injury or bruise does not cause cancer. If you are unsure about what you hear or read, talk with your health care provider.

Look for information about cancer that has been medically proven to be true. The NCI has good online information (cancer.gov) to help survivors learn about cancer. You can also read about cancer myths at cancer.gov/about-cancer/causes-prevention/risk/myths.

SIGNS AND SYMPTOMS

Some people experience early signs or symptoms that something is wrong. They might feel that something different is happening in their body. They may experience fatigue or weight changes that cannot be explained. Others might have a type of cancer that develops slowly and has no early symptoms.

Cancer may be discovered through a number of ways such as:

- Routine physical exams
- Follow-up exams because of a lump or growth
- Lab testing of blood, urine or tissue
- Screening tests, such as a Pap test, mammogram, fecal occult blood test or a colonoscopy
- X-rays and digital imaging done for other reasons such as an injury

Digital imaging may include computed tomography (CT or CAT) scans, positron emission tomography (PET) scans or magnetic resonance imaging (MRI) testing.

DIAGNOSTIC TESTS

If cancer is suspected, your health care provider will schedule tests to confirm a diagnosis. The following are some of the most common tests:

- Biopsy involves either surgery or a hollow

needle. A small amount of tissue, bone or bone marrow is collected. The sample is then sent to a pathology lab to check for cancer cells under a microscope.

- Blood or urine testing is done to learn more about the type of cancer and if it is affecting other parts of the body.
- Imaging studies (such as a CT, PET or MRI scan) are done to show the presence, location and size of an abnormal mass (tumor).

Before you go through testing, you are likely to have important questions. Ask your health care provider if some types of tests are better for your situation than others. For example, if you want to have children in the future, your provider may decide to avoid certain types of procedures.

Ask a friend or loved one to go with you to medical appointments. He or she can provide support and help you keep track of information.

Some medications that may be used during testing have side effects. For example, some can make you very tired. Find out if you will need help getting home after the testing.

Be sure to tell your health care provider about any physical and emotional concerns that you have as you go through the diagnosis process. Concerns could include depression, fatigue, pain, sexual issues, digestion and urinary or bowel problems. Information that you share can help your provider make the diagnosis and plan for the best treatment.

Your health care provider may prescribe fur-



Ask your health care provider questions about the diagnostic tests such as:

- What will this type of test tell us?
- What are the risks or side effects of each test?
- Are there other tests that have fewer side effects?
- What can I expect during the test?
- How do I prepare for the test?
- How do I get scheduled for the test?
- Do I need to take anything with me when I go for testing?
- When will I get the results?
- Will my insurance cover all of the costs for testing?
- Will I need to have someone drive me home after the test?



ther testing to identify the stage of cancer. The stage describes how it has affected the body. It is based on:

- The size of a tumor
- Whether cancer is in the lymph nodes
- Whether cancer has spread to other parts of the body (metastatic) or is limited to a certain area (localized)

With certain types of cancer, health care providers use the term “grade” to describe the way thin slices of cancer tissue appear when they are viewed under a microscope. There are a number of types of grading systems. For example, the Gleason grade scale is often used with prostate cancer. Grading generally ranges from very well differentiated or nearly normal (grade 1) to very poorly differentiated (grade 5).

Lower numbers (Stages I and II) are used for the early stages of cancer. Higher numbers (Stages III and IV) indicate that the disease is more advanced.

Early diagnosis and treatment methods have greatly improved the chance of recovery for many types of cancer. Testing has become more accurate.

A wrong diagnosis is possible but rare.

Most health care providers agree that it is a good idea to get other medical opinions before making decisions about treatment. Talk with at least one other medical expert (oncologist) who specializes in treating your type of cancer. Getting more than one medical opinion may help you make the best choices.

TEENS AND YOUNG ADULTS WITH CANCER

Adolescents (teens) and young adults (younger than age 40) generally have very specific concerns when they are diagnosed with cancer. A cancer diagnosis can interfere with plans for school, dating, careers and starting families. This is also a time when many young adults want to meet and form close relationships with others their age. There may be concerns about body image and intimacy. Preserving fertility is often important at this age and needs to be addressed before treatment is started. Call 855-220-7777 or schedule a call at [Livestrong.org/CancerSupport](https://www.Livestrong.org/CancerSupport).

Connecting and sharing with other young adults with cancer can be an important part of the healing process. Although there are many information resources for cancer, it can be difficult to find information meant specifically for teens and young adults.

Critical Mass: The Young Adult Cancer Alliance (criticalmass.org) can help cancer survivors, families and health care professionals locate accurate cancer information specifically for young adults about:

- Types of cancer
- Physical issues
- Emotional and relationship concerns
- Day-to-day concerns
- Community resources

The Ulman Cancer Fund for Young Adults provides critical information and support services to help with many issues unique to adolescents and young adults including:

- Support and networking groups
- Information about college scholarships and other education concerns
- Patient advocate/navigator program
- Network for survivors and loved ones
- The *No Way It Can't Be* survival guide for young adults

Visit The Ulman Cancer Fund for Young Adults website at ulmanfund.org or call 888.393.3863.



Seek support from loved ones and friends for your cancer journey:

- ☐ Talk with those you trust about your fears and concerns.
- ☐ Let others know when you need help or support.
- ☐ Tell others what they can do to be helpful to you.

The National Cancer Institute also offers information specifically for adolescents and young adults at cancer.gov. Read about cancers in young people (ages 15–39) including information about diagnosis, treatment and support resources. For more information about cancer stages and other terms used to diagnose, visit cancer.gov/about-cancer/diagnosis-staging.



Livestrong means asking questions and learning about your cancer diagnosis.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding My Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Finding Meaning
- Living With Uncertainty
- Hope

Your Feelings About Cancer

Life is immediately changed by the words, “You have cancer.” At first, you may not be able to think about anything beyond those three words. Many people describe feeling shocked or numb. It may be hard to believe what you have heard.

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“It was demoralizing. I was 29 years old when I was diagnosed, and I thought, ‘There’s no way.’ I wanted to curl up and stay in bed. Family, friends and my spouse were a major support for me in regards to gathering information and providing love and support.”

—CHRIS O.

Cancer affects each person differently. There may not be a way to identify a specific cause or reason for your cancer. It may make no sense. You might wonder why this happened to you. There is no right or wrong way to feel. Accepting your feelings without judging them is a good way to start your cancer journey.

DENIAL

You might experience denial when cancer is first diagnosed. It can be hard to accept that you have cancer. Yet, denial can serve a good purpose. It might give you time to adjust to the diagnosis.

If denial lasts too long, it can keep you from getting the support and early treatment you need. Fortunately,

most survivors are soon able to move on to acceptance of the cancer diagnosis.

If there are signs that denial has gone on longer than is healthy, talk with your health care team. Ask for a referral to a social worker or other qualified counselor to help you deal with the experience of cancer.

FACING FEARS

There is no way to know in advance what your cancer journey will be. You are likely to face some fears. Most people find that fears lessen as they move forward and begin cancer treatment. In time, you will discover that you are not alone in your fight against cancer. Your health care team, friends and loved ones are fighting with you.

As you begin your cancer journey, think about how you have overcome other difficulties. A trusted loved one or friend may be able to help you do this. Write down ways you have coped with challenges in the past. You will find that you have many strengths and abilities that you can use to deal with cancer. Use your best coping methods in this fight.

Your ability to cope may be made stronger by things such as:

- Finding a support system of friends and loved ones
- Getting support from other cancer survivors
- Having spiritual beliefs
- Learning new things



Ask your health care provider questions about your cancer diagnosis such as:

- Can the cancer diagnosis be a mistake?
- What caused the cancer?
- What are the best treatments?
- Will there be physical changes?
- How will my life change?
- Will I still be able to work?
- When should I tell others?
- What can I tell them about my diagnosis?

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“You can look at it one of two ways: You have cancer, or cancer has you.” —RICK S.

- Knowing what is most important to you
- Using a sense of humor
- Having a fighting spirit

Some individuals deal with fears by learning as much as they can about their type of cancer and treatment. This may help you keep as much control in your own life as possible.

You may find it helpful to talk about concerns and fears with your health care team and loved ones. You may also want to discuss thoughts and feelings with a licensed social worker, counselor or clergy person, or join a cancer support group.

Some people decide not to discuss their cancer diagnosis with anyone for a while. This is a very personal choice. You have the right to handle the cancer journey in your own way.

Many people wonder whether they could die from their type of cancer. This can make anyone feel very fearful. Fear is a common feeling for anyone facing a serious disease—especially in the early stages of diagnosis and treatment. These feelings often lessen with time as treatment begins.

Some people believe that cancer is a death sentence, but this is not true. Today, there are close to 12 million cancer survivors living in the United States—and 28 million worldwide. Many cancer survivors are living healthy lives many years after their cancer diagnosis and treatment.

FINDING HOPE

Hope is the belief that a positive outcome lies ahead. Hope is a way of thinking, feeling and acting that can help you find ways to live with difficult situations. Even if some things about your future appear difficult, you can choose how you will face these challenges. Attitude affects everything.

Keep in mind that a cancer diagnosis is often not what it used to be. There have been major advances



Seek support from loved ones and friends for your cancer journey:

- ☐ Talk with those you trust about your fears and concerns.
- ☐ Let others know when you need help or support.
- ☐ Tell others what they can do to be helpful to you.

in technologies, treatments and pain management options in recent years.

You might be a person who finds it easy to feel hopeful. On the other hand, you may think hope is important but are not sure how to create hope in your own life. Hope is very personal and is different for every person.

Some people think that to be hopeful, you have to pretend things are going well when they really are not. While hope can help ease overwhelming doubts and fears, it is not the same as denial.

Hope is being honest with yourself and positive about your future. Working with your health care team to make treatment choices may help you feel hopeful about your future.

NEW PRIORITIES

Priorities are those things in your life that you think are important. As you deal with cancer, you may find that your priorities change. Setting priorities means deciding what is important to you in your current situation. Your most important goals become your top priorities. These will generally guide the way you organize your life.

You may find that cancer itself causes your priorities to change. For example, you may have less

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“When you are dealing with cancer, there is so much chaos going on in your life. I think that you have to always be on the lookout for that bright, little shining star in the midst of all that chaos, because it’s there.” —ANNA J.



Consider ways to build hope such as:

- ☐ Talking with loved ones and friends
- ☐ Discussing challenges and joys with other survivors
- ☐ Joining a support group
- ☐ Taking part in projects, hobbies or activities
- ☐ Learning about cancer and treatment
- ☐ Finding comfort and guidance through spiritual faith and personal beliefs
- ☐ Planning or looking forward to events or special occasions

energy or feel fatigued during treatment. You might decide to spend less time doing some activities. You might even decide to spend more or less time with certain people.

Changes in your priorities can be confusing to both you and others at first. Talk with friends and loved ones about your needs. Help them understand that there are reasons that your priorities have changed. Most are likely to accept and support your choices.

POSITIVE EFFECTS OF THE CANCER EXPERIENCE

Keep in mind that the cancer journey can also bring good things. The Foundation has done surveys of post-treatment cancer survivors. The majority said that the cancer experience had a positive effect on their lives.

Some of the positive effects reported by cancer survivors included:

- Made me appreciate life more
- Helped me recognize what is important in life
- Renewed my sense of spirituality
- Became better able to cope with problems
- Inspired me to help others

As you go through the cancer experience, you will find what works best for you. You have the right to choose how you want to live your life.



Livestrong means honoring what is important to you.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Emotional Support
- Finding Meaning

Dealing With Emotions

Mood swings and changes in emotions are common during the cancer journey. You might think that you should always feel strong and positive in order to heal. However, feelings like sadness, worry or fear are natural for most people.

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“When I went [for treatment] ... I looked at all these people that had cancer. At first, it frightened me because they were like me. They were frightened. But, as I got to know people, they became fast, furious friends. It is a whole new set of friends, and it has been a wonderful experience. It is broadening my world. We have that in common, and we are supposed to.”

—LISA J.

Dealing with emotions may not be easy at first. When you are diagnosed with cancer, it may be difficult to find the time to identify and honor your feelings. Yet, working through your emotions can help lower stress. This may lead to improved mental and physical health.

Accept your feelings. Be kind to yourself and avoid judging your emotions. Paying attention to what you are feeling can help you better deal with strong emotions. Spend time with people who are positive and uplifting.

Many emotional challenges will lessen or go away as you move into and through cancer treatment. Your sense of hope is likely to increase with time. The experience of dealing with cancer typically helps confidence grow.

It is natural to feel loss after receiving a cancer diagnosis. At first, the thought of living with cancer and treatment can be overwhelming. Some might even feel like giving up hope.

Having a support system is an important part of dealing with emotions. Support from others is very helpful. It is also important to have a health care team that you feel is supportive and works with you during and after cancer treatment.

As you complete treatment and regain your strength, sadness or a mildly depressed mood usually lessens. However, if these types of feelings get stronger or do not go away, talk with your health care provider. Ask him or her to refer you for professional help.

DEPRESSION

The National Institute of Mental Health

(nimh.nih.gov/health/topics) defines depression as a common but serious illness. Depression involves feeling “down” or “hopeless” for weeks at a time. Signs of depression may include:

- Feeling confused
- Being overwhelmed or losing hope
- Having problems with memory or thinking
- Getting too much or too little sleep



Use methods to help you deal with emotions such as:

- ☐ Writing in a journal or notebook
- ☐ Drawing, painting, sculpting or doing other forms of art
- ☐ Doing physical activities such as walking, running or bicycling
- ☐ Practicing yoga, meditation or other methods of relaxation
- ☐ Playing or listening to music
- ☐ Using positive affirmations or sayings
- ☐ Sharing feelings with trusted friends and loved ones
- ☐ Focusing on parts of your health that you can control such as healthy eating

- Feeling extreme fatigue or no energy
- Having little appetite or not wanting to eat
- Feeling very sad and helpless
- Experiencing weight loss or weight gain

Many people need medical treatment to deal with depression. Your health care provider may prescribe counseling and medication. Let your provider know as soon as possible if the depression gets worse or does not improve. He or she might need to change the medication you take and find what works well for you.

Contact your health care provider right away if you experience any of the following:

- Problems in your life due to depression
- Problems in the lives of others due to your depression
- Thoughts of harming yourself
- Thoughts about harming others

Always contact your health care provider immediately or go directly to a hospital emergency room for help if you are thinking about hurting yourself or others. Call 911 and ask for help if you cannot reach your provider.

Adolescents and young adults have specific concerns when they are diagnosed with cancer. This is a time when many want to be meeting others and forming close relationships. It is a time when they may want to focus on careers and start families. A cancer diagnosis can interfere with these important issues. Young adults might have to again depend on others for care and finances at a time when they want to be independent. They are also likely to be worried about body image, dating and intimacy. Family planning and fertility issues may also be a concern. Sharing thoughts and feelings with others, especially other young adults who are also dealing with cancer, can be very helpful.

DEALING WITH THE WORDS AND EMOTIONS OF OTHERS

Dealing with the emotions and beliefs of other people about cancer can also be challenging. For example, those closest to you might worry about losing you. There may also be concerns about how the changes in your life might affect them. It can be hard for you to deal with their fears while you are facing your own.

Sometimes people are not sure what to say when they learn you have cancer. They may not know how to react. Even as they try to offer support, some might say or do things that hurt your feelings or offend you. Some people are uncomfortable thinking about the possibility of cancer in their own lives. Because of their own fears, they may not know what to say to you about your illness. They might not know the best way to help you. Some things that people say may be helpful to you. Other comments might frustrate or upset you. People also can pass on information that is not correct. There are many false beliefs and myths about cancer. For example, although we do not yet know what causes most types of cancers, others might try to tell you a reason for your cancer. They may state their opinion about the best cure for cancer. Some might share ideas and beliefs that are different from your own.

If this happens to you, speak up and let others know that you do appreciate their concern. Feel free to tell them if what they are saying is not helpful to you. If the comments of others concern you, talk with someone you trust about what has been said. When you are not certain about medical advice that has been shared, discuss it with your health care team.

FINDING SUPPORT

Living with a cancer diagnosis can leave you feeling alone. At first, you may wonder how you will cope.

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“I was really concerned about dating after being diagnosed. I was so involved in fighting the disease. Then I started to feel like ... [there] might possibly be a cure. So I started dating someone. Even with that, I was somewhat concerned about how she was going to react when I finally told her that I had cancer. What surprised me was ... it was fine with her—she was willing to accept it. We’re going to get married in September.”

—SCOTT T.

“

“I think there is a tendency ... to want to baby the survivor. It’s an interesting balance, because there are times when we need help, but there are times when we don’t want help.”

—AMY D.

Survivors often find strength in sharing thoughts and feelings with others who understand what they are going through.

Many hospitals and cancer centers have oncology social workers or navigators on staff. They specialize in working with cancer patients and can help you communicate with your health care team and others. They can help you talk about your experiences and find ways to cope. Social workers also provide help with insurance and financial issues. If you have not already met with a social worker, you can ask your health care provider to make a referral.

Cancer support groups can provide a safe place to share experiences with others who are dealing with cancer. Keep in mind that each support group is different. You may need to try several groups to find the one that works best for you. Your health care team may have information about finding cancer support groups in your area. Ask about the location, size and type of group to find one that meets your needs.

OTHER TYPES OF SUPPORT

Many nonprofit cancer organizations offer a variety of resources and support services for patients. For example, the Foundation’s cancer navigation services provide free one-on-one professional assistance. Call toll-free at 855.220.7777 or go to Livestrong.org/WeCanHelp.



Find out more about cancer support groups in your area:

- ☐ Ask your health care team about support groups for your type and stage of cancer.
- ☐ Find out if support groups are available in your clinic or hospital.

The Foundation’s cancer navigation services will help any person affected by cancer with issues such as:

- Concerns about finances, insurance and employment
- Emotional or counseling needs
- Help finding cancer programs or resources in your area
- Information about cancer treatment options

Imerman Angels offer free support by matching cancer patients with a person who has survived the same type of cancer. It is a service for people who have been touched by any cancer, at any stage, living anywhere in the world. Go online to imermanangels.org to learn more.

The **Cancer Support Community** also offers support groups in many locations. Go online to cancersupportcommunity.org or call 888.793.9355.



Livestrong means finding the support you need.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Emotional Support
- Finding a Counselor
- Meeting Other Survivors

Telling Others

There will be decisions to make about telling others about your cancer diagnosis. This is a personal choice. There is no one right time or way to do it. Some individuals may openly share their experience with other people. Others might decide not to share any information – at least not right away.

“

“Going through cancer was a good learning process. I’ve always taken life for granted. It made me realize how many people actually love me and how many people care about me.”

—BLANCHE T.

TALKING WITH LOVED ONES

Talking with loved ones about cancer might be challenging. They are likely to have their own concerns and emotional reactions. It may be difficult for them to hear what you have to say. They may also need time to adjust to the shock of the diagnosis.

After sharing your diagnosis, it may be helpful to allow time for others to talk by listening without interrupting. Then ask them to do the same for you. Discuss the best ways to support one another during the cancer journey.

Telling others about your cancer diagnosis may be especially important when:

- Your diagnosis affects another person’s life.
- You are acting differently.
- You want to explain things that have changed since your diagnosis.
- You want to share your emotional experience.
- You need help with day-to-day matters.
- You need financial assistance.



Decide how to tell others:

- ☐ Decide if, when and what you will tell others about your cancer diagnosis.
- ☐ If you are not sure what to say to someone, ask a loved one, friend or social worker for help.
- ☐ In certain cases, you may want to ask someone else to tell others for you.

Talking With Children and Teens About Cancer

There are important things to consider when talking to children and teens about cancer. Much depends on the age and personality of the child. Both children and teens need time to deal with their feelings.

Younger children need shorter talks with clear and simple facts. They need you to talk about the present. Older children and teens generally want specific information. Teens may want to talk about both the present and the future.

Generally, all children affected by cancer need to be able to talk openly. They need to feel free to ask any questions. Sometimes children can be very direct. They might ask about the possibility of dying. They want to know how this will affect them and who will take care of them if this happens.

Tell your child that he or she can ask you to talk any time. Find out what the child is thinking and feeling. Help the child or teen to communicate their needs, fears and concerns in a way that is appropriate for his or her age. Let the child know that it is also okay to ask you how you are feeling at any time.

A child needs to know that he or she:

- Is not responsible for the illness or the healing
- Cannot catch cancer from another person
- Cannot give someone else cancer
- May sometimes feel angry, sad or scared, and that is okay
- Will always be cared for, no matter what
- Is loved and always will be
- Can continue to live a normal life

Some children can put feelings and thoughts into words, such as writing a poem or in a journal. Others may be better able to express emotions and concerns another way, such as drawing a picture, sculpting with clay or acting out feelings through play. Find a way that works well for each child.

If you need to go away for treatment, your child may find comfort in something you give him or her before you leave such as a special photo or toy.

Help your child find a support system. Good support might come from:

- Teachers
- Counselors
- Support groups with members of the same age group

The National Cancer Institute (NCI) offers good information about helping children and teens cope. Go online to cancer.gov/cancertopics or call toll-free at 800.422.6237. Brothers and sisters of a child with cancer might also be deeply affected. Siblings may be very close. Some may be confused about certain feelings. There may be fear, anger or jealousy.

Parents may be overwhelmed with concerns about the child going through cancer treatment. Siblings may need support that lets them know that they are not alone. A support program may help empower them and ease fears. It may also have a positive effect on the healing process of the entire family.

SuperSibs! is a national program that helps bring hope, belonging and self-esteem to brothers and sisters of children with cancer. It provides free programs and outreach education. There are also college scholarships for siblings. This program works with children and teens between the ages of 4 to 18 years. Call **SuperSibs!** toll-free at 866.444.7427 or go to supersibs.org to request more information.

Livestrong at School can help children and their friends and loved ones deal with cancer. Go online to Livestrong.org/what-we-do/program/livestrong-



Ask yourself the following as you decide how to talk about your cancer diagnosis:

- What do I feel comfortable saying?
- When do I want to tell each person?
- How much personal information do I want to share?
- How will telling others affect my employment situation?

[at-school](#) to find free lesson plans for teachers. The lessons teach children (K–12) about cancer in a way that is hopeful and inspiring. Lessons include videos and activities for different ages.

If a child has cancer, returning to school can build hope for the child and his or her loved ones. School can be a big part of feeling normal and productive. Yet going back to the classroom can also bring new challenges to families whose main focus has been getting through treatment.

The Foundation and the Leukemia & Lymphoma Society have worked together to create resources that address the educational needs of children and adolescents with cancer. Go to mskcc.org/sites/default/files/node/1228/documents/learning-livingwccancer-pdf.pdf to download the booklet, *Learning and Living With Cancer: Advocating for Your Child's Educational Needs*. This booklet provides:

- Insights about what a child may face and what can be done
- Information about the laws that protect the educational needs of children
- Specific ways that schools can help meet the child's educational needs

FRIENDS AND COWORKERS

Many survivors find that it can be hard to know when (and if) to tell others about a cancer diagnosis.

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“My sister said that, for probably about a year, nobody asked about her. My brother was little enough that he did not understand a lot of what was going on. Now he says that he wished people had told him more. ... Instead, he imagined things that were probably much worse than what was going on.”

—AMY D.

It may be easier to talk with friends and coworkers that you have known for a long time. If you do not know someone well, it may be more challenging to decide what to say.

Tell friends and coworkers specifically what information you want them to share with others. For example, you may discuss your health situation with your boss, but also ask him or her not to share certain information with others. This can help you control what information is discussed with other people.

Only you can decide when it is the right time to tell another person about a cancer diagnosis. A good rule of thumb is to tell others when you feel comfortable doing so. If you cannot decide what to do or want help, discuss this matter with a trusted friend, loved one, licensed social worker or counselor.

After you tell family and friends, you may want to find an easy way to keep them up to date on your progress during cancer treatment. It can be hard to manage phone calls, emails and other contacts. One way to do this is by using one of the free websites designed for this type of communication. You can ask a friend or loved one to help you set up your own website. It is then easy to provide updates to others. They can also use the site to send messages that support you during this time.

If this sounds like a good method for you, look into online nonprofit organizations that make it easy to build your own website such as:

- CaringBridge.org
- LotsaHelpingHands.org
- MyLifeLine.org

Friends and loved ones may ask you how they can help. Some of these websites also help you organize ways people can get involved. They can sign up to help with tasks such as cooking, cleaning or transportation.



Livestrong means finding the best way to live your life.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Telling Others You Are a Survivor
- Communicating With Your Partner
- Setting Priorities

Starting to Deal With Cancer

It is important to find ways to move forward with your life after the initial shock of a cancer diagnosis.

Include the following steps as you begin to deal with cancer:

- Learn as much as you can about your type and stage of cancer.
- Find the best health care providers and facilities for you.
- Learn about all of your treatment options and the possible side effects.
- Identify specific concerns and needs you have.
- Find the help you need.

Knowledge is power. Knowing what is happening and what you need to do to meet your needs will make the cancer journey easier.

LEARN AS MUCH AS YOU CAN ABOUT YOUR TYPE AND STAGE OF CANCER

Knowledge can help you make good health care decisions. Learn as much as you can about your type of cancer. Find quality information that can help you make important treatment decisions.

Many patients and their loved ones use the Internet to learn more about cancer and treatment. Some use online support groups, blogs or chat rooms. This can be a good way to share experiences. However, always evaluate the information that others share.

Also, be certain that the source of medical information is qualified to provide that type of help. Talk with your health care team to find out if information is current, accurate and applies to your situation.

FIND THE BEST HEALTH CARE PROVIDERS AND FACILITIES

One of the most important things you must do is to find the health care providers that are best for you. Be certain that the members of your health care team

have experience treating your type of cancer. It is important that you have a good relationship with your team. You need to be able to trust them and feel that you can talk openly. You and your team should be able to work together to make health care decisions.

Many nonprofit cancer organizations can help you find the best health care providers for your type and stage of cancer. They can also tell you about local and national resources that are available and how to use them.

For example, the **National Cancer Institute** provides information about how to find a health care provider or treatment facility. Call 800.422.6237 or visit cancer.gov/about-cancer/managing-care/services/doctor-facility-fact-sheet to request information.



Get more information about your type of cancer:

- ☐ Talk with health care providers such as your physician, nurse practitioners, or physician assistants.
- ☐ Learn about cancer terminology, lab reports and medical reports.
- ☐ Find online cancer information provided by government agencies such as the National Cancer Institute at cancer.gov or call 800.422.6237.
- ☐ Contact nonprofit cancer organizations for more information such as:
 - Cancer.Net at cancer.net or 888.651.3038
 - American Cancer Society at cancer.org or 800.227.2345
 - Centers for Disease Control and Prevention at cdc.gov/cancer or 800.232.4636



Ask your health care team about cancer treatment options:

- Can you tell me about successes you have had with different types of treatment?
- What clinical trials are available?
- What are the benefits of each type of treatment?
- What are the risks of each?
- What would you recommend to one of your loved ones?



Find the right health care providers for you:

- ☐ Ask members of your health care team for their opinions.
- ☐ Talk with loved ones, friends and cancer survivors about their experiences.
- ☐ Contact nonprofit cancer organizations to request help.

LEARN ABOUT ALL OF YOUR TREATMENT OPTIONS AND THE POSSIBLE SIDE EFFECTS

Look into your options for cancer treatment. Ask for information that is specifically related to your type and stage of cancer. Start by talking with members of your health care team. They can help you identify a treatment plan for your needs.

Seek other medical opinions about treatment options as well. For example, you may find that an oncology surgeon will recommend surgical treatment. Another health care provider might recommend

chemotherapy. You will need to find the method that you prefer. Loved ones, friends and other survivors may have experiences to share. Most cancer centers have oncology social workers or patient navigators to provide the support and information you need to make good decisions. In the end, you will need to be the one to decide.

Talk with your health care team about complementary or alternative medicine (CAM) treatments. CAM treatments such as acupuncture or massage may be added to your main cancer treatment plan. Learn more about options by contacting the **National Center for Complementary and Integrative Health**. Go online to <https://nccih.nih.gov/> or call 888.644.6226.

IDENTIFY SPECIFIC CONCERNS AND NEEDS YOU HAVE

Identifying needs early can be very helpful. Think about how cancer treatment could affect your life. Talk with your health care team about those needs. For example, if you want to have children in the future, find out how certain treatments might affect that possibility. In this case, you may want to ask for a referral to a fertility preservation specialist before you begin treatments.

FIND THE HELP YOU NEED

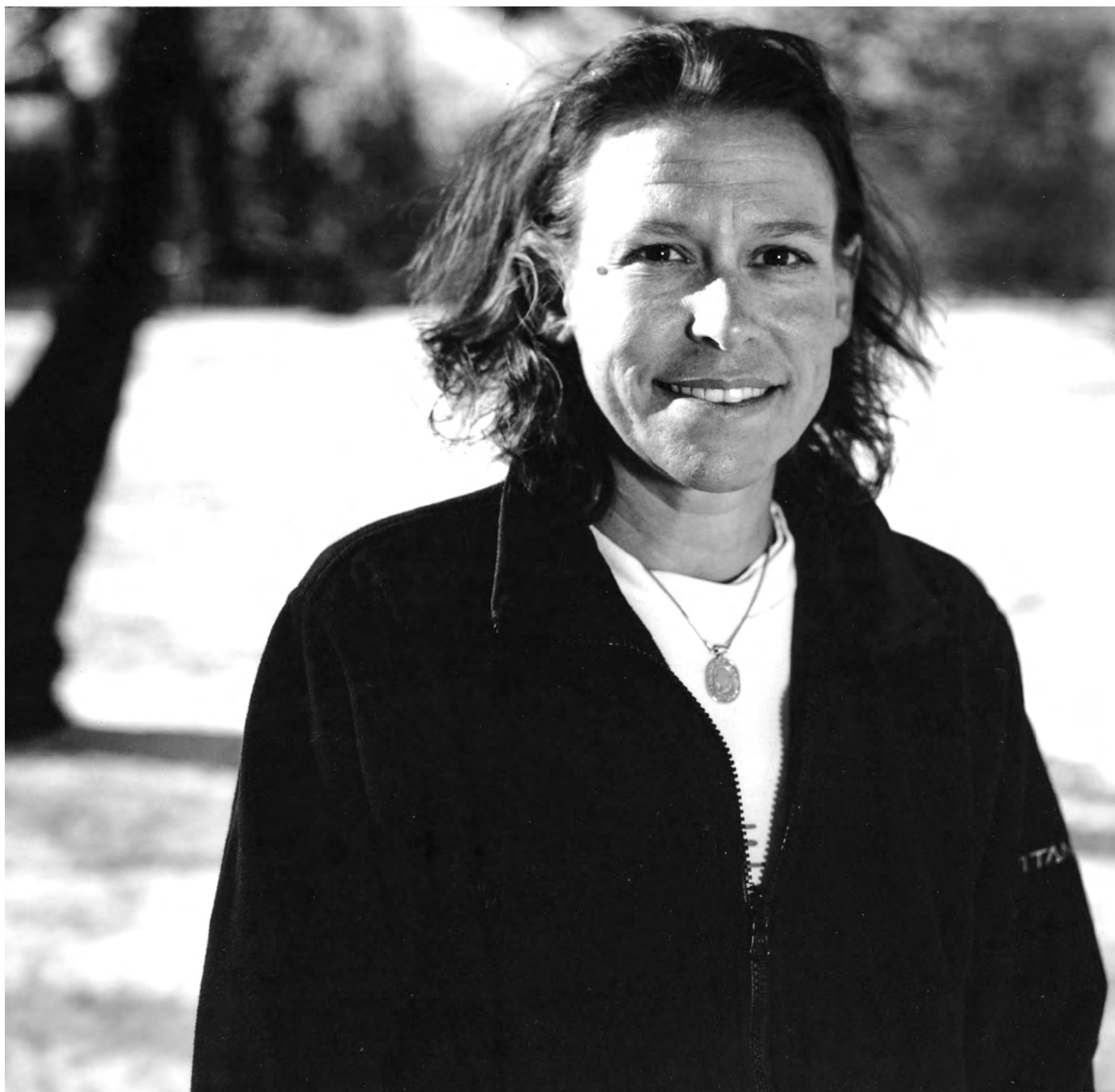
Your health care team will help you get the medical care you need. They can also refer you for support services. Many nonprofit cancer organizations offer services to help you find resources and answers to your questions.

For example, the Foundation's cancer navigation services offer a variety of support that is provided by professionals in the cancer field. Call toll-free at 855.220.7777 or go online to Livestrong.org/WeCanHelp.



Ask yourself questions about your needs such as:

- Are there concerns about having children in the future?
- What effect will cancer treatment have on my ability to work?
- How will cancer treatment affect my loved ones?
- What would be the best way to address my concerns?



Livestrong means finding the way that is best for you to deal with cancer.

See the Livestrong Guidebook Planner and Journal pages:

Just Diagnosed: Finding My Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Telling Others You Are a Survivor
- Communicating With Your Partner
- Setting Priorities

Developing Your Support System

Some cancer patients receive a lot of support from loved ones, friends or caregivers. Others go through the cancer journey with little or no help. In either case, there may be times when extra support will be needed.

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“This website [Lotsa Helping Hands] has been invaluable in assisting my friend in getting meals and help with her kids. We have 35 people signed on, and it has gone so smoothly thanks to your wonderful site. Thank you for setting it up. It is genius.”

—ANNIE

You do not have to go through the cancer experience alone. If you do not know of anyone who can help you, ask your health care provider to refer you to a social worker or nurse navigator. They can help you develop a support system made up of volunteers, members of nonprofit or faith-based organizations or cancer program staff.

Members of your support system can help you:

- Keep track of your health care records and appointments
- Talk with your health care team
- Find information and services you need
- Set up child care services or transportation
- Solve problems by listening and talking with you
- Get through the health care system
- Find help with insurance and financial matters
- Get help with day-to-day needs

ADVOCATES FOR YOU

There may be times when it is important to advocate or speak up for yourself. Yet, you may not always feel well enough to do everything on your own. During these times, others may be willing to speak on your behalf. Advocates care about you and want to support your healing process.

Keep in mind that those who are helping you are not there to make decisions about your health care. However, you might ask them to help you find new health care providers or the treatment you need.

Some hospitals and cancer centers have patient navigation programs. Patient navigators guide individuals through the complex health care systems to get quality care. Ask your health care provider to help you find a patient navigator.



Develop your support system:

- ☐ Make a list of activities others can do to help you.
- ☐ Make a list of people who can provide help and support.
- ☐ Find out when and how others are willing to help.
- ☐ Write down a schedule of dates, times, tasks and who has agreed to help.
- ☐ Share the schedule with all of the people who will be helping you.

ORGANIZING HELP

Most people feel good about helping others. Loved ones, friends, coworkers and neighbors often want to provide support. Let them know what you need, as well as how and when they can help. You may find it difficult to ask for or accept assistance. Yet, think about how willing you would be to help others in a similar situation. Keep in mind that allowing others to help may also help them deal with the cancer diagnosis.

An easy way to organize and schedule helpers is through **Lotsa Helping Hands**. This free online



service offers a private calendar to share with your family and friends. It helps you keep loved ones updated on your health status. You and others can also share messages and photos. Call 866.673.7205 or visit lotsahelpinghands.com.

CaringBridge is another nonprofit organization that offers free and easy-to-create websites for people dealing with health challenges. This service can help family and friends stay connected during

the cancer journey. Instructions and help are provided to create and update your own personal website. Visit caringbridge.org or call 651.789.2300 for more information.

A good support system can help reduce stress. It can allow you to focus on your healing process. If you need help finding support, ask your health care provider to refer you to a social worker, counselor, patient navigator or support group that is right for you.



Livestrong means finding the best support system for your cancer experience.

See the Livestrong Guidebook Planner and Journal pages:

Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Telling Others You Are a Survivor
- Communicating With Your Partner
- Setting Priorities

Personal Beliefs and the Cancer Journey

Every person has his or her own personal beliefs and ideas by which to live. These may also include certain beliefs about spirituality and religion. Many people affected by cancer find that the cancer journey deepens some beliefs. Some find that it even changes the way they think about life.

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“Whatever you believe in, I think that plays a role in it. That provides comfort. I think you get out what you put in.”

—CHRIS O.

Having a belief system can offer a sense of comfort, purpose and connection to others. This is especially true during challenging times. Beliefs may affect the healing process and improve quality of life.

For some, sharing thoughts and feelings can make adjusting to cancer easier. It might also lessen anxiety. The result can be an increased sense of well-being and personal growth.

Let your health care team know if you want them to consider certain spiritual, religious or personal beliefs when developing your treatment plan. Some health care providers may wait for you to bring up this topic. Others might ask you questions about your personal preferences. For example, when you start working with them, they might ask if you follow a specific faith. Providers may also ask about other matters such as your diet or willingness to receive blood products if needed.

If you have specific requests, ask your health care providers to include them in your treatment plan. However, keep in mind that each of the members of your health care team will have their own beliefs. Some may want to avoid certain practices.

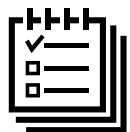
Talk openly with your team if you are concerned that something could interfere with your treatment plan. Work with them to find the best way to deal with concerns.

DEALING WITH DOUBTS

Living with cancer can cause some individuals to question beliefs. This can result in confusion and feelings of doubt. These may add stress and make it harder to deal with the experience of cancer. If you encounter this type of conflict, try talking about your feelings with a loved one, friend, social worker or other counselor.

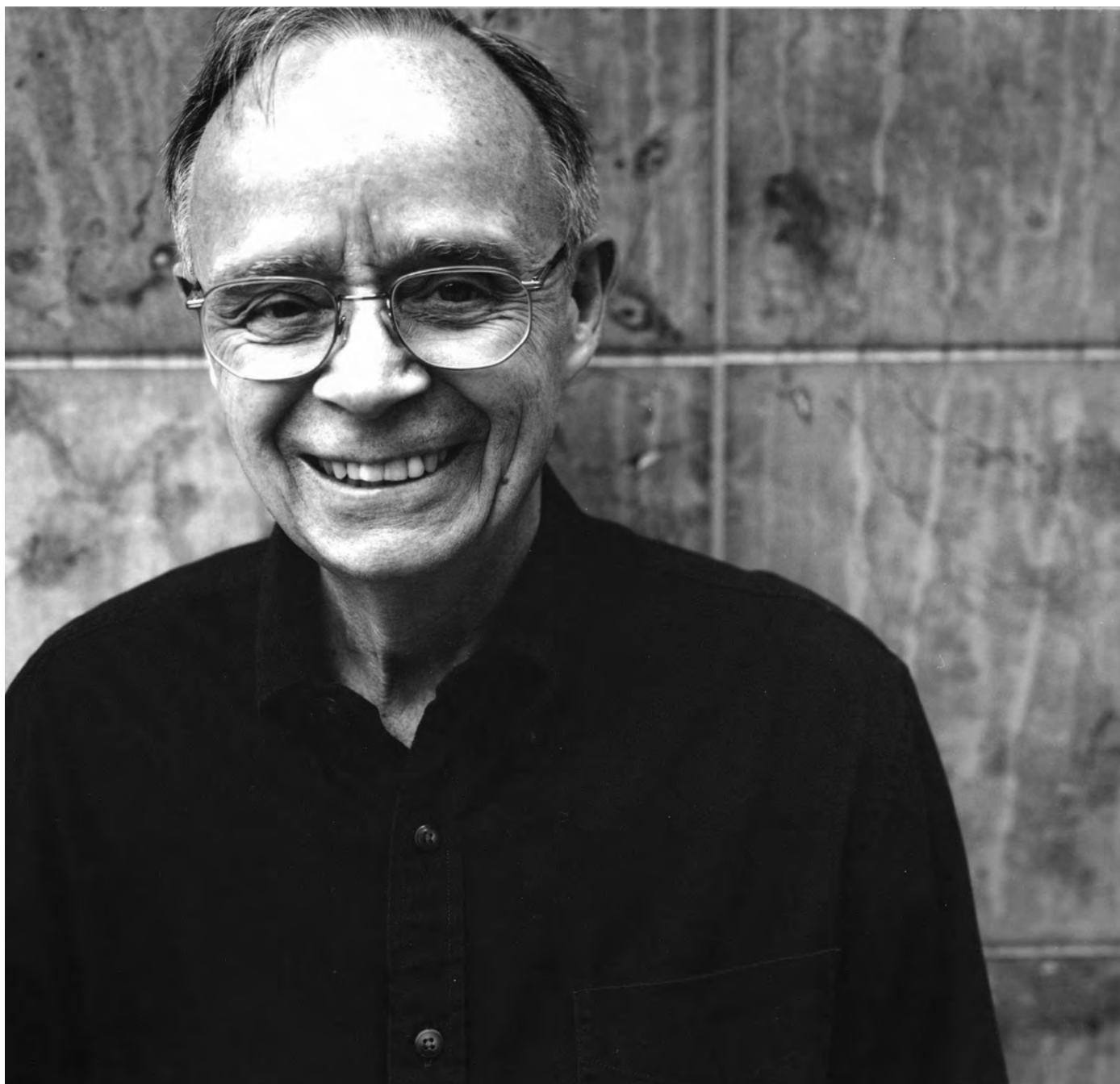
Some people find spiritual or religious support by sharing their feelings with a spiritual counselor or clergy person. Hospital chaplains are also willing to help.

It is normal to question old belief systems during challenging times. Many people have this experience. Yet, the process may lead to deeper understanding and greater peace of mind.



Consider your own thoughts and feelings about important matters including:

- ☐ Beliefs about the purpose of life and connection to others
- ☐ Spiritual or religious beliefs
- ☐ Importance of certain practices such as prayer and meditation
- ☐ Thoughts about faith and loss of faith
- ☐ Beliefs about life after death



Livestrong means facing cancer with the beliefs that support you.

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See the Livestrong Guidebook Planner and Journal pages:

Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Emotional Support
- Finding a Counselor
- Meeting Other Survivors



Just Diagnosed:

MEDICAL CONCERNS

This section includes information that is helpful when you are faced with the need to find and work with a good health care team. It includes resources for finding information and making decisions about cancer treatment options. The following topics are included:

- > Evaluating Cancer Information and Services
- > Learning About Health Care Teams
- > Choosing Your Health Care Team
- > Starting to Work With Your Health Care Team
- > Learning About Cancer Treatment Options
- > Considering Clinical Trials
- > Physical Concerns
- > Developing Your Treatment Plan
- > Life Expectancy and What It Means

Evaluating Cancer Information and Services

Nonprofit cancer organizations and hospital cancer centers offer information and many services for cancer patients and their loved ones. The quality programs are based on current research. Good services come from proven best practices in the cancer field.

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“I think it is very important to make a fully informed decision. Download information, studies and resources, and bring it to your physician so you can start a dialogue.”

—ANN F.

There are also companies that make a profit selling information, products or services. In certain cases, important research has not been done. Always evaluate the information and services you find. Consider who is providing it and why. This is especially important if a product or service is being sold to treat cancer.

EVALUATE WRITTEN CANCER INFORMATION

Cancer information may come from books, pamphlets, brochures and fact sheets. A lot of information can also be found on the Internet, including cancer articles, blogs and websites. Quality information is available. However, not all online and printed information is current and accurate. Some information has not been researched and may even be harmful. When you evaluate cancer information, ask the following:

Who wrote the information?

Find out who is providing the health information. Check on their qualifications to give this type of advice. If possible, find out who wrote the information.

When was the information written?

Information about cancer can change. New information is often released. Yet, some

printed information is not updated. Find out when the information was published and updated. Cancer advice should always be based on current facts.

Who paid for or published the information?

Some companies sponsor resources, including websites, to make a profit. Be very careful if the information tries to sell a product, service or medication. If you are asked to pay for something, it may be that the main purpose is to make a sale.

What does my health care team think of the information?

Some information may not be right for your type and stage of cancer. Your health care team can explain things that are confusing or unclear. They can also recommend websites and resources that provide quality information for your cancer.

EVALUATE PRODUCTS AND SERVICES

Many organizations and companies offer products and services for people affected by cancer. Check the website of each carefully or call their toll-free phone number to ask questions.

Some businesses make false claims or promote unproven cancer cures. Some products have not been clinically tested. There is a risk that these types of products may not work or could even be harmful. At the very least, they may be a waste of money.

The U.S. Food and Drug Administration (FDA) and the Federal Trade Commission (FTC) work together to stop companies from selling drugs or supplements with false cancer cure claims. The FDA has a “Fake Cancer Cures” web link that lists companies and their products: [fda.gov/Drugs/GuidanceComplianceRegulatoryInformation/EnforcementActivities-byFDA/ucm171057.htm](https://www.fda.gov/Drugs/GuidanceComplianceRegulatoryInformation/EnforcementActivities-byFDA/ucm171057.htm).

USE RELIABLE SOURCES OF CANCER INFORMATION

Finding and using good resources can support your healing and recovery. Good information and services may also improve your quality of life. If you do not feel well enough to do this type of research during treatment, ask loved ones, friends and caregivers to help you. Your health care provider can also refer you to a social worker or patient navigator for help.

Some good resources for cancer information and services include:

Livestrong Foundation

- Visit the Foundation’s website at [Livestrong.org/WeCanHelp](https://www.Livestrong.org/WeCanHelp) to find programs and educational materials. Resources include survivor stories, worksheets and information for more than 70 cancer topics.
- Contact the Foundation’s cancer navigation services for free one-on-one help call toll-free at 855.220.7777 or online at [Livestrong.org/WeCanHelp](https://www.Livestrong.org/WeCanHelp).



Evaluate resources by asking:

- What kinds of services are offered?
- Who provides the services?
- Are health care providers on staff?
- Is the information reliable and up to date?
- Is there a cost for products or services?
- What does my health care team think about the resource?

Other nonprofit cancer organizations and government resources

- **American Cancer Society** at [cancer.org](https://www.cancer.org) or call 800.227.2345
- **Cancer.Net** at [cancer.net](https://www.cancer.net) or call 888.651.3038
- **Cancer Support Community** at [cancersupportcommunity.org](https://www.cancersupportcommunity.org) or call 888.793.9355
- **Centers for Disease Control (CDC)**, Cancer Prevention and Control at [cdc.gov/cancer](https://www.cdc.gov/cancer) or call 800.232.4636
- **National Cancer Institute** at [cancer.gov](https://www.cancer.gov) or call 800.422.6237



Livestrong means finding the right help to get through your experience with cancer.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding My Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Finding and Evaluating Resources
- Health Care Assistance Programs
- Transportation and Other Support Services

Learning About Health Care Teams

It can be helpful to understand what each member of your health care team does. If you are not certain about the role of a care provider, ask him or her to explain it to you. You might work with the following health care providers during cancer treatment:

ABOUT PHYSICIANS

Physicians are all trained in general medicine. Some specialize in family practice or internal medicine. Some get more training in a specialty such as pediatrics, hematology, radiation therapy, oncology or oncologic surgery to treat cancer.

If you are being treated in a university or teaching hospital, you might work with one or more of the following types of physicians:

Attending physicians have a doctor of medicine (MD) or doctorate in osteopathic medicine (DO) degree. They have completed residency training. If they are specialists, such as oncologists, they have also completed fellowship training. The national medical board certifies them. Attending physicians have final responsibility for the care of their patients.

Fellows have completed medical school and residency training in a general area of medicine like family practice. They are doing further specialty training such as in oncology.

Residents have graduated from medical school and have completed their internship. They are working with an attending physician to get further training to be certified in a certain area of medicine such as pediatrics.

Interns have graduated from medical school and are training in a general area of medicine such as internal medicine. A senior physician must supervise interns.

Medical students have completed two to three years of medical school and are working in hospital settings supervised by attending physicians.

ABOUT CANCER CARE TEAM MEMBERS

Each member of the health care team is trained to help with certain aspects of treating cancer. A patient's team may include:

Physicians and Health Care Providers

Primary care, general practitioner or internal medicine physicians provide general health care. They usually refer patients to oncologists for cancer care. Your oncologist may want you to continue to work with your usual primary care provider for general health care such as treating high blood pressure.

Medical oncologists, hematologists and radiation oncologists are physicians who specialize in the treatment of cancer. They often work with certain types such as breast or prostate cancer or leukemia.

Pathologists are physicians who diagnose cancer by studying cells and tissues under a microscope. A pathology report is provided to your treating doctor.

Pediatric oncologists specialize in treating the special needs of children and adolescents with cancer.

Surgeons are physicians who can operate and remove the cancer.

Anesthesiologists specialize in giving drugs or other treatments to prevent or relieve pain during surgery and other procedures.

Physiatrists have specialty training to treat pain, fatigue and muscular, skeletal and neurological problems. They prescribe therapies and medications. They also recommend nutrition, fitness and lifestyle changes.

Physician assistants (PAs) are licensed health care providers. Some have a master's or a doctoral degree. Their training and experience along with state laws determine what they can do from diagnosis to treatment. PAs are supervised by physicians.

Nurse practitioners (NPs or APNs) are registered nurses who also have a master's or a doctoral degree. They are licensed practitioners who can work independently or with other providers to diagnose, treat, manage care and prescribe medications. They often work closely with physicians.

Nurses

Registered nurses (RNs) have completed years of training and have a nursing degree. They can administer medications and provide care ordered by a physician, NP or PA. Oncology nurses specialize in cancer care.

Certified nursing assistants or aides (CNAs) have completed months to years of training. Registered nurses or other medical providers supervise them. They provide less technical care such as assistance with bathing and taking vital signs.

Other Health Care Team Members

Social workers may have a bachelor's or master's degree in social work. Oncology social workers provide specialized counseling and support to people who are affected by cancer. Social workers can assist with financial and insurance matters. They can also help set up services including home care, transportation and referrals to resources.

Child life specialists assist, support and advocate for children and their families. They help them through the emotional and physical demands of hospitalization and promote family-centered patient care.

Patient navigators (PNs) may set up health care visits, maintain contact between patients and physicians, arrange transportation, help with insurance forms and generally assist you through the complex health care system. PNs may be nurses, social workers or community health workers.

Diagnostic radiological technologists (RTs) have advanced training to operate diagnostic equipment such as MRI, CT or PET scanners and mammogram machines.

Case managers and care managers coordinate patient care from diagnosis through recovery. They may work for the health care center or for insurance companies. They are often registered nurses.

Physical therapists (PTs) have advanced degrees in physical medicine and rehabilitation. They are licensed to test and treat people in areas related to strength and the ability to move and do physical activities.

Occupational therapists (OTs) have advanced training. They help people improve or return to the ability to do activities such as dressing, eating, working and other tasks that are often part of day-to-day life.

Dieticians and nutritionists are health professionals with special training to help with nutritional choices.

Psychiatrists, psychotherapists and psychologists treat people with mental or emotional concerns. They often help people cope with the challenges of an illness. Psychiatrists are medical doctors and are able to prescribe medications such as anti-depressants.

Dentists and oral surgeons treat some types of cancer and provide important care during and after treatment.

You may also work with other health care professionals such as pharmacists. Hospital chaplains will work with patients and their loved ones of all faiths to help them deal with spiritual and emotional challenges during a hospital stay.

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“Patients need to get both the best professional care and human care. I think it’s more difficult and more demanding on physicians, but that’s just an absolute mandate of how you have to care for a family and a patient with cancer.” —STEVEN W.

HOSPITALS, CANCER CARE CENTERS AND OTHER HEALTH CARE SETTINGS

You may work with different types of health care providers during your cancer journey. Some provide short-term care and others offer long-term care.

Health care services can include:

Outpatient services are often provided in a medical office or clinic. They may be offered in a hospital or cancer clinic if care is to be provided for less than 24 hours. Services might include exams, lab work, radiation therapy or chemotherapy treatments.

Inpatient services are provided when you are admitted to a medical facility. Inpatient providers include hospitals, cancer care centers, nursing homes or assisted living facilities.

Licensed home health care services are offered through home health care agencies. Services are provided in the patient’s home. Services must be prescribed by your health care provider to be covered by insurance. This type of service can be costly, but some people pay for these services on their own.

Cancer care centers are often located within a hospital or medical center. Most treat adults and children in separate areas. There may be clinics for specific types of cancer, as well as labs and treatment areas.

Ask if you do not understand the role of any members of your health care team. You can usually learn more about each member on the Internet such as where he or she was trained. You can also find out if providers are certified by medical specialty. Contact the **American Board of Medical Specialties** at abms.org or call 312.436.2600.



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Read more about living with cancer at Livestrong.org/WeCanHelp

- Communicate With Your Health Care Team
- Individual and Group Health Insurance
- Federal and State Benefit Programs

Choosing Your Health Care Team

Choose a health care team that has had success treating the type of cancer you have. A good team will work with you. They will help you find and get the best treatment for your type and stage of cancer.

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“He [the doctor] gave me absolutely no hope. I had a lot of options. The way he painted the picture was completely different from what the reality was. I went from him, who had performed six surgeries a year, to a doctor who performs six a day—the person who pioneered the technique.” —CHRIS C.

FINDING HEALTH CARE PROVIDERS

Choosing health care providers is often based on the type and stage of cancer. When cancer is diagnosed, your primary care physician, nurse practitioner or physician assistant will likely refer you to an oncologist he or she trusts for cancer treatment. Friends and loved ones might also suggest providers they have worked with. If your provider does not suggest a referral to an oncologist, ask for one. It is considered to be the best practice to have an oncologist lead your cancer team.

INSURANCE COVERAGE

Some health plans allow you to go where you want for treatment. Others only cover expenses for medical providers who are members of their plan. Find out if the health care providers and treatment facility you choose are covered by your plan.

If a provider is not a member of your plan, you may have to pay some or all of the costs. Find out in advance what your portion of the costs are expected to be.

Some plans require advance approval by the insurer before they will pay for services. Make certain that your provider's office has the pre-approval before you start tests, treatments or hospital stays. If they do not, you might have to pay for some or all of the services.

If you are using Medicare or Medicaid benefits,

find out in advance if the health care provider will accept this type of coverage.

INTERVIEWING HEALTH CARE PROVIDERS

Set up a meeting to interview the health care provider before you decide to work with him or her. You can also call or go online to learn more about the hospitals, cancer centers and medical schools that the provider works with.

Send a request for your medical records to the office of your primary care provider. Ask to have the records sent to the oncologist before your first appointment. The oncologist will then have time to review them before your meeting. This can make the time spent with you more productive.

Provide a copy of your medical history, any test results, diagnosis and treatment records each time you meet with a new health care provider. This can save a lot of time.

The **Office of the U.S. Surgeon General** provides an online tool to create your own family health history at familyhistory.hhs.gov. The tool takes the information that you provide and creates a drawing of your family tree and a chart of your family health history. You can print the chart and share it with family members and your provider. This information can help you to talk with your doctor about disease prevention strategies that are right for you.

Your meeting with a new health care provider will

give you a good idea about whether you want to work together. A sense of trust and the ability to work with your health care team are very important.

Do the following during your first meeting with the oncologist:

- Discuss your current diagnosis, pain problems, symptoms and any treatments you have already had.
- Provide information about past health problems including cancer and other medical conditions.
- Ask the provider about the cancer treatment plan he or she suggests for you.
- Find out about the quality of the medical facilities the provider intends to use.

There are many types of cancer. Your oncologist should have experience treating your specific type and stage of cancer. If the provider is not right for you, continue interviewing others until you find one you trust.

Even after you have started to work with a health care provider, you have the right to make a change if you have concerns. You can ask someone you trust, such as an oncology social worker, for suggestions and help to make the change. Check with your insurer to be certain that your plan will cover the services of the new care provider.



Take the following steps when you are looking for your providers:

- ☐ Make a list of the providers you want to interview.
- ☐ Call each provider's office to discuss your diagnosis with a nurse.
- ☐ Make an appointment to meet with the health care provider you like as soon as you can.
- ☐ Get approval for coverage from your insurer before the first meeting.
- ☐ Ask the insurer if other medical opinions will also be covered.
- ☐ Send your health history, list of medications, test results and other medical records to the provider before the first meeting.
- ☐ Take X-rays, MRI and CT films to your appointment to avoid repeating tests.



Ask new health care providers questions such as:

- Can you tell me about your experience successfully treating my type and stage of cancer?
- Which health care facilities do you use for treatment?
- What treatments do you recommend for my situation and why?
- What risks are involved with this type of treatment?



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- Individual and Group Health Insurance
- Federal and State Benefit Programs

Starting to Work With Your Health Care Team

After you have chosen your oncologist and health care team, find out how they want you to work with them. You should be able to talk openly with your health care team members about your symptoms, pain and other changes in your body. You will also want to be able to ask questions and discuss your concerns.

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“I do not think anybody should leave the doctor’s office after an examination or after an interview with the doctor with questions still on their mind.” —BRIAN H.

Members of your health care team are likely to be very busy. It could appear that there is no time to discuss your questions and concerns. Some providers do have a general time limit to spend with each patient. If this is the case, you may need to ask to be scheduled for a longer meeting. Ask for the time you need to discuss your questions.

Some people fear that it is disrespectful to question a physician or other members of the health care team. Asking questions does not mean that you do not respect them. You have the right to understand what is happening with your care.

You have an important role in developing your cancer care plan. If you can talk openly with your health care team, they will be able to work with you to create the best treatment plan. You can then feel confident about the health care you are receiving.

If you feel too ill or do not know what to say, ask a trusted friend, loved one, patient navigator or social worker to help you bring up concerns and questions during your appointment.



Ask your health care provider questions about treatment options such as:

- What are the best treatment options for this type of cancer?
- How long will treatment last?
- How often are treatments required?
- What side effects (both short- and long-term) could come with treatment?
- How will side effects, such as pain, be controlled or managed?
- Can this treatment affect fertility or cause changes in sexual functioning?
- Is it possible that this type of cancer will spread?
- What is the expected outcome (prognosis) for this type and stage of cancer?
- Is it possible to get a secondary cancer from the treatment?
- Is there anything more that can be done to help the healing process?

PREPARING FOR APPOINTMENTS

Always prepare for appointments you will have with members of your health care team. When you begin to work with each, ask what he or she wants to know from you during your meetings. Also, ask how the business office will handle billing and pre-approval of insurance coverage for tests and treatments.

Use a notebook, such as the Livestrong Guidebook Planner and Journal, to keep track of your daily experiences. Write down questions that come up between appointments. Also, keep track of new symptoms you experience.

Keep an up-to-date list of your medications and dosages. Include all vitamins, supplements and over-the-counter medications you take in your list. Review this list with your provider at each of your appointments. Some patients find that it works best to bring all of their medicine containers with prescription information to all medical appointments. This is especially true if you take medications for other problems such as diabetes or heart conditions.

Be sure to tell your provider about any allergies, side effects or reactions to medications you have had in the past. This information is very important when starting treatment with new doctors or during any visits to the emergency room.

Let your health care team know if there is anything you do not understand. Feel free to bring up concerns that you have. Write down information you are given or specific instructions you need to follow as part of your care. You can also ask your health care team members to write down the information for you.

KEEPING TRACK OF INFORMATION

It can be difficult to remember all that your health care team tells you. This may be even harder to do if you are stressed or not feeling well. Yet it is important to keep track of the information you are given such as how to take medications and when to contact your provider.

You may find it helpful to have someone take notes for you during appointments. If there is no one who can go with you, ask a nurse, navigator or social worker to help you. Many providers now allow patients to record their discussions. That makes it easy to go back later and listen to the information that was provided. Talk with your provider about any plans to record your meetings.

EMERGENCIES

Call your health care provider right away if you experience pain or fever. Use words to describe how the pain feels such as “burning,” “aching” or “sharp.” Tell the provider how often you have pain. Also, keep track of



Write down the following information for your next appointment with your health care provider:

- ☐ Concerns and things you want to know
- ☐ New symptoms, side effects and pain problems
- ☐ Current medications and dosages
- ☐ Other treatments you have had such as acupuncture or massage
- ☐ Current list of food supplements
- ☐ Emotional concerns such as depression

what you have tried to do to relieve the pain and how well it worked. Share this information with the provider.

GETTING AN INTERPRETER

Some people have a hearing loss. Others speak and understand a language that is not the same as that of the health care team. If either of these is true for you, ask your health care provider to arrange for an interpreter during appointments.

An interpreter can ensure that both you and the health care provider understand one another. Do not use a child to interpret because a child is not able to accurately understand or describe medical issues. It also may be difficult for a teen to discuss medical issues with a parent or family member. If you need an interpreter, ask a nurse or social worker to set up this service. Many states now require that large hospitals and cancer centers have interpreters available to assist patients.

HEALTH CARE PROVIDER POLICIES AND PROCEDURES

Every health care provider has their own policies and procedures set up to handle patient needs. Ask about these during your first meeting with the provider.

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“Take somebody with you when you go to the doctor, somebody who knows how to listen to what the doctor is saying. I did not hear the important information until way later. I was not as keyed in to how important it was for me to do things I needed to do in terms of the treatment plan.”

—SUSAN C.

Find out what you should do in case of the following:

If you cannot reach your health care provider

There may be times when you have questions or need to speak with a health care professional between appointments. Ask how you can leave a message for your provider if your needs are not urgent. This may be possible through a phone call, email or a messaging system. Sometimes a nurse will contact you first to find out what you need.

Find out how emergency calls are handled if your provider is not available. In most cases, you will be told to contact a hospital emergency room or call 911 if you have urgent concerns.

If you are waiting for test results

Find out how you are to get diagnostic test results. Some providers will call you or have a nurse contact you. Others ask you to call them or a messaging service for test results. Be certain you understand what your health care provider wants you to do. This will help you avoid delays and missed information.

If you have questions or concerns about test results, contact your provider's office. Because so many tests are done every day in a health care facility, mistakes can happen. On rare occasions, test results may be misplaced or even given to the wrong patient. Always feel free to ask questions to get more information.

If you have questions about medications or side effects

Ask your health care provider what to do if you have side effects caused by medications or treatments. Learn about the medications you take. Find out why you are taking each of them. Discuss how to contact your provider or get other medical help if problems develop.

Some medications can interact with others. There is also the possibility of an allergy or a reaction to certain medications. Give each of

your health care providers and pharmacists a record of your known allergies and reactions to medications. Find out what to do if you have a reaction.

If there is a need to share or keep medical information confidential

The Health Insurance Portability and Accountability Act (HIPAA) requires that health care providers protect the privacy of patients. The provider must give each patient a written explanation of how they meet HIPAA rules.

Each of your health care providers will ask you to read and sign the HIPAA form before you begin working with them. You must list the names of the people with whom you are allowing your health care team to share medical information. Ask questions before signing the form. Find out who else the provider will share your information with such as your insurance company.

GETTING ANOTHER MEDICAL OPINION

You have the right to ask for a second or third medical opinion (or more). Another opinion may help you make better decisions. You also have the right to change members of your health care team. Tell the health care provider that you respect his or her opinion. Let the provider know that, because this is such an important decision, you would like to get another opinion before deciding what to do.

There is no need to feel guilty about asking for another opinion. This is an important patient right. Many providers suggest that patients consider additional medical opinions before making health care decisions.

Keep in mind that you may need to get approval from your insurer before meeting with another provider. If you do not, you might have to pay some or all of the costs.

If you do not know where to go or how to get another opinion, ask for help. Your health care provider, a social worker or nonprofit cancer organization can help.

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“I hear over and over again from friends that their doctor won't call them back. They have had an MRI or some big test, and they are sitting at home waiting for the doctor to call them back. The ones who seemed to do the best said, 'You know, I'm really a part of this team, and I do have a voice here.'”

—SUSAN C.

“

“I did a lot of research with doctors.... People need to get the confidence. It is all right to ask for second, third, fourth opinions until you find somebody you are comfortable with.”

—CHRIS O.

RESOLVING PROBLEMS WITH MEMBERS OF YOUR HEALTH CARE TEAM

Sometimes your personal style may not be a good fit with a member of your health care team. If this happens, talk with someone you trust about your concerns. Consider whether it is possible to improve the situation. It may be that the health care provider has excellent medical skills, but there is a problem with communication.

Look for a way to discuss your concerns with the health care team member. That may improve things. If you are uncomfortable talking directly with him or her, ask a loved one, friend or social worker to help you. Many health care facilities now have patient advocates on staff. Their job is to solve problems between patients and health care providers.

If a problem cannot be resolved, you may need to consider changing medical providers or using a different health care facility. It is important that you trust your health care providers and that you can work as a team during treatment.



Livestrong means finding the best way to work with your health care team.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Working With My Health Care Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Finding and Evaluating Resources
- Transportation and Other Assistance Programs
- Communicate With Your Health Care Team

Learning About Cancer Treatment Options

Learn as much as you can about your type of cancer and treatment options. Start with information you get from your health care team and the opinions you get from other health care providers.

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“You have to be informed. You are playing with your life and have to be the one who takes charge of your own outcome—so you have to educate yourself.” —CHRIS C.

Cancer treatments can include one or more of the following treatment options:

- Chemotherapy
- Radiation therapy
- Biological therapy that works with the immune system
- Surgery
- Hormone therapy
- Treatment to manage pain
- Stem cell transplant
- Clinical trials
- Treatment to control swelling (such as lymphedema)
- Complementary and alternative medicine (CAM)

RESEARCHING OPTIONS

Schedule a meeting with your provider to discuss what he or she thinks may be the best treatment option for your situation. Before this meeting, research information about treatment methods recommended for your type and stage of cancer.

Learn about current recommendations for treating your type of cancer. Use reliable, high-quality resources such as the online information from the **National Comprehensive Cancer Network (NCCN) Clinical Practice Guidelines in Oncology** (nccn.org).

Write down questions and concerns to share with your provider. For example, you may be concerned about certain side effects such as hair loss or fatigue.

Ask for help if you do not understand the NCCN guidelines. Your provider should be familiar with these.

If your provider suggests a treatment method that is not the same as the NCCN guidelines, ask him or her to discuss the reasons with you. Tell him or her about your concerns.

Loved ones, friends and other health care team members may also share information. You can contact nonprofit cancer organizations for information about treating your type of cancer.

When you start working together, tell your health care provider how much you want to know about your type and stage of cancer. For example, you may or may not want to discuss life expectancy statistics. Discuss the treatment that the provider recommends for your situation. He or she will want to know what you think about each option.

Consider your own preferences for cancer treatment. Find out if there is another option if a treatment method has serious side effects. You may want to ask your health care provider if you can talk with another patient who has already completed the treatment recommended for you. It can be very helpful if that person was diagnosed with the same type and stage of cancer as you.

DEVELOP A TREATMENT PLAN

Work with your health care provider to develop your cancer treatment plan. There are benefits and risks involved with any testing or treatment. Talk to your provider about both. You will be asked to read and

sign an informed consent agreement that indicates that you understand the risks when you decide on and begin treatment.

You and your health care team will also need to update your plan as you go through cancer treatment. This will help ensure that the best decisions are made for you. Ask a loved one, friend or patient navigator to go to appointments with you to provide support, ask questions and record the information provided by the health care team.

TRAVEL FOR MEDICAL TREATMENT

You have the right to get the best possible health care. Some patients travel outside their communities to get another medical opinion. Others travel to receive cancer treatment.

If you have health insurance, ask for approval in writing from the insurer before you travel. Ask them to also put in writing what they will cover and how much they will pay.

Contact a social worker at the treating hospital or medical center for help finding support services. Non-profit cancer organizations can also help you find services. The Foundation provides written information about assistance programs for cancer patients online at Livestrong.org/tags/assistance-programs. There are also more resources listed in this book in the “Additional Resources” section.

Some cancer centers help patients who travel for care by providing short-term housing for loved ones. Some nonprofit programs provide help with air and ground transportation to travel for treatment.

The National Association of Hospital Hospitality Houses can help you find lodging and support



Ask your health care provider questions about each type of treatment such as:

- What are the treatment options for this type and stage of cancer?
- Will treatments occur in the clinic (outpatient) or in the hospital (inpatient)?
- How long will each type of treatment last?
- What side effects are possible?
- What can be done to control side effects?
- Can this type of treatment affect sexual function or fertility?
- Will treatment affect the ability to do day-to-day activities?
- What would you (the provider) choose as treatment for yourself or a loved one?
- Will you provide a treatment plan for the entire length of therapy?
- Can I work during treatment?

away from home. Contact them online (nahhh.org) or call 800.542.9730.

If you need to travel by air for treatment, you can contact the **National Patient Travel Center** for help. They provide free referral services for medical air travel. Based on need, they can refer you to an appropriate patient air transportation program. They can help arrange bed-to-bed air ambulance services. You can also find information on charitable or discount airline ticket programs for patients and their escorts. To learn more, contact them at 757.512.5287 or visit patienttravel.org.



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- Diagnosis and Treatment Information
- Finding and Evaluating Resources
- Transportation and Other Support Services
- Health Care Assistance Programs

Considering Clinical Trials

Clinical trials are scientific studies. They test treatments that are in development. Trials also study other ways of using current treatments. Look into whether a clinical trial could be right for you. Discuss this option with your health care provider as you work together to develop your cancer treatment plan.

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“I had complete confidence that I could potentially be helped by the trial that was proposed for me. No medical institution or government body wants anybody to be harmed by a trial.”

—BARBARA H.

Participation in clinical trials isn't supposed to happen only when there aren't any other options. Keep in mind that you can look into whether you can participate in a clinical trial at any time during the cancer treatment process. In some cases, it may not be possible to discontinue a current treatment to start a clinical trial treatment.

Each clinical trial studies a certain type and stage of cancer. The purpose is to learn how well a treatment method works. The study compares the trial method to the current standard or most commonly used treatment. Physicians and researchers monitor patients closely.

Clinical trials may study:

- Medications
- Vaccines
- Surgical methods
- Radiation therapy treatments
- Ways of combining treatments

Each study has its own criteria about who can participate. These may include specific ages, medical history, past treatments or current health status.

Patients must always give their permission to be involved in clinical trials. Clinical trials for cancer treatment provide at least the standard of care. Treatment clinical trials are designed to seek better treatment or compare ways to prevent or detect cancer.

Participants in clinical trials are randomly assigned to study groups. This means that a computer program or a table of random numbers is used to assign patients

to study groups. This helps avoid biases or preferences that can exist in human choices and beliefs. Biases can weaken study results.

Clinical trial treatments can be given in a health care provider's office, clinic, cancer center or hospital. These studies occur in steps or phases. A patient might participate in more than one clinical trial during his or her cancer treatment—but only one phase at a time.

The National Cancer Institute (cancer.gov/clinical-trials) generally defines the phases of clinical trials as:

Phase I: A treatment method is tested for the first time in humans with a very small group of people during the first phase. The study looks at treatment safety only. This may include information about safe dosage and side effects. There can be no guarantee that this method or medication will be effective at getting rid of a particular cancer.

Phase II: The second phase builds on the information gained from the first phase of the study. The treatment method is used with a larger group of people. Studies further evaluate safety and effectiveness. For example, after defining the safe dose of a medication, a study might then determine if the treatment is also effective with other types of cancer.

Phase III: Treatment is given to large groups of people in this phase. Studies further evaluate

and confirm the effectiveness of a treatment for a specific type of cancer. Side effects are compared to those of other commonly used treatments. Some clinical trials compare the current best treatment to the one being studied. Cancer patients receive the best standard treatment or a treatment that researchers believe will be at least as good.

Phase IV: Studies continue after the treatment has been released to the market. Information is collected about the effect of this treatment method in different groups of people. Side effects are studied for long-term use.

If you want to be part of a clinical trial, you will be asked to read and sign an informed consent form. This is to make certain that you understand the benefits and risks that are possible. These may include:

Possible Benefits

- The treatment might be available only through the clinical trial.
- The treatment used in the clinical trial could be more effective than the current standard treatment.
- Those in the clinical trial receive regular and careful attention from doctors and other members of the research team.
- Results from the study could help others in the future.

Possible Risks

- The drugs or treatment being studied are not always better than the standard treatment methods.
- The treatment could cause side effects or risks that doctors do not yet know about or expect.
- If it is a randomized trial, participants are not able to choose whether they will get the trial treatment or the current standard treatment.
- Health insurance and managed care providers might not cover all trial care costs.

FINDING CLINICAL TRIALS

Before you decide to participate in a clinical trial, talk with your provider and other health care experts. Find out what the purpose of the clinical trial is, as well as who is sponsoring the study.



Ask questions if you are considering becoming a participant in a clinical trial such as:

- Who has reviewed and approved this study?
- Has the treatment been used in other clinical trials for my type of cancer? If so, how successful was it?
- What are the short- and long-term benefits?
- What are all of the possible risks and side effects?
- How would side effects be treated?
- Are there other treatment options?
- What are the costs for treatments, tests and other services?
- Will my health insurance or benefit program cover all costs?
- Can I withdraw from the clinical trial once I start?

If a clinical trial is right for you, ask about those that are available locally. Also, ask about those that are occurring outside the area in which you live. If the clinical trial is not offered where you live, you would be required to travel for treatment. Participants might be required to have more visits to the health care provider than they would have for standard treatment.

The Livestrong Foundation will help you search for clinical trial options that match your treatment history as well as your type and stage of cancer. Talk with your health care team each time you have to make a treatment decision. Go online to Livestrong.org/Cancer-Support or call toll-free at 855.220.7777.

The following organizations also offer free and confidential information about clinical trials:

- **National Cancer Institute's Cancer Information Service** at cancer.gov/clinicaltrials or 800.422.6237, or TTY 800.332.8615
- **National Institute of Health** at clinicaltrials.gov or 301.496.4000, or TTY 301.402.9612

If you participate in a clinical trial, find out which expenses your insurer will cover. Ask them to put it in writing before you begin treatments.



Livestrong means learning about all of your treatment options.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Working With My Health Care Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Diagnosis and Treatment Information
- Finding and Evaluating Resources
- Transportation and Other Support Services
- Health Care Assistance Programs

Physical Concerns

Cancer patients often have questions about physical changes that could happen during and after cancer treatment. Some changes might occur right away. Others can happen long after cancer treatment is completed.

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“I think it is very important for all of us to be aware of ways to go forward with making ourselves feel comfortable with our bodies again.”

—ANN F.

Cancer treatments affect each person differently. Some notice few physical changes. Others may experience visible changes, such as hair loss, weight gain or weight loss.

Your health care team can help you learn what to expect. They will explain what is likely to occur based on the treatment method and your type and stage of cancer.

You may need time to learn enough about your type of cancer to fully understand all that the health care team tells you.

Many nonprofit cancer organizations and health care facilities can also help you learn about cancer. They provide diagnosis and treatment information for specific types of cancer.

MANAGING PAIN

Talk with members of your health care team if you are having pain. No one will think that you are complaining. Most pain can be medically managed. There is no need to put up with it. Pain can interfere with healing. Ignoring the pain can make it harder to manage over time.

You will need to describe the pain to your health care provider. Use a pain scale to rate your level of pain such as the following:

HOW TO KEEP TRACK OF PAIN FOR YOUR HEALTH CARE PROVIDER

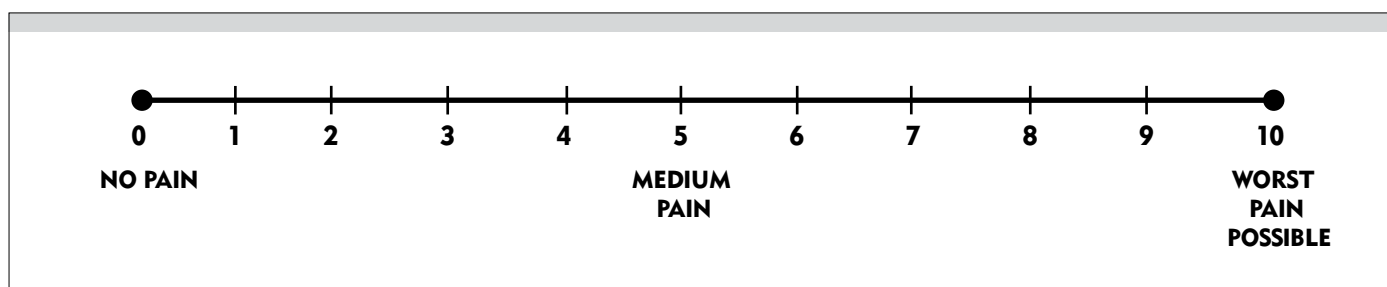
1. Choose a number on a scale of 1 through 10 to let your providers know how much pain you have:
 - 0 means you have no pain
 - 1–5 means you have mild to medium pain
 - 6–9 means you have medium to severe pain
 - 10 means you have the worst pain possible

2. Keep track of your pain scale numbers in a notebook or your **Livestrong Guidebook Planner and Journal**, in the section called **During Treatment: Working With My Health Care Team**.
3. Write down the dates you have pain and note how long it lasts.
4. Describe your pain by using terms such as “burning,” “aching” or other words.
5. Write down what you did to treat the pain and how well it worked.
6. Take this information with you each time you see your health care provider.
7. Show your provider your pain diary so that he or she can see when and how much pain you experience.
8. Ask your health care team what can be done to treat the pain.
9. Ask about the risks and benefits that can come from each of the suggested treatments.



Ask your health care team questions about physical concerns such as:

- Will treatment leave a scar?
- How might my appearance change?
- Will my hair fall out?
- Can the medications make me lose or gain weight?
- Will the treatments put me at risk for a serious infection?
- What should I do if I have fatigue and a loss of energy?
- Will I be able to work or be active during treatment?
- Can cancer and treatment affect my sexuality or fertility?
- Will cancer treatment be painful?



DEVELOP A PLAN TO MANAGE PAIN

Work with your health care team to develop a plan to manage pain. Learn about the risks and benefits of each of the options before starting treatment. Your provider may recommend one or a combination of treatment methods such as:

- Prescription and over-the-counter medications
- Surgery
- Physical therapy
- Relaxation techniques such as deep breathing
- Counseling to help cope with stressors

Talk with your health care provider about adding complementary or alternative treatment methods to help control pain such as:

- Physical or occupational therapy
- Massage
- Yoga, tai chi or other types of exercise
- Meditation or relaxation
- Diet changes
- Acupuncture
- Biofeedback treatments

It is important to get the best care possible. Tell your health care team what you need. If your pain continues or you have trouble getting treatment, ask for a referral to a pain specialist.

The National Cancer Institute (cancer.gov)

offers a great deal of information about living with cancer. This includes a booklet about the types and causes of cancer pain as well as pain control. Call 800.422.6237 to request free printed information or find it online at cancer.gov/cancertopics/paincontrol.

CONCERNS ABOUT SEXUALITY

You may be concerned that cancer could affect your sexual life. This may or may not be true. Physical and emotional changes often occur during treatment. Some changes, such as fatigue, may lessen interest for a while.

However, going through cancer treatment does not mean that you cannot be intimate. Many people are able to continue their sexual relationship or start a new one. Trust and closeness with a loved one may actually increase as you go through the cancer journey together.

Some people find it hard to discuss sexual issues. However, talking with your health care provider or other members of your health care team may be the only way to get the answers you need.

If you have specific concerns, ask for a referral to a licensed therapist who can help with sexuality during cancer. Many cancer care centers have these therapists on staff.



Describe your pain to your health care providers including:

- ☐ How much pain you have
- ☐ Where the pain is located
- ☐ How often you have pain
- ☐ What the pain feels like
- ☐ What has already been tried
- ☐ What, if anything, lessens the pain

ADDRESSING CONCERNS ABOUT FERTILITY BEFORE TREATMENT

Not all types of cancer or treatments affect the ability to have children. Yet, some types of cancer treatments can cause birth defects in unborn children. Birth control can be important during this time.

If the ability to have children in the future is important to you, talk with your health care provider before treatment begins.

Your provider can help you find information and other resources to help you preserve your ability

to have children. If needed, ask to be referred to a fertility specialist. Talk with this specialist about fertility preservation before you begin cancer treatment.

Livestrong Fertility (Livestrong.org/Fertility) provides reproductive information, support and hope to cancer patients whose medical treatments present the risk of infertility. You can also call 855.220.7777 or schedule a call at Livestrong.org/CancerSupport. If you decide to preserve your fertility, **Livestrong Fertility** may help you reduce expenses through partnerships with other organizations.

MyOncofertility.org is a free online resource for cancer patients and their loved ones. It provides easy-to-use information about fertility options before, during and after cancer treatment.

PHYSICAL ACTIVITY

Cancer treatment may make you feel tired and weak. Yet, many people with a cancer diagnosis find that physical activity helps them feel better. Being active may help you regain strength, control stress and focus your mind in a positive way. Some enjoy walking, bicycling or swimming. Others do activities like dancing or practicing yoga or tai chi.

Ask your health care provider if physical activity is right for you. You might be able to start slowly, even if you have never been active before. Sometimes five or ten minutes a day can be helpful. Your provider should tell you when and how to add to your level of activity as you get stronger. He or she might also refer you to a physical therapist or other rehabilitation professional for help with this process.



Ask your fertility specialist questions such as:

- Do you have experience using freezing techniques (for sperm, eggs, ovarian tissue or embryos)?
- What is the best way to increase my chances for fertility in the future?
- What are the costs for fertility procedures?
- Will my insurance cover all the costs?



Ask your health care provider questions about fertility such as:

- Will this type of treatment affect my future ability to have children?
- Are there other treatments with fewer fertility side effects?
- Is it safe to delay treatment until after a fertility preservation procedure?
- Will you refer me to a fertility specialist?



Livestrong means choosing to do the things that work best for you.

See the Livestrong Guidebook Planner and Journal pages:

During Treatment: Working With My Health Care Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Chronic Pain
- Female Fertility
- Male Fertility
- Male Sexual Dysfunction
- Female Sexual Dysfunction

Developing Your Treatment Plan

You and your health care provider should work together to develop a cancer treatment plan. This is the guide for your cancer care and treatment. Take the time to learn about your type of cancer and the current treatment options. This will help you identify the best option for your situation. Ask questions and discuss what you learn with your health care team.

If you do not feel well enough to do this on your own, ask someone you trust to help you. This can be a loved one, friend or social worker. Tell your provider if you prefer to wait until later in your treatment process to get involved in these types of decisions. You can always choose to become more involved at a later time.

Your cancer treatment plan should be based on:

- The type and stage of your cancer
- Results of physical exams, lab results and other diagnostic tests
- Results of X-rays and digital imaging such as CT, MRI and PET scans
- Your medical history including other chronic health conditions
- Information about all treatments available for your type and stage of cancer
- Discussion and review of clinical trial options

It is also important to consider information such as:

- The risks and benefits of each treatment option
- Information about effects that may be long term, also known as aftereffects or late effects
- What you want, including concerns about pain and quality of life

Talk with loved ones and close friends about how treatment might affect your life. You might decide that certain side effects are reasons to avoid some methods. Keep in mind that it may be possible to work with your health care team to lessen some side effects.

Discuss ideas with your provider such as adding complementary or alternative treatments. These may include acupuncture, nutrition, massage, counseling and other healing methods.

It is very important to tell your provider everything you are doing or want to do to get better. Some things, such as herbs or supplements, may cause unwanted side effects when combined with certain treatments. They could also decrease the effectiveness of some cancer therapies.

Your provider will offer you his or her best medical knowledge and recommendations. You must decide on the treatment that is best for you. If you need help, ask a loved one, social worker or a patient navigator to assist you in weighing the options. You can also ask for another medical opinion.

The National Comprehensive Cancer Network (nccn.org) offers guidelines to help you obtain the most current recommendations for treating specific types and stages of cancer. Ask your health care provider if your care plan follows the NCCN Clinical Practice Guidelines in Oncology™. You can look up the most current **NCCN Guidelines for Patients** at nccn.org. If your care plan is different than the NCCN



Work with your health care team to develop your treatment plan:

- ☐ Talk with your provider about his or her treatment recommendations.
- ☐ Work with your provider to write down the treatment plan.
- ☐ Talk with your provider about adding complementary treatments such as massage or acupuncture.
- ☐ Talk with loved ones about the effects of treatment.

recommendations, discuss the reasons. If you are not comfortable with the reasons your provider gives you, ask to be referred for another opinion.

YOUR TREATMENT CARE PLAN

After you and your health care provider have agreed on your plan for cancer care, ask for a written treatment care plan summary. This should include:

- The specific types of cancer treatments that will be used
- How long and how often you will get treatments
- Where you will go to get these treatments
- Whether you will receive inpatient or outpatient treatments
- What to do if you have pain or new changes to your body
- Special instructions for you or others about treatments
- Information about over-the-counter medications or supplements you are taking

A treatment care plan should also include information about how to manage care at home. You can also ask for a list of resources to get help with certain issues such as insurance, finances or emotional support.

If you will have chemotherapy, ask your provider to give you a “chemotherapy road map.” This includes a calendar to keep track of the medication dosages you are given and when you need the next cycle of treatment.

Find out when and how your health care team will decide whether the treatment is working.

Talk with your provider if you think a treatment care plan change may be needed. It is possible to do this even while you are in treatment. Keep in mind



Ask your health care provider to include the following information in your treatment care plan:

- ☐ The types of cancer treatments that will be used
- ☐ The schedule of treatments (including any breaks in treatment that are expected)

that it may take some time to identify other options that might work better for you.

Choosing the best cancer treatment is very important. You have the right to request opinions from other medical experts. Let your health care provider know if you think this is something you want to do. Taking part in the treatment planning process can empower you. There may also be greater peace of mind because you understand and have a role in what is happening.



Livestrong means choosing how you want to be involved in the medical process.

See the Livestrong Guidebook Planner and Journal pages:

During Treatment: Organizing Medical Information



Read more about living with cancer at Livestrong.org/WeCanHelp

- Diagnosis and Treatment Information
- Aftereffects of Cancer Treatment
- Hope

Life Expectancy and What It Means

Everyone responds to treatment differently. There is no way to know in advance how effective cancer treatment will be. There is also no way to know how long anyone will live—with or without cancer.

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“Every cancer has survival. There are always survivors. ...I just want people to remember that.”

—BETH S.

Some people want to know right away about the chances of surviving their specific type and stage of cancer. They begin talking to their loved ones and health care team about life expectancy during treatment. Some will focus on quality-of-life issues instead of cancer treatment. Still others choose never to talk about these things with anyone. You have the right to choose to discuss or not discuss the issue of life expectancy. You also have the right to decide when to do this.

The health care team and your loved ones may wait for you to bring up the topic of life expectancy. Others might ask you to talk with them about it. You have the right to tell them if you are not comfortable discussing this matter. It is important to find the ways that work best for you during your cancer journey.

SURVIVAL RATES

Knowing about survival rates can give you a general idea about how long other people diagnosed with your type of cancer have lived. Yet, your experience may be very different. Survival rates are only estimates, and many cancer survivors prove them wrong.

Survival estimates are based on the experiences of cancer patients in studies done during and after cancer treatment. There is no way of knowing how estimates will apply to your situation. For example, some studies were done five to 10 years ago. Your treatment may be very different from the method used in the study. Medications may have changed. There may be new ways of doing surgery, radiation therapy and chemotherapy.

The life expectancy for a specific type of cancer is often reported as a five-year survival rate. This does not mean that survivors do not live more than five years. Some studies only follow up with study participants for that long. In addition, the concern about cancer recurring generally lessens after five years.

Survival rates are usually stated as a percentage. A health care provider might say, “People with this type of cancer generally have a 60 percent five-year survival rate.” This means that 60 out of 100 people who were treated for this type of cancer during the research studies were still living after five years. It does not mean that they lived only five more years.



Ask your health care provider questions about life expectancy such as:

- How does my treatment compare to that used in the study?
- Can other health conditions affect my survival rate?
- Are there other treatments that may be helpful?
- What types of healthy living habits might help me?
- What can I do to increase my life expectancy?

“

“They all gave me statistics – six to 18 months to live – so that was a big thing to overcome. That was the initial shock, and then it was a matter of doing as much research as you can so you are not in that group of statistics.” —CHRIS O.

Cancer survivors often live much longer than these estimates. Every cancer survivor is different. Most importantly, you are not a statistic!

FINDING SUPPORT

Life expectancy numbers are only estimates. They cannot predict how long you are going to live. Yet, receiving this information may be confusing. If you feel worried, set up a separate meeting to discuss your concerns with your health care provider. This will allow both of you time enough time to talk until your questions are answered.

A patient may feel very upset if told there is not a high survival rate for his or her type of cancer. Hearing this type of news can be overwhelming. Talking with loved ones, trusted friends or a faith-based counselor may help.

Your provider can also refer you to a licensed counselor or social worker for help dealing with the stress of cancer. Some counselors specialize in working with cancer patients and their loved ones.

Many people affected by cancer find it helps to share thoughts and feelings with others who are in a similar situation. If this interests you, find out about cancer support groups in your area. Keep in mind that each group may have a unique way of offering support. You may want to try several before deciding if one fits your needs better than others. Or you may prefer to find peer-to-peer support instead of joining a group.



Find support services in your area:

- ☐ Ask your health care provider to refer you to an oncology social worker or patient navigator.
- ☐ Find out if there are cancer support groups that meet in your clinic or hospital.
- ☐ Visit the Foundation's cancer navigation services online at Livestrong.org/WeCanHelp or call 855.220.7777 for free support services during the cancer journey.
- ☐ Contact nonprofit cancer organizations such as the American Cancer Society. Go online to cancer.org or call 800.227.2345.

Imerman Angels pair individuals who have been affected by the same type of cancer. This can include people diagnosed with cancer. Cancer caregivers, including loved ones and friends, can also receive one-on-one connections. This is a free service for anyone living anywhere in the world. Go online to imermanangels.org to learn more.

If you prefer to work with a counselor, the **American Psychosocial Oncology Society** has a free hotline to connect cancer patients and caregivers to counseling services in your area. Call 866.276.7443 or email info@apos-society.org.



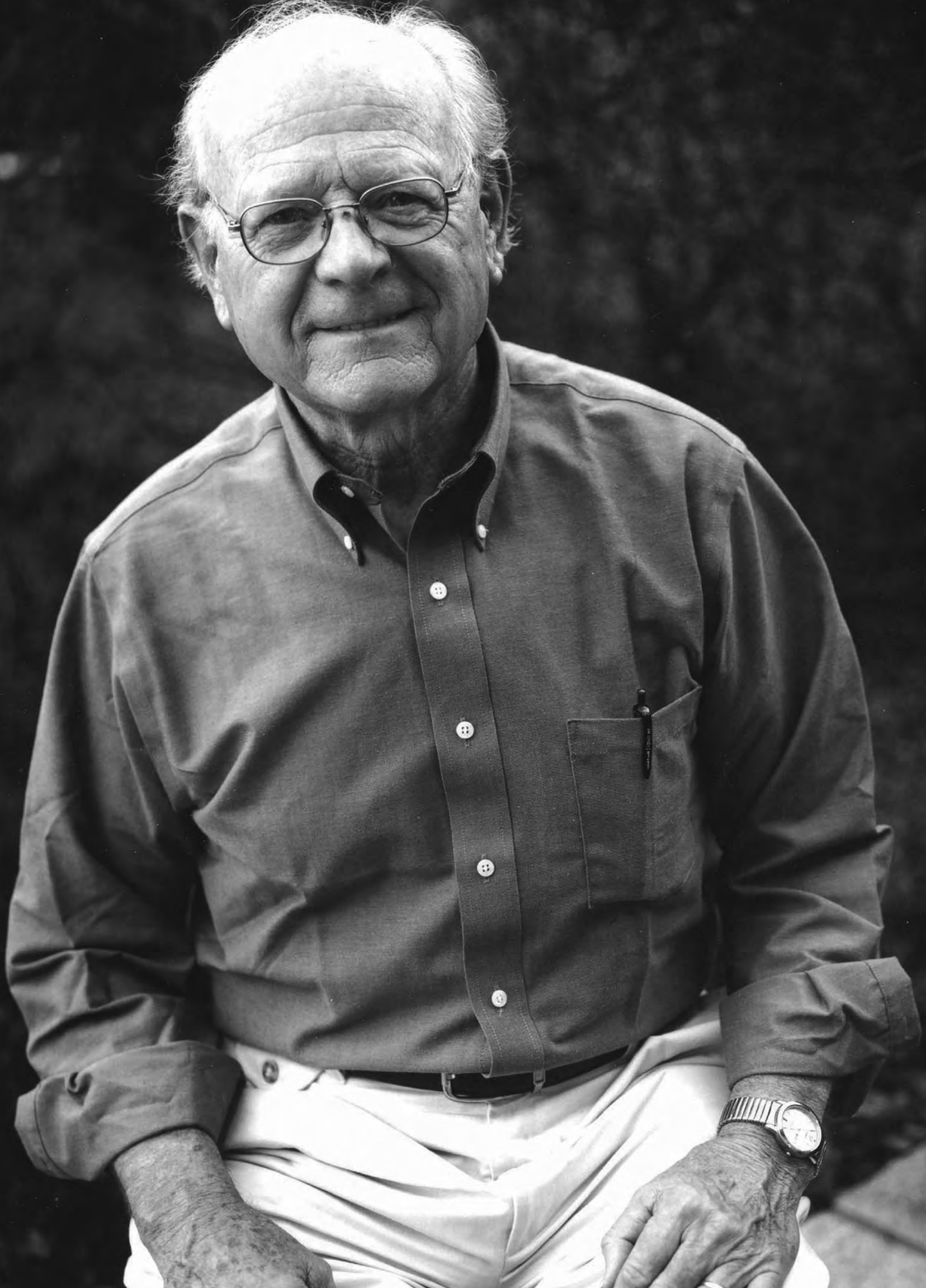
Livestrong means finding the answers to your questions.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Life Expectancy
- Living With Uncertainty
- Hope



Just Diagnosed: FINDING ASSISTANCE

This section includes information that may help cancer patients find health and disability coverage. It also includes resources for other types of assistance programs. The following topics are included:

- Health and Disability Insurance
- Federal and State Benefit Programs
- Other Types of Assistance Programs

Health and Disability Insurance

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“You need to stay on top of health insurance...make sure that when the bills come in from the hospital that you are not double paying because they send bills very quickly.”

—CINDY C.

Most adults affected by cancer need to understand health and disability insurance. This section provides an overview of some of the things you need to know under current laws. To learn more, consult with people who know about insurance matters. If you are working, be sure to talk with your employer's benefits coordinator and the insurer.

At the federal and state levels, there are often changes in how people in the United States receive health care coverage. Some of these changes may benefit people affected by cancer. To learn more and stay up to date, visit HealthCare.gov.

The Foundation offers much more information about insurance and other cancer-related issues online at Livestrong.org/WeCanHelp. You can also contact the Foundation's cancer navigation services at Livestrong.org/CancerSupport or call 855.220.7777.

IF YOU HAVE HEALTH INSURANCE

Read your policy to learn what is covered and not covered. Talk with the insurer to get answers to your questions. You also need to understand what the plan requires. For example,

there may be certain limits on when you are allowed to submit insurance claims or to appeal claim denials.

If you do not have a copy of your insurance policy, ask the insurer for another. You do not have to tell the insurer about your cancer diagnosis at the time you request the copy.

Continue to pay the full amount of your insurance premiums on time. This will keep your health coverage active. An insurer cannot deny benefits for covered medical services when your policy is active.

If you do not pay the full premium on time, your policy will be closed (or lapse). If your policy is closed, health coverage will stop.

After a cancer diagnosis, it can be very hard to find new coverage if an existing insurance policy lapses. If a new policy can be purchased, it will likely cost much more and have longer waiting periods. It may also exclude certain benefits due to medical history.

Follow all of the insurance plan's rules. For example, many insurance plans require that you contact them to get specific medical services pre-approved. This means that your health care provider's office should contact the insurer before sending you for tests or other treatment.

Make a list of all your current health care



Review your insurance policy if you already have health insurance:

- ☐ Know what is covered by your insurance plan.
- ☐ Pay your premiums in full and on time.
- ☐ Do what your plan requires for payment.
- ☐ Keep good records of all contacts with the insurer.
- ☐ Know your rights to appeal.

needs. Include services and treatments that you may need in the future. Compare your health plan benefits to expected medical needs. This will help you decide whether you already have the coverage that you need.

IF YOU HAVE NO HEALTH INSURANCE

Many people get group health insurance through their employer. Yet, some cancer survivors cannot work. Others may be in danger of losing health insurance coverage. There are also employers that do not offer health insurance.

Begin to look for ways to find coverage if you have concerns about having no health insurance. Check out options such as:

- Group insurance through a union or as a member of another group
- An individual health insurance policy that you buy for yourself
- Federal or state benefit programs that are based on your income and disability
- Services through county, community and hospital programs
- Insurance coverage under the health plan of a loved one
- A new job that offers group health coverage
- The insurance options finder tool at finder.healthcare.gov

TYPES OF INSURANCE COVERAGE

The two main types of health insurance are:

Group health plans that are offered through groups with employees or members such as:

- Employers
- Credit unions
- Labor unions
- Trade groups
- Organization or association groups

These plans cover a large group of people. The insurer cannot refuse to insure any members of the group health plan. However, health conditions that existed before enrolling in the plan (called pre-existing



If you are going to purchase insurance, find out what medical costs will be covered such as:

- ☐ Fees for physicians and other health care team members
- ☐ Expenses for hospitals and other cancer care
- ☐ Costs for lab and testing services
- ☐ Fees for treatments such as physical therapy or acupuncture
- ☐ Costs to you for both brand-name and generic prescriptions

conditions) may not be covered right away. This is defined by the policy.

Individual health plans that are purchased by one person. The cost is usually much higher than group plan coverage. This type of plan may not cover certain pre-existing health conditions. When you apply, the insurer will review your medical history and decide what a plan will cost. They may decide not to sell the health coverage to you.

High-risk pools—Many states have organized private, self-funded insurance coverage offered through high-risk pools. These are plans for people who have not been able to get other insurance. Proof of this inability to get other insurance may be required when you apply such as copies of denial letters from insurers.

The National Association of Health Underwriters (NAHU) offers a consumer guide to high-risk health insurance pools. For more information, call the NAHU at 703.276.0220 or go online to nahu.org/consumer/hrpguide.cfm.

LAWS THAT AFFECT

“

“The paperwork for short-term disability can be very intimidating. So it is good to have someone to help you with that sort of thing.”

—CINDY C.



HEALTH INSURANCE COVERAGE

Be sure to keep your health insurance if you have it. This will help ensure that medical care continues with no breaks. If you lose your insurance, it may take time or cost more to purchase another health policy.

Three important laws that affect health insur-

ance coverage are:

Affordable Care Act of 2010: The Affordable Care Act was signed into law to put health insurance reform into effect over a period of years. The following changes in insurance coverage may help people affected by cancer:

- Private insurance companies cannot deny coverage to children (under age 19) with pre-existing conditions such as cancer.
- Health plans cannot drop a person from coverage when they become sick.
- No lifetime dollar limits on coverage through individual and group health insurance plans.
- Young adults can be covered under a parent's insurance policy until they reach age 26.
- Seniors with Medicare benefits to receive discounts on brand drugs by 2013. The coverage gap will be closed completely by 2020.
- High-risk insurance pools set up in every



Look into high-risk pool coverage if you are having trouble getting insurance:

- ☐ Contact the National Association of Health Underwriters for a consumer guide to high-risk insurance coverage.
- ☐ If you decide to apply for high-risk coverage, follow the directions exactly as they are given.
- ☐ Be prepared to submit proof that you have been unable to get insurance coverage.

- state to provide coverage for the uninsured.
- Medicare and new private health plans will cover preventive services (like breast, cervical and colorectal cancer screening) with no co-pays and deductibles.

For more information and updates about the Affordable Care Act, visit healthcare.gov.

Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA): COBRA is a federal law that provides the right to continue health benefits for a certain amount of time after leaving a job. The former employee must sign up within a certain time frame and pay the full premium amounts. It also applies to loved ones who were covered by the employee's health insurance plan.

If you know that you will be leaving your job:

- Talk with your employer's benefits department. Find out how and when leaving your job will affect your health benefits.
- Learn about the COBRA coverage that will be offered when you leave your employer. Ask how much it will cost.
- Find out about the dates for signing up and for making payments. Pay the full amount on time every month.
- Ask when COBRA payments will start and how long the health benefits will last.
- If needed, ask if you can get insurance benefits beyond the initial COBRA coverage period. Some plans allow this in certain cases.
- Find out if your state offers insurance programs or other ways to keep your health insurance after COBRA.

Health Insurance Portability and Accountability Act of 1996 (HIPAA): HIPAA is a federal law. It protects those covered by group health insurance plans. It limits the length of time a group plan insurer can refuse to cover pre-existing health conditions. It also protects personal privacy.

Under HIPAA, you may be able to keep health coverage if you go from one group plan to another. For example, if you change employers, the new group plan must cover a pre-existing medical condition without an exclusion period if:

- You have had health insurance with no gaps

- in coverage for longer than 63 days and
- You have had health insurance for at least the previous 12 months

HIPAA does not protect the coverage provided by individual health plans. If you try to change to a different individual plan, the new insurer can legally turn you down.

Some states have health insurance protection laws that are similar to federal laws. Check to see if your state has laws that can help you get or keep health coverage. Read more about HIPAA protections at hhs.gov/hipaa/.

DISABILITY INCOME INSURANCE

Group and individual disability income plans provide benefits if you are not able to work.

There are two types of disability policies:

- **Short-term policies** pay a weekly income benefit for a short period, such as up to two years.
- **Long-term policies** pay income benefits for the time specified by the policy. This could be as long as the rest of a person's life. It might be up to the age when a person can retire (65 or 67).

Some employers offer short-term disability insur-



Take the following steps if you need to appeal a benefit claim denial:

- ☐ Ask the insurer to explain the reason for the denial in writing.
- ☐ Review your policy to see if you should be covered.
- ☐ Ask the medical provider to help you get answers from the insurer.
- ☐ Take notes about all discussions with the insurer and the health care provider (include dates, names and what was said).
- ☐ Keep copies of all medical bills, claims and decisions of the insurer.
- ☐ Follow up with the health care provider and the insurer.
- ☐ Make certain that claim forms and appeals are sent and received on time.

“

“If you are getting reimbursement for any of your payments, stay on top of that. It is a strain when you are ill. If you can have someone help you out with that, it certainly is a good thing to do.”

—CINDY C.

ance. The income benefits start soon after you cannot work. They may continue until long-term benefits start.

Even if you become unable to work, pay the full insurance premium on time. Keep paying until you get a written notice to stop. If you do not pay, the insurer will cancel your policy.

Long-term benefits continue as long as you are disabled. The insurer will review your case regularly. Benefits will stop if you go back to work. They will also end if a health care provider informs the insurer that you are no longer disabled.

DEALING WITH INSURANCE AND BENEFIT CLAIM DENIALS

Always look into insurance and benefit claim denials. If you are denied benefits, you may need to appeal the insurer's decision. An appeal must be filed within the time allowed by the insurer.

You or someone else may have to advocate or fight for your rights. Ask the insurer to answer your questions about the denial decision. Use all of your appeal options.

If you believe that a claim denial is unfair, contact an advocacy organization for help such as:

- **The Patient Advocate Foundation** through the Foundation's cancer navigation services. Call toll-free (855.220.7777) or go to Livestrong.org/WeCanHelp.
- **The Cancer Legal Resource Center.**

Call toll-free (866.843.2572) or go to cancerlegalresources.org.

- **Your state insurance commissioner's office.** Call the **National Association of Insurance Commissioners (NAIC)** to find contact information for your state insurance commissioner. Contact the NAIC through the toll-free Consumer Hotline (866.470.6242) or go to naic.org/state_web_map.htm.

As you go through treatment, you will need to share information with insurers and health care providers. If you are not feeling well enough to do this, ask someone you trust to help. He or she can keep track of insurance applications, claims, payments, denials and appeals. Your health care provider can also refer you to a social worker for help.

If you have questions about an insurance denial, an appeal or your rights, you can contact the **Employee Benefits Security Administration**. They are part of the U.S. Department of Labor and will offer free, confidential assistance. Go to dol.gov/ebsa to request help or call 866.444.3272.



Livestrong means finding resources and services to help you go through the cancer journey.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Individual and Group Health Insurance
- Disability Income Insurance
- Federal and State Benefit Programs

Federal and State Benefit Programs

Federal and state benefit programs offer help to meet health care and income needs.

“

“I didn’t realize it, but I was eligible to get Social Security disability. I went three years with nothing, and I had no idea. I do get that now, and I can work a couple days a week so that helps out.”

—CINDY D.

If you cannot work due to cancer, treatment or after-effects, check into these programs.

The most common federal and state benefit programs include:

- Social Security Disability Income (SSDI)
- Supplemental Security Income (SSI)
- Medicare
- Medicaid

FINDING GOVERNMENT BENEFIT PROGRAMS

The following services can help you find benefit programs:

The Benefit Eligibility Screening Tool (BEST) is a free online tool provided on the Social Security Administration (SSA) website (ssa.gov/best). The BEST is not used to apply for benefits. This tool is to help you find out if you might qualify for SSA programs.

Benefits.gov is a free online screening tool. It provides a list of government programs for which you may be eligible. It also tells you how to apply for benefits.

FEDERAL AND STATE BENEFIT PROGRAMS

Read about the federal and state programs before you apply for benefits. Learn about the medical requirements that make you eligible for benefits. Contact information for the major government benefit programs is as follows:

U.S. Social Security Administration (SSA)

Phone: 800.772.1213

TTY: 800.325.0778

ssa.gov

In addition to calling the SSA or visiting the website, you can contact your local Social Security office for more information.

The largest of the federal disability programs are: **Social Security Disability Income (SSDI)**

This program pays income benefits to people who are disabled. Benefits may also be provided to certain family members. You must have worked and paid Social Security taxes for a certain number of years to qualify.

Supplemental Security Income (SSI)

This program pays income benefits to disabled adults and children who have limited income and resources. Benefits may also be paid to people over age 65 who are not disabled if they meet the financial need requirements.

Apply for benefits as soon as cancer is diagnosed. The process takes an average of 65 days. SSDI benefits generally do not start for about five months after the date you are found to be eligible.

The SSA website provides information including:

- Who qualifies for benefit programs
- How to apply for benefits
- How to appeal denial decisions



**Centers for Medicare & Medicaid
Services (CMS)**

Phone: 800.633.4227

TTY: 877.486.2048

cms.gov

The CMS website helps you find answers about Medicare and Medicaid. There are online tools to help you compare and find the best Medicare prescription drug plan for your situation.

CMS also provides contact information for all state health departments. You can then contact your state or county Department of Health and Human Services office for help.

APPLYING FOR BENEFITS

Talk with your health care provider if you can no longer work or do your job duties. Your health care team may have ideas about changes that could help you continue to work. For example, you might ask your employer to change your work hours or some of your job duties for a time.

If your provider believes you should not work for a while, ask him or her to note this in your medical file. Also, try to get a letter from the provider stating this medical opinion. You can include a copy of this letter when you apply for benefits.

If you decide to apply for federal or state benefits, take the following steps:

Prepare your case. Read about each benefit program. Understand what is required before you apply. This will help you include the documents that are needed such as medical reports.

Get a copy of the Listing of Impairments from the SSA (ssa.gov). Read about what qualifies you as disabled. The SSA website provides good information about the medical proof that is required.

Talk with your physician and other members of your health care team. Tell them about your symptoms. Give examples of how this is affecting your work and personal life. Ask that this be noted in your medical records. This information will be important to the SSA as your medical records are reviewed when you apply for benefits.

Talk with your health care team about applying for disability benefits. Ask them to write down treatment side effects and physical limitations in your medical records.

Talk with your health care provider to find out if he or she will support your application for benefits. If your provider believes you should not work for a while, ask him or her to give you a note or letter stating why you should not work at this time.

Consider your provider's opinions and recommendations about your ability to work. If you and your provider do not agree, you can seek other medical opinions. To qualify for benefits, proof of your disability is required from a health care provider.

Keep good records. Keep track of all letters, bills and claims information. Also, keep notes about discussions between you and your health care team, the insurer and others. Write down dates, names of people and what was said. These records may be useful if there are questions or concerns in the future. Always keep copies of information received from or sent to insurers and benefit programs.

FIND HELP TO APPLY

Ask for help if applying for disability benefits seems too difficult. For example, a social worker, friend, loved one or a nonprofit legal services group may be able to help you.

You can also contact nonprofit cancer organizations for help with insurance and benefit matters. For example, call the Foundation's cancer navigation services toll-free at 855.220.7777 or go to Livestrong.org/WeCanHelp.

You can contact the **National Cancer Legal Services Network** to locate free legal services to address insurance, employment and financial issues. Visit nclsn.org and legalhealth.org for more information.



Livestrong means finding health care benefits to get the best cancer care.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Keeping Important Records



Read more about living with cancer at Livestrong.org/WeCanHelp

- Individual and Group Health Insurance
- Disability Income Insurance
- Federal and State Benefit Programs

Other Types of Assistance Programs

Many programs help people affected by cancer both during and after treatment. The support services they offer might help you meet challenges.

Assistance programs may provide:

- Help getting or paying for prescription medications
- Legal help
- Housing assistance
- Help with transportation or lodging for medical care
- Support returning to work
- Services for child care
- Counseling and emotional support
- Help meeting basic needs

The following types of individuals and organizations can help you find support services:

- Loved ones and friends
- Health care team members
- Caregivers
- Patient navigators
- Social workers
- Faith-based organizations
- Case managers
- Nonprofit cancer organizations

Check into the many cancer support programs listed in the Additional Resources section of this book (page 155).

The Foundation's cancer navigation services offer free help to all cancer survivors. This includes the cancer patient, caregivers, loved ones and friends. For one-on-one assistance, call 855.220.7777 or go to Livestrong.org/WeCanHelp.

The Foundation also provides information about many types of assistance programs and other cancer topics online at Livestrong.org/CancerSupport.

DECIDING TO WORK WITH AN ASSISTANCE PROGRAM

If you decide to work with an assistance program, find out when the services will start. Ask whether delays are common before benefits begin. Also, be certain you understand if there will be any costs to you.



Livestrong means knowing about assistance programs that can help survivors.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding My Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Prescription Assistance Programs
- Transportation and Other Support Services
- Federal and State Benefit Programs







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“I felt like after going through it, I had to prove something to myself and started training for a triathlon. I had to prove that I could come back. Just because I had cancer doesn't mean it was gonna control my life.”

—LAURA T.



During Treatment:

TREATMENT CONCERNS

This section includes information that may be helpful to cancer patients and caregivers who are dealing with cancer treatments and side effects. The following topics are included:

- > Your Feelings During Treatment
- > Common Treatments and Side Effects
- > Pain Management
- > Changes to Your Treatment Plan

Your Feelings During Treatment

As you go through cancer treatment, there may be times when you have little energy or interest in things that used to be important to you. There may be conflicting emotions about your fight with cancer. This is a normal part of living with cancer. Each phase of the cancer journey brings new experiences.

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“Talking about emotions is a difficult thing for guys...to express your emotions and still be the stoic guy that everybody wants to be...I am stronger than I ever was. But it doesn't mean that the little insecurities and little voices aren't there.”

— BRIAN H.

On the one hand, you may have confidence that you can beat cancer. You may be ready to tackle the physical, emotional and mental challenges that can come with cancer treatment. You may also feel good about your health care team and the support you receive from others.

At other times, you may feel unsure about what will happen. There may also be concerns about protecting loved ones. You may attempt to hide some things from them. There may even be times when you feel alone or withdraw from others.

It is normal to feel emotional and have mood swings during cancer treatment. You may feel peaceful and balanced one day, yet stressed and fearful on another. Strong emotions and reactions might occur when you are not expecting them. It is often best to allow yourself to have these feelings without judging them as right or wrong.

The following mix of emotions are common for people who are beginning treatment:

- Relief about starting to fight cancer
- Hope about beating cancer
- Concern about physical changes
- Worry about whether the treatments will work
- Sadness about the challenges cancer can bring
- Anxiety or fear about the future
- Distress about the changes cancer and treatment might bring to your life
- Anger about having cancer
- Uncertainty about the future

DEALING WITH LOSS

Cancer patients might experience losses. Some may be easy to see and name such as physical changes. Others, like the loss of a sense of control, can be harder to recognize. A loss may be temporary or permanent. A loss can be life changing or a minor inconvenience.

You might find that some people around you seem not to recognize your losses or feelings of grief. Some may find it hard to talk about feelings. They might want to help you, but do not know how. If this happens, remind them that you need the support of having someone listen to you. Let them know that you do not expect them to have answers or to be able to make everything better.

DEALING WITH EMOTIONAL DISTRESS

Stress that is ongoing can become serious emotional distress. Symptoms may include changes in blood pressure, chest pain, headaches, depression or anxiety. If this starts to happen to you, try using some of the methods you have used to deal with difficult times in the past.

You may already know some good ways to cope. Some people use exercise or meditation. Many keep a personal journal to record thoughts, feelings and experiences. Writing about challenges may help you deal with them and reduce stress. As much as possible, focus only on what needs to happen today.

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“I think that you are emotionally changed by any of these kinds of experiences as a human being and in your daily life.”

—ANN F.

Talk with your health care team about what you are experiencing. A referral to a social worker or licensed counselor may help you to identify steps to lessen stress. Share your feelings with a trusted loved one or friend. If you feel that you have concerns about faith or spiritual issues, a clergyperson or member of a faith-based organization may be able to help.

Many individuals find comfort in talking with others who have gone through a similar experience. Consider asking your health care team to help you find an in-person or online support group of cancer survivors. Keep in mind that each support group is different. You may have to try a few of them to find the one that best meets your needs.

SERIOUS EMOTIONAL REACTIONS

Some emotional reactions can be overwhelming. If you think that stress has become emotional distress, seek the help of your medical team right away. This is especially true if you think about hurting yourself or someone else.

Contact your physician, nurse or social worker and tell them how you are feeling. A loved one, caregiver or friend may be able to give you emotional support until you can get medical help.

There can be different reasons for some emotions such as depression or anxiety. For example, certain medications can cause depression or suicidal thoughts in some people. If this could be happening to you, contact your health care provider and pharmacist immediately.

In some cases, there may be a need to change your medication. You may also need the support of a counselor. If you cannot reach your health care provider, call 911 or go to a hospital emergency room. It is important to treat serious emotional distress as quickly as possible.

FINDING SUPPORT

An important part of healing is finding the support you need. Many patients and caregivers find comfort in talking with others who are familiar with the cancer journey. Support can come from loved ones, friends



Ask your health care team questions that will help you find emotional support such as:

- How can I talk with my loved ones about what I am feeling?
- Can my cancer treatment contribute to emotional side effects?
- How can I find other cancer survivors to talk with?
- What can be done to help me feel more balanced emotionally?
- What can be done to treat the symptoms I am experiencing?
- Who can help me deal with my feelings?

and professionals. There are many cancer support resources to assist you. You do not have to deal with cancer alone.

Support often comes from members of the health care team such as an oncology social worker or a patient navigator. Your health care provider might suggest a support group for you or your loved ones.

Support groups can allow people who are affected by cancer to share common experiences. These groups also provide a chance to learn new ways to deal with problems. Some cancer programs offer support groups for cancer survivors and their loved ones right in the clinic or hospital. There are also support groups for caregivers.

Nonprofit cancer organizations offer many types of support. They can refer you to the right local and national resources including support groups and peer-to-peer support.



Find out more about support that is available in your area:

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- ☐ Ask members of your health care team to help you find a counselor or support group.
- ☐ Contact free programs through nonprofit cancer organizations such as the Foundation's cancer navigation services. Call toll-free at 855.220.7777 or go to Livestrong.org/CancerSupport.



Livestrong means facing your emotions and dealing with them in the way that works best for you.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Organizing Medical Information



Read more about living with cancer at Livestrong.org/WeCanHelp

- Emotional Support
- Finding a Counselor
- Meeting Other Survivors

Common Treatments and Side Effects

The most common cancer treatments today are surgery, chemotherapy and radiation. A cancer patient may receive one or a combination of these or other types of treatment. The type of treatment you receive depends on the type and stage of cancer.

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“If you do not have someone [to go to appointments with you], take a tape recorder, keep the tapes and listen to them.”

—SUSAN C.

PREPARING FOR TREATMENT

Find out if you need lab work before your treatment. Ask your health care team about the best ways to prepare for your treatment sessions. Your provider may have advice or give you a prescription for medication that can help you avoid side effects such as nausea.

Many cancer patients prepare a special tote bag or backpack to bring along to treatment sessions. They include items that will provide comfort and something to do during treatment.

Some good items to include in a treatment bag:

- Sweater and comfortable clothes
- Music player, headphones and favorite music
- Blanket and pillow
- Reading materials
- Crossword puzzles or other activities
- Deck of cards
- Lip balm
- Body lotion
- Calming teas like peppermint
- Notepad or journal and pen
- Bootie socks
- Cookies, crackers or other snacks
- Stress ball

COMMON TREATMENT SIDE EFFECTS

Some treatments bring side effects. However, not all cancer patients will experience the same thing. Knowing what you might experience can help you feel more in control. Talk with your health care team

about any side effects you could experience. Medical care can often lessen the effects and problems associated with treatment.

Ask your health care team for information about what to eat and what to avoid eating or drinking during your treatment. There are many types of foods and beverages to consider for each type of treatment.

The following is an overview of the three most common types of cancer treatment and some of the side effects that are possible:

Surgery

Improved surgical methods now help limit damage to normal tissue. They have also reduced risks and side effects. Surgery is often used to find out if cancer cells are present such as with a biopsy. It is also used to remove tumors. Sometimes surgery is done to rebuild (reconstruct) or reshape physical changes.

A medical device (port) is sometimes surgically placed under the skin. The port can



Find out about side effects that might occur with each type of treatment.

- ☐ Talk with your health care providers about what you can expect.
- ☐ Learn what can be done to manage the side effects.
- ☐ Prepare a backpack or bag to take to treatment sessions.

be used to give medications.

Depending on where on the body the surgery is done, side effects may include:

- Scarring
- Movement limitations
- Inability to do some activities on a temporary or long-term basis
- Changes in sexual function or fertility
- Changes in ability to judge, learn or remember (such as after brain surgery)
- Fatigue
- Swelling or lymphedema

Chemotherapy

Chemotherapy uses medications to kill cells and stop cell growth. These medicines can be given as an oral tablet. They can also be given by injection or through a vein (with an IV) or a port. The medicines get into the bloodstream and circulate through the entire body. Side effects occur because the medicines affect both cancerous and non-cancerous cells. Side effects can occur when healthy cells are damaged.

High doses or repeated chemotherapy may cause side effects. Many of the medicines interfere with the rapidly growing cells of the body. These cells may be in the stomach and intestinal lining, hair, skin, nails or bone marrow. There may be side effects, such as hair loss, because certain cells are affected. Chemotherapy is done in repeated cycles to allow the body to recover between doses.

Chemotherapy treatments can cause nausea and vomiting. Ask your health care provider about anti-nausea medications that may help. Some patients recommend not eating your favorite foods right before or after treatments. This might result in your associating the food that you eat at those times with the upset stomach that comes from chemotherapy. Later on, when it is important to rebuild your appetite and weight, you might not feel like eating those foods again.

Talk with your health care provider if you want to have children in the future. Fertility preservation decisions should be made before starting treatment. Be sure to let your provider know if there is any possibility that you or your partner could already be pregnant. Chemotherapy can harm an unborn child.

Chemotherapy can cause side effects such as:

- Anemia
- Decreased immunity
- Fatigue
- Mouth sores
- Forgetfulness
- Nausea or vomiting
- Hair loss
- Skin rashes
- Bruising and bleeding
- Cataracts

Chemotherapy affects people in different ways. Some have very few side effects, while others have more. Side effects have nothing to do with how well the treatment is working.

Chemotherapy may temporarily affect the ability to concentrate. The result may be mild forgetfulness. This is sometimes called chemo fog or chemo brain. Calendars, lists and messages on voice mail can be helpful if this happens to you.

Side effects usually begin to improve or go away as normal tissues repair themselves. This may start about three weeks after the treatment. Hair can start to grow back even before the treatment is finished.

It is hard to know how long side effects will last. Not all chemotherapy treatments cause the same effects. Some may be related to specific medicines. Others may occur when chemotherapy is given with other types of treatments.

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“My life partner was just great. He said, ‘No matter what happens, no matter what kind of surgery you have, you will always be attractive to me.’ He has been good about things, continuing to say that the scar didn’t make any difference to him.”

— BETH P.

“

“One of the most important things for me in learning how to deal with my new body and my new scar was understanding that sharing with other people is going to make it easier. My policy was always to tell anybody that wanted to hear and be as open as possible about what was going on in my life.”

— AMY D.

Talk with your health care team about what side effects you might expect. There are many new ways to help patients be more comfortable during treatment. For example, your provider may prescribe medications to control nausea. He or she may recommend a specific diet during treatment.

Always tell your health care provider about any side effects that occur during chemotherapy such as:

- Extreme fatigue
- Bleeding
- Numbness and tingling in limbs (neuropathy)
- Difficulty breathing
- Eating or drinking problems
- Problems with urination or bowel movements
- Memory loss and inability to focus
- Pain
- Infection
- Fever

Chemocare.com provides information on the aftereffects of chemotherapy drugs and how to manage those effects. You can search by the name of your treatment drug. There are also tips for eating well during treatment and suggestions on when to contact your health care provider.

Radiation Therapy

Radiation therapy is the use of X-rays directed at a tumor. This might be done externally (on the surface of the skin) or internally (inside the body). The doses may be high or low. They are not the same as the X-rays used to take a picture of a tumor.

Lead shields are used to protect vital organs during treatment. This minimizes radiation damage to normal tissues that surround the cancer. It also helps direct treatment to the same location each time.

Damage to normal cells or structures of the body can cause radiation side effects. The health care provider will try to limit radiation damage to those areas that are close to the tumor during treatment. Still, some healthy tissue and organs may be involved in an effort to be certain all of the cancer is treated.

Talk with your provider if there is a desire to have children in the future. Decisions about fertility preservation options should be made before starting radiation treatment. Women need to let the health care team know if there is any possibility of pregnancy because radiation could harm a fetus.

Ask your health care provider to discuss side effects that radiation therapy could bring for your type of cancer. Following treatment, report any side effects to your provider as soon as possible. Early medical care for side effects is very important.

Radiation side effects generally depend on the area of the body that is treated. They may include:

Head

- Hair loss and changes to hair
- Earaches
- Redness and irritation in the mouth
- Dry mouth, trouble swallowing or changes in taste
- Changes to teeth, gums, mouth or throat

Body

- Bone growth changes in children who are still developing
- Dry, irritated or reddened skin
- Nausea, vomiting or bowel changes
- Eating and digestive problems
- Irritation of the bladder
- Effects on fertility or sexual functioning
- Breast size changes
- Lung fibrosis (stiffening or scarring)
- Osteoporosis or bone loss

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“I still get fatigued. I do not have the energy that I once had, but the time that I do have, I make sure it is pretty much all out. I exercise ... spend time relaxing with my wife ... I take naps every day too.”

—CHRIS O.



Keep track of what happens between medical appointments:

- ☐ Write down dates of side effects and symptoms as well as what you experienced.
- ☐ Note how long the symptom lasted and what did and did not help.
- ☐ If you develop pain or other serious concerns, contact your doctor right away or go to the hospital emergency room.

General

- Fatigue or weakness
- Swelling and soreness
- Cough or shortness of breath
- Low white blood cell counts or low levels of platelets (rare)
- Emotional effects

HORMONE THERAPY

Hormone therapy is a treatment that adds, blocks or removes hormones. During this type of treatment, surgery may be needed to remove a gland that makes a certain hormone. In some cases, hormones may be given to adjust low hormone levels. Synthetic hormones or other drugs may be used to block the body's natural hormones in order to slow or stop the growth of certain cancers. This may be done for prostate and breast cancer. Talk with your health care provider about the benefits and risks (such as osteoporosis) of this type of treatment. If you want to get pregnant after undergoing this type of treatment, ask about risks and recommended waiting periods.

Livestrong Fertility offers reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility. You can call 855.220.7777 or go to Livestrong.org/fertility. **Livestrong Fertility** may be able to help reduce fertility preservation costs for qualified patients.

CANCER TREATMENT AND FATIGUE

Fatigue or feeling physically exhausted is a very common side effect of cancer treatment. You may have no energy to do things that are important to you. Fatigue can also affect you mentally and emotionally.

The causes of fatigue can include physical problems such as pain, stress, anemia or the side effects of treatment. Sometimes the cause is emotional such as depression. Other times, the cause might not be clear. Yet, fatigue can usually be successfully medically managed.

Tell your health care provider if you are fatigued. Describe your level of fatigue by using terms like mild, moderate or severe. Your health care team will try to find out what is causing the fatigue so they can provide the best treatment to help relieve it.

DEALING WITH TREATMENT SIDE EFFECTS

It is very important to talk with your health care team about reactions to or side effects from treatment. Ask the provider if you are unsure whether your symptom is related to your treatment.

Your health care team members will be able to help you with treatment and side effects by:

- Telling you how to deal with a medical emergency such as a fever
- Providing information about your specific cancer treatment plan
- Describing risks of treatment and possible side effects
- Helping you manage side effects
- Managing pain medically
- Identifying specialized care that may be needed
- Referring you to other health care providers
- Creating a plan for follow-up health care when treatment ends



Livestrong means making the best decisions for safe and effective cancer treatment.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Organizing Medical Information



Read more about living with cancer at Livestrong.org/WeCanHelp

- Aftereffects of Cancer Treatment
- Chronic Pain
- Lymphedema

Pain Management

Not all cancer patients experience pain during cancer treatment. However, some patients need to have pain managed by the health care team. Each individual's experience is different. What happens to one may not happen to another. If you have pain, talk to your health care team right away. There is no need to suffer with unmanaged pain.

“

“If you are experiencing pain, discomfort or a strange symptom, don't just assume it is supposed to be that way and not mention it. Tell your doctors. They are there to help you.”

—CURTIS B.

Decisions about pain management should be made with your health care provider. If pain continues, you or someone acting on your behalf should contact your provider and ask for more help. There are many different pain medicines. It may be that a prescribed change in the dosage or another type of medication would work better for you.

COMMUNICATE WITH YOUR HEALTH CARE TEAM

If you have pain problems, contact your physician or other members of your health care team right away. It is important to get the best treatment possible as soon as you can. If pain becomes severe, it can become more difficult to manage.

Tell your health care provider if you have:

- New pain
- Long-term or constant pain
- Pain that continues after treatment

- Pain that feels different than what you have had before
- Pain and swelling in an arm or leg
- Pain, numbness, tingling or a burning sensation in your hands or feet.

Keep a record of your pain. Take this information to your appointments with members of your health care team.

Cancer pain is often treated with one or more medications. If you have concerns about taking certain treatments, discuss these with your provider and pharmacist. Your health care team will want to address your concerns while effectively treating your pain.

Give your health care team enough information to correctly assess your pain situation. Many providers ask patients to rate their level of pain using a pain scale. A rating of zero means no pain. A rating of 10 stands for the highest level of pain. This method gives the provider a better idea of the level of discomfort.

Pain can affect your ability to sleep, eat, work and spend time with loved ones and friends. Tell your provider how the pain is affecting your life. Describe how it interferes with your activities.

Relief from pain can positively affect your overall health, strength and ability to heal properly. Your provider may try several methods to find what works best to relieve your pain.

Be certain that members of your health care team have the experience and skills to treat your specific condition. You deserve to receive good pain care.

When you talk with your provider about pain symptoms, he or she should ask questions. Tests



Ask your provider questions about pain medications such as:

- What pain medications are available for this type and stage of cancer?
- Are there likely to be side effects to the treatment prescribed for pain?
- Could there be interactions with other medications?
- Do you recommend any other treatments?
- Are there any concerns about trying different treatments?

should be done to identify the cause of the problem. It is important that the members of your health care team listen to you.

Some nurses and physicians, such as physiatrists and anesthesiologists, specialize in managing pain. If you think your provider is not having success treating your pain, ask for a referral to a pain specialist.

The Center to Advance Palliative Care (CAPC) is a website that provides important information about pain care and support. This includes a Palliative Care Directory of Hospitals and a description of what palliative care is and how it is different from hospice. The website (getpalliativecare.org) also provides a questionnaire to help you decide whether palliative care is needed.

PAIN RELIEF TREATMENT OPTIONS

Stress can make pain worse. It can also lessen the effect of medications. Sometimes a health care provider may recommend counseling to help a patient cope. This may lessen the pain. It may also help improve the effectiveness of the pain medication.

Other types of treatment may be used along with pain medications to provide relief. These methods are called complementary, alternative or holistic medicine. They include massage, acupuncture, bio-feedback and hypnosis.

Occasionally, health care professionals are not aware of some types of complementary therapies. Others might think that these methods do not work. To learn more about these types of therapies, call the **National Cancer Institute** toll-free at 800.422.6237 or visit cancer.gov/cancertopics/factsheet/therapy/CAM.

Talk with your health care provider if you are interested in adding another method of treatment. Your health



Ask yourself the following questions to find out whether your pain is being managed well:

- Are your reports of pain taken seriously by your health care team?
- Has your health care provider told you what may be causing your pain?
- Have you been told about all of the pain treatment options?
- Do you understand the benefits and risks of each treatment option?
- Are you involved in decisions about managing your pain?
- Have you been referred to a pain specialist for pain that is ongoing?



Give your health care team members specific information about your pain including:

- ☐ Where the pain is located
- ☐ How much it hurts (mild, moderate or severe)
- ☐ When you experience the pain
- ☐ What seems to lessen or increase the pain
- ☐ How often you have pain
- ☐ How long the pain lasts
- ☐ How much any current pain medication helps
- ☐ Whether the pain affects your ability to sleep, eat or do daily activities

care team also needs to know about supplements and herbs that you take or want to try. Some types of therapies or alternative treatments could affect the cancer treatment that has been prescribed by your provider.



Livestrong means getting the right kind of help to manage cancer pain.

See the Livestrong Guidebook Planner and Journal pages:

During Treatment: Working With My Health Care Team



Read more about living with cancer at Livestrong.org/WeCanHelp

- Aftereffects of Cancer Treatment
- Chronic Pain
- Quality of Life and Palliative Care

Changes to Your Treatment Plan

There may be reasons to consider changes to your cancer treatment plan. For example, you or your health care provider could have questions about continuing current treatment methods. You could also learn about a new type of treatment.

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“I think it is going to be worse for the cancer because now I can put all my energy toward getting rid of it. So now the thing has no chance. It’s going to be out of me. I’m going to beat it. I’m going to attack it. I’m going to kick the hell out of it!”

—ERIC S.

Certain tests may be performed during and after treatment to learn if there have been changes. Cancer could go into remission. This means that current tests can no longer detect active cancer. You and your provider might decide to change your treatment plan based on new test results.

CHANGING YOUR TREATMENT PLAN

Stay involved with any updates to your treatment plan. Ask questions if you do not understand something or need more information.

Reasons that you may want to consider different treatments can include:

- Concerns about possible side effects of the current treatment
- New treatments or resources that were not options in the past
- New information about successful treatments for your type of cancer
- The first type of treatment was not as effective as your provider had expected
- Changes in your insurance or health care benefit coverage

Medical journals and scientific articles provide information about treatment options. These can be found in medical libraries as well as online.

New information about treatment options can also come from loved ones, friends and health

care team members. Nonprofit cancer organizations provide current information about treatment options as well.

The Foundation provides consultation services from experienced nurses. They will work with you to answer questions. They can also provide information about your type of cancer and treatments available. Call 855.220.7777 or go to Livestrong.org/CancerSupport.

Although your health care provider may recommend new treatments, you are the one who will make the final decision. Your first choice may not always have to be final. In some cases, you may be able to change your mind later.

NEW TREATMENT PLAN

If there is a change in treatment, ask your provider to give you a new treatment plan summary. Make certain that it includes updated information about:

- Types of cancer treatments used
- Schedule of treatments (how often and how long)
- Symptoms, side effects and aftereffects
- Pain management methods



Livestrong means getting the treatment that is best for your situation.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Organizing Medical Information



Read more about living with cancer at Livestrong.org/WeCanHelp

- Communicate With Your Health Care Team
- Hope



During Treatment:

DAY-TO-DAY CONCERNS

This section includes information that can be helpful to those who are dealing with changes during the cancer journey. The following topics are included:

- Relationships During Cancer Treatment
- Home Health Care Needs
- Making Changes to Your Home
- Employment Issues
- Dealing With Finances During Cancer
- Important Legal Documents
- Organizing and Keeping Important Records

For help finding support and resources for child care, transportation and other types of assistance, see the Finding Assistance section of this Guidebook.

Relationships During Cancer Treatment

Changes that affect the roles and relationships in your daily life may be especially challenging. Cancer treatment can cause a change in energy level. Side effects could affect the way you feel about yourself for a while. During a time like this, what is most important to you might change. There may be less time and energy to do certain things with others.

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“I think it was extremely hard on my husband. He had side effects from it that I did not realize. It was always centered around me, because I was the sick one. I don't think we ever focused on him. We have had our problems and our difficulties, and we can work through anything. We worked through cancer.”

—BLANCHE T.

If you find that cancer and concerns about your life become overwhelming, find a way to talk with those who are affected. Discuss reasons that they or you might be acting differently. Talking about concerns and feelings early on can help resolve problems before they get out of hand.

SPOUSE OR PARTNER RELATIONSHIPS

Spouses or partners are often the main source of support for one another. The level of support felt between loved ones is affected by the ability to talk openly about concerns and challenges. Feelings such as fear, anger or guilt can build up if communication stops. The distress that one person feels may affect the stress level of the other. In time, high levels of stress can strain a relationship. Talking openly is the best way to break this cycle.

Some people find it hard to ask for help. They may not want others to have to take on new roles and responsibilities. This is often true for those who have always been the one who helps others. In this case, a cancer patient may try to do tasks that are too emotionally or physically challenging. Yet, an important part of the healing process is getting the help that is needed.

Some cancer patients are worried about the stress their loved ones feel. They may try to protect

others by not sharing information or feelings. Important planning might be avoided. If you feel that you cannot discuss certain things with loved ones, ask someone you trust to help you. A social worker, hospital chaplain or a member of your faith-based group can provide the support you need.

Sometimes you may think that loved ones and friends are too protective. Other times you might find that the long-term effects of cancer treatment, such as fatigue or pain, are hard for others to understand. If you look healthy or the cancer is in remission, others may want to forget about cancer so life can get back to normal. People affected by cancer often find that talking about these experiences with others who have similar experiences can be helpful.

GETTING HELP

Look for good ways to share thoughts and feelings with others during times of stress. Try to learn and practice good communication skills. If stress starts to build in your relationship, consider getting help from a licensed social worker or counselor. You may be better able to face challenges and focus on your healing when you feel supported by others.

The following are signs that it is time to work on communication skills:

- Frequent misunderstandings or disagreements
- Use of criticism, sarcasm or name calling
- Fewer expressions of love and affection
- Not wanting to ask for needed help or support
- Feeling hurt by things a loved one says or does
- Physical and emotional withdrawal by you or your loved one

STARTING A NEW RELATIONSHIP

If you are single, you may have concerns about starting new relationships during cancer treatment. You may worry that some people will not know how to handle the situation. There might be questions about how fair it is to become involved with someone new at this time in your life. Keep in mind that no one can know what will happen in the future in any relationship.

You will have to decide how much to share about your diagnosis with each person in your life. If you are not sure what to say, talk with a friend or a counselor about how you feel. Chances are that others will be understanding and accepting.

CHILDREN AND TEENS

Children and teens are likely to need help dealing with the wide range of emotions that come with cancer including sadness and fear. Talking openly with them about cancer and treatment can help lessen stress. Allow them to continue to ask questions and talk about the experience. Give the child or teen permission to ask you about your feelings as well. A child's age and personality will influence how often they will want to talk. Provide clear and concrete information. Reassure the child that his or her needs will continue to be met. Children and teens need to feel that it is okay to continue with their activities and interests.

Help children discuss and express feelings in a variety of ways. This may include working with art, music or writing. Physical activity can also help release emotional tension. Allowing them to continue life in as normal a manner as possible will be helpful.

Sometimes a child needs extra support. A family member, trusted friend or teacher may be able to help. If the child or teen is very distressed, seek the guidance of a licensed social worker, child psychologist or a psychiatrist.

Contact a nonprofit cancer organization for referrals to good programs for children and teens. Many are free for families affected by cancer.

Camp Kesem is a free summer camp for kids with a parent who has (or has had) cancer. The one-week camps give kids, ages 6–13, a chance to have fun and just be kids. Camp Kesem provides the extra support and attention that the kids need. There are nearly 40 chapters in more than 20 states. To learn more, visit campkesem.org or call 734.657.0057.

CureSearch.org is a free online resource for families dealing with children's cancer. This website provides information to help families learn about treatments and how to manage the emotions that come with caring for a child with cancer.

The **Livestrong at School** program can help children and their friends and loved ones deal with cancer. Go online to Livestrong.org/what-we-do/program/livestrong-at-school to find free lesson plans for teachers. The lessons teach children (K–12) about cancer in a way that is hopeful and inspiring. They include lessons, videos and activities that were prepared for different ages.

If a child has cancer, returning to school can build hope for the child and his or her loved ones. School can be a big part of feeling normal and productive. Yet going back to the classroom can also bring new challenges to families whose main focus has been getting through treatment. The Foundation and the Leukemia & Lymphoma Society have worked together to create resources that address the educational needs of children and adolescents with cancer.



Find ways to help children and teens deal with cancer:

- ☐ Talk openly about the disease with children and teens.
- ☐ Provide concrete information that is appropriate for the child's age.
- ☐ Help the child discuss and express his or her feelings.
- ☐ Assure the child that he or she can continue to live life as normally as possible.

Go to mskcc.org/sites/default/files/node/1228/documents/learning-livingwccancer-pdf.pdf to download the booklet, *Learning and Living With Cancer: Advocating for Your Child's Educational Needs*. The information includes:

- Insights about what a child may face and what can be done
- Information about the laws that protect the educational needs of children
- Specific ways that schools can help meet the child's educational needs

Adolescents (teens) and young adults (younger than age 40) generally have very specific concerns as they go through their cancer journeys. Many teens and young adults have concerns about issues such as:

- Reentry into school
- Returning to the workforce
- Insurance coverage
- Relationship concerns
- Family planning and fertility issues

Critical Mass: The Young Adult Cancer Alli-

ance provides a free online resource that offers information and links to many resources for young adult survivors and their loved ones. Visit criticalmass.org to learn more.

The Ulman Cancer Fund for Young Adults offers information and support services to help with many issues unique to teens and young adults including:

- Concerns about independence
- Personal finances
- Education or career interruption
- Dating
- Fertility
- Emotional concerns

Visit the Ulman Cancer Fund for Young Adults website at ulmanfund.org or call 888.393.3863.



Livestrong means having a support system that works well for you.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Communicate With Your Partner
- Telling Others You Are a Survivor
- Dating and New Relationships

Home Health Care Needs

Some cancer patients require specialized health care assistance. This might happen during or after cancer treatment. Home health care services can provide certain types of temporary or ongoing medical care at home. The goal is to make it possible to remain safe and comfortable at home while having a good quality of life.

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“It is important to have a great caregiver. I do not think anyone can get through this on their own.”

— BOB B.

HOME HEALTH CARE SERVICES

A member of your health care team might suggest adding home health care services to your treatment plan. This type of care is usually less expensive than care provided in a medical facility. Yet, if needed, you will be able to use hospitals or other health care facilities.

Home health care workers may include:

- Home health aides
- Nurses
- Social workers
- Physical therapists
- Occupational therapists
- Speech therapists

Home health services may include:

- Lab draws
- Nutritional planning
- Home-delivered meals
- Use of medical supplies or equipment
- Help with personal needs such as bathing
- Administering medications such as antibiotics

TYPES OF HOME HEALTH CARE

There are generally two types of home health care services following an illness or injury:

Short-term (or acute) care helps you take care of yourself. It helps you to be as independent as possible.

Long-term care helps you adjust to and manage changes caused by health issues. It supports you to be at the highest level of function and health.

Talk with your health care provider if home health care services are needed. Discuss any problems you are having with daily activities. Ask about the types of health care services that may be available to you at home. Your physician must prescribe the services in order for insurance to pay. Also, talk with your insurance provider to find out about your plan's home health care coverage. Ask the insurer to put information in writing for you.

Your physician, nurse, patient navigator or social worker can recommend specific, quality home health care service providers in your area. Friends and loved ones may also have information to share.



Ask your health care provider questions about home health care such as:

- Would home health care services be helpful in my situation?
- Will you prescribe home health care services?
- What types of services do you suggest?
- Do you recommend specific home health care providers?
- Will my insurance cover all of the expenses of home health care?

HOME HEALTH CARE COSTS

Home health care services can be costly. You might have to pay for some long-term home care with personal funds. Private health insurance or disability policies may cover some of the expenses. State and federal Medicaid and Medicare programs may pay some of the costs. Contact your local human service programs for more information. Your local **Area Agency on Aging** (n4a.org) should also be able to provide information about help in your area.

In certain cases, you may need to find a companion and not someone skilled in medical care. It can cost less to hire on your own. Yet, it could take a lot of time to find the right caregiver, and it may be more complex than you think. For example, you may be legally required to pay taxes or purchase insurance for the caregiver. Talk with an expert about what is required if you employ the caregiver yourself. You will also want to carefully check references if you do not already know the caregiver.

HOME CARE OPTIONS

Some families use a formal caregiver contract to hire a loved one to do home care for a family member. This is called a personal service or personal care agreement. If you are thinking about doing this, get legal guidance from an attorney who specializes in this area.



Livestrong means finding the best way to meet your home health care needs.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Organizing Medical Information



Read more about living with cancer at Livestrong.org/WeCanHelp

- Home Health Care
- Federal and State Benefit Programs
- Transportation and Other Support Services

Making Changes to Your Home

A cancer patient may benefit by making certain physical changes to his or her home. These changes (also called accommodations) can make life easier and safer during and after cancer treatment.

CHANGES TO A HOME YOU OWN

Some changes are easy to make. If you or loved ones own the home in which you live, it may be possible to make bigger changes.

Changes that might be helpful include:

- Easy-to-reach clothing rods in closets
- Cordless phone or speaker phone
- Kitchen appliances and sinks set up for easy access
- Bed at the right height for transfers
- Carpeting or floor surface that is easy to walk on, or to use a walker or wheelchair on
- Cart with wheels to lessen the need to carry things
- Door lever handles instead of turn knobs
- Ramps for easy entry into the home

Simple changes can also be made in a bathroom such as adding a:

- Shower seat
- Hand-held shower head
- Safety or grab bar
- Raised toilet seat or commode

Some types of physical changes may not require a contractor. Loved ones, friends or a volunteer may be able to do the work. More complex changes, such as designing and building a ramp, may need to be done by a contractor. Find out if you will need a building permit to make more complex types of changes to your home.

Centers for Independent Living (CIL) are nonprofit agencies run by people with disabilities within local communities. CILs provide information, peer support, skills training and advocacy services.

Many CILs work with nonprofit assistive technology programs. These programs can suggest changes

that might be made to your home to help meet your needs. They generally do not sell products or charge a fee for their services.

To find a state-by-state listing of Centers for Independent Living go to ilru.org/html/publications/directory/index.html.

MAKING CHANGES TO RENTAL PROPERTY

State or federal laws may apply to you if cancer has caused a disability. The Americans with Disabilities Act (ADA) is a federal law that supports rights to make needed changes. You can read more about how the ADA may protect you at hhs.gov.

If you rent your home, the property owner must approve changes before you make them.

Some changes at a rental property might include:

- Allowing a renter to move to a lower floor if necessary
- Adding grab bars in the bathroom or hallway
- Lowering countertops or widening doorways if a wheelchair is needed
- Permitting a renter to live with a service animal



Think about making changes in your home that can help you.

- ☐ Make a list of things that are difficult to do in your home.
- ☐ Write down things that can be done to make life at home easier for you.
- ☐ Make a list of the names of people who are willing to help you make the changes.
- ☐ Make a list of the steps you need to take if you need permits or permission to make changes.



Take these steps if you need to make changes to your rental home:

- ☐ Learn about housing rights for people with disabilities.
- ☐ Think about specific changes that you need.
- ☐ Talk with the property owner about changes that are needed to make the home safer because of your disability.
- ☐ Make a formal request for the changes.

- Providing a reserved parking space
- Providing property rules and documents in large print
- Allowing a live-in aide

You can ask for changes to rental property due to a disability. However, you will most likely have to pay the costs of making the changes. The owner of the property can also ask you to pay the costs of returning the property to the way it was when you move out.

LEGAL PROTECTIONS

Review your rental lease if you plan to ask for changes. The lease may already allow you to do some things. If it does not, check into state and federal fair housing laws. These laws protect people with disabilities. Some of the laws apply to housing issues such as the fair sale, rental or financing of a home. They can also help people make needed changes to their home.

If you meet program requirements, you may be able to get a deferred, interest-free loan to:

- Buy a home
- Build a home
- Make needed changes to property
- Get assistive technology and services

For more information, contact the **U.S. Department of Housing and Urban Development** (HUD) at hud.gov or call 800.333.4636.

HUD provides online and printed information about the Fair Housing Act and other housing laws (hud.gov/renting).

Also, check with your state's Medicaid program to find out if you qualify for financial assistance (cms.hhs.gov).

HOUSING AND OTHER ASSISTANCE PROGRAMS

Assistance programs help those who do not have the income for basic needs. Housing is a basic need. Other basic needs include food, health care and utilities. If you need help, contact your local human services office to find out what is available in your area.

Housing assistance programs usually have very long waiting lists. Apply for these and other types of services as early as possible. When you apply, ask if your health condition will be given priority. If it is considered to be a priority, there may be a much shorter waiting period.



Livestrong means having a safe and supportive home for your recovery.

See the Livestrong Guidebook Planner and Journal pages:

Just Diagnosed: Support Resources



Read more about living with cancer at Livestrong.org/WeCanHelp

- Prescription Assistance
- Health Care Assistance Programs
- Federal and State Benefit Programs
- Transportation and Other Support Services

Employment Issues

Cancer and treatment can make it difficult to work. Prepare early if you think it is possible that you will not be able to work for a while. If you work now, start by considering your current job. Think about whether you will be able to continue to do the required job duties. If not, think about ways your job might be changed so you can keep working. Also, consider future possibilities for work. These may be with the same employer or with a new employer.

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“I really have had to look at the hard cold facts and realize that I need to keep my health insurance. I am lucky enough to have a job I love.”

—SUSAN C.

Some patients want to keep working during cancer treatment if possible. This is often because there is a need for income and health insurance coverage. Some go back to work after cancer treatment. Other survivors go to a part-time work schedule or work from home for a while. Still others decide to find a new type of work or not work at all.

Your decisions about work are likely to be based on your type and stage of cancer. Treatment and its effect on you will also be important things to consider. Some treatments require a stay in the hospital. You are the one who can best decide what is right for your situation.

CONTINUING TO WORK

Cancer and treatment may or may not affect your ability to work. Telling your employer about the cancer diagnosis is a personal choice. If your ability to do your job will not be affected, you might decide not to tell your employer right away. On the other hand, there may be certain things that could be done to make it easier for you to continue to work if you tell your employer.

If you decide to talk with your employer about your cancer diagnosis, write down what you want to say. Go over it with loved ones and friends. Get their feedback before you meet with the employer. Practice what you want to say until you feel comfortable. Provide only as much information as you want to.

When you talk with your employer:

- Try to find a solution that works for everyone

- Show him or her that you feel confident about returning to work
- Tell him or her what he or she needs to know including:
 - How long you will be able to continue working
 - Whether you will be able to continue to do all of your job duties
 - If you need to take time off from work for treatment, when you are likely to be able to return to work

Some patients can work during treatment only if the employer allows changes in job duties (accommodations). Talk with your health care provider if you are thinking about asking the employer to make changes at work. Ask for his or her advice. Your provider may be able to write a note explaining what changes are needed and why.

Some examples of changes include:

- Altering a work schedule
- Doing different job duties for a while
- Working from home for a time



- ☐ Decide whether you want to keep working during cancer treatment.
- ☐ Decide whether you need to tell your employer about the cancer diagnosis.
- ☐ Talk with your employer about your needs if you will need to make changes to continue to work.



If you are leaving your job, ask your employer about:

- Benefits and insurance coverage that you currently have
- COBRA benefits that will continue insurance coverage for a period after you leave your job
- How much the COBRA benefits will cost
- The COBRA sign-up and payment due dates

Talk with your human resources director and your supervisor about your needs. Any job changes will have to be approved by your employer.

UNABLE TO WORK

Talk with your employer about your health situation if you will not be able to work for a while. Discuss your desire to return to the company when your health improves.

Ask your human resources director to explain all of the benefits that will be available if you cannot work such as:

- Short-term disability income insurance
- Long-term disability income insurance
- Dental and vision insurance
- Long-term care insurance

Be certain that you know how to keep your job and benefits while you are not working. Find out how much you will have to pay to continue your insurance coverage.

If you are leaving your job, ask about COBRA benefits. These benefits continue insurance coverage for a period after you leave a job.

It is very important to know about COBRA application and payment deadlines. Be certain that you request and submit the paperwork and payments on time. If you are late, you will lose the opportunity to keep your benefits.

Look into applying for disability income benefits if you will not be able to work for a while. These may be provided through your employer. There are also government benefit programs. A social worker can help you find information about these resources.

The employer should not share medical information with coworkers unless you have given your consent. Yet supervisors need to know certain things.

For example, they need to know about changes in job duties or work schedule. It may be hard to keep the details of your health condition completely private.

FEDERAL LAWS RELATED TO EMPLOYMENT

Many employers are supportive of employees who are dealing with cancer. Yet, unfair things can happen at work. It is important that people affected by cancer understand employment laws.

The following is a brief overview of two of the most important federal laws that protect employees:

Americans with Disabilities Act (ADA)

The ADA applies to employers with 15 or more employees. It also applies to those who work for state and local governments. Generally, if you are able to perform the duties of your job, an employer cannot treat you unfairly (or discriminate). In fact, the employer may need to allow some changes to help you do the job. Examples of changes an employer might make are light-duty work, flexible hours or leave time.

State employees cannot sue their employer for money. However, they may be able to sue the state to get their job back. They may also have additional protection under their own state laws.

If cancer, treatment or side effects keep you from being able to do your job, learn more about the ADA. Go online to ada.gov or call the ADA Information Line at 800.514.0301.

Family and Medical Leave Act (FMLA)

The FMLA can help cancer survivors and their caregivers. This law generally applies to employers with 50 or more employees. An employee must have worked for the company for at least one year (1,250 hours) to take leave under the FMLA.

Under this law, an employee can generally take a certain number of weeks of unpaid medical leave in a year for a serious medical condition. FMLA can also be used to care for a seriously ill spouse, parent or child.

You will not be paid wages when you take FMLA leave. However, your job and benefits remain protected. This means that the employee can return to the same position or one that is generally equal. If the employer pays for the health insurance, that will continue while the employee is on FMLA leave. You will

also need to continue to pay your portion of the cost for these benefits.

Some states also have FMLA laws that protect people with cancer. These laws may apply to employers with fewer than 15 employees. Find out about the laws in your state.

To learn more about FMLA, go online to dol.gov/whd/fmla/index.htm#Forms or call the toll-free help line at 866.487.9243.

- Department of Justice, Disability Rights Section
justice.gov
202.514.2000
- Equal Employment Opportunity Commission
eeoc.gov
800.669.4000
- Department of Labor
dol.gov
866.487.2365

OTHER IMPORTANT FEDERAL PROTECTION LAWS

Employee Retirement Income Security Act (ERISA): This law protects employees who use the rights provided by a benefit plan such as health insurance.

Consolidated Omnibus Budget Reconciliation Act (COBRA): This law allows certain employees to continue their health insurance coverage after leaving a job. The employee must take over payment of premiums. Coverage is allowed for a certain length of time.

Health Insurance Portability and Accountability Act (HIPAA): This law limits how an insurance company can refuse to cover health conditions that started before the policy took effect. It also protects the privacy of patients.

Rehabilitation Act of 1973, as amended (Federal Rehabilitation Act): This law provides many ADA protections to employees of the federal government. It also covers those who work for employers who receive money from the federal government.

Learn about these federal laws and get answers to your questions from the following agencies:

- Social Security Administration
ssa.gov
800.772.1213

JOB SECURITY

Get a written copy of your employer's personnel policies. They are often provided in an employee handbook. Read about medical leave and other benefits. Ask questions about the company's policies if things are not clear. Be certain you understand required timelines. This can help you avoid future problems.

Employers do not have to hold a job forever. The medical leave policy may specify a time limit. Generally, an employer is not required to hold a job so long that it becomes an unfair hardship.

An employee cannot lose his or her job just because he or she has a disability. However, employers can fire or lay off employees for many reasons. An employee can be fired for not doing a good job. A company can also lay off a number of employees at the same time (or downsize) if they think it is for the good of the company.

EMPLOYMENT DISCRIMINATION

Federal law requires that employers make decisions fairly. This means decisions regarding employees should be based on the ability of a person to perform the duties required by a job. Discrimination happens when employment decisions are based on other factors such as:

- Race
- Age
- Gender
- Physical ability
- Religion

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“One thing I have learned from talking to cancer patients is that a high percentage of them do not go back to doing what they did before. There is no way I could do that at this point, nor would I want to.”

—CHRIS O.



- ☐ Tell your employer about things that are related to your job.
- ☐ Work together to develop a plan.
- ☐ Provide needed information without revealing more than you want to share.
- ☐ Give your employer information about the length of treatment.
- ☐ Work with your employer to find ways to deal with changes that affect your ability to do the job.

Some cancer survivors feel supported by their employer and coworkers. Others may experience unfair treatment or discrimination at work. Sometimes discrimination is due to fears and ideas about cancer that are not based on facts. You may have to help educate your employer about your situation and what to expect.

Keep in mind that your employer is likely to have questions about what you will or will not be able to do in the workplace. It is not a good situation when an employer makes decisions based on guesses or inaccurate ideas.

Your employer may have concerns that you will need to address such as:

- Uncertainty about what you can or cannot do
- Concerns about time away from work for cancer treatment and other health care
- Fear that insurance costs will go up for the employer
- Uncertainty about whether you will be able to continue to perform your job duties
- Worry that you might decide not to come back to work after treatment

LEGAL RIGHTS DURING A JOB SEARCH

Some cancer survivors may no longer be able to do the same or different work for their employer. It could become necessary to look for work with a new employer.

There can be advantages to going to work for a new employer in some cases. For example, you may find a job with a better schedule or lighter workload. A new employer might also offer a good group health insurance plan that will cover your pre-existing cancer condition. However, be sure to review the plan to be certain that this is the case.

People who have had cancer do not have to talk about health conditions when applying for a new job. On the other hand, if you have a disability, a reasonable modification might make it possible to do the job. In this case, there will be a need to discuss the reason the adjustment would be helpful. For example, if you cannot carry heavy items, the employer may agree to let you use a cart to carry the items.

An employer generally cannot ask about a medical condition. However, they can ask if you are able to perform all of the required (or essential) duties of the job. For example, an employer may ask that all who work in a certain job be able to lift a certain number of pounds a certain number of times each hour. In this case, you may have to show that you can do this.

Employers can ask new employees to take a medical exam if a job offer is based on passing the exam. If this is required of one person, it must also be required of others for that position. The employer cannot take back the job offer if the exam is passed.

RESOLVING PROBLEMS

There are laws that can protect you from being treated unfairly by employers. **The Equal Employment Opportunity Commission (EEOC)** enforces these laws.

Employers are often willing to make changes to help people with disabilities. However, sometimes it may not be possible to reach an agreement with an employer. Then you must decide what action to take. Some people may want to go to another job and not fight with the employer. Others may seek legal action. Each survivor must decide what is best for his or her situation.

If you have questions, call the EEOC toll-free at 800.669.4000 or visit eeoc.gov.

The Foundation partners with the **Patient Advocate Foundation** to help patients and their insurers, employers and creditors resolve insurance and job retention issues. Call 855.220.7777 or go to Livestrong.org/CancerSupport.



Livestrong means knowing your employment rights.

See the Livestrong Guidebook Planner and Journal pages:
Just Diagnosed: Finding Support



Read more about living with cancer at [Livestrong.org/WeCanHelp](https://www.Livestrong.org/WeCanHelp)

- Preparing for Not Working
- Employment Laws
- Employment Discrimination

Dealing With Finances During Cancer

A cancer diagnosis can bring financial challenges. Consider how you can prepare for your own unique needs. For example, you may want to purchase disability insurance to cover credit card accounts, mortgages and loans. You may also want to think about new sources of income that will be available if needed.

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“It is hard to know what expenses are going to be. You go through life planning on living until you are 100 and putting away investments and that sort of thing. Now, I have no idea how to project into my future.”

—BARBARA R.

FINDING HELP

There can be a number of ways to get help during a time of need. You may need to start by looking into nonprofit programs that offer free or low-cost health care. Some programs can help you get medications. There are also programs that help with insurance co-pays or travel expenses for health care. Contact a social worker or your local human services agency for help finding these resources.

Nonprofit cancer organizations also offer a wide range of free services to help people affected by cancer. For example, you can call the Foundation's cancer navigation services toll-free at 855.220.7777 or go to Livestrong.org/WeCanHelp. A cancer navigator will work with you to help you solve problems and find programs in your area.

The **American Cancer Society** also offers support services to people affected by cancer. These may include help with lodging and transportation for cancer treatment. To learn more, call toll-free at 867.228.2345 or go to cancer.org.

FINDING EXTRA INCOME

Consider options you may have for extra income. For example, you might decide to sell personal items or property. You may think about cashing in an insurance or financial policy. However, before you make this type of decision, talk with loved ones and close friends. There may be someone who can help with a personal loan or another type of support.

Always look into the benefits and risks of each option before you act to increase your income. Learn about the effect any action you take will have on your taxes.

Getting Income From Personal Assets or Valuables

Personal assets are items that you own that are worth money. These may include:

- Furniture
- Vehicles
- Jewelry
- Antiques
- Art
- Stocks
- Bonds
- Certificates of deposit



If you are thinking about selling personal items:

- ☐ Make a list of things that you could sell for income.
- ☐ Talk with loved ones about how they feel about selling certain items such as those passed down in the family.
- ☐ Consider the effect on your taxes.

There may be good reasons to sell some of your personal assets. For example, you may want to move to a smaller home. However, keep in mind that selling valuable items can affect your tax status.

Getting Income From Retirement Accounts

You might think about using money from your retirement account for extra income. Some people borrow or withdraw money from a plan before reaching retirement age.

Each retirement plan has its own rules about taking money from the account. Some plans allow you to do this early. However, there may be fees and taxes that you will have to pay if you do so.

There are other things to consider about using retirement funds early:

- The amount of money in your retirement account will be reduced.
- The ability to build tax-free or tax-deferred income on the money that is taken out will be lost.
- You could also lose important credit and tax benefits including protection from creditors.

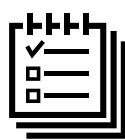
Talk with loved ones if you plan to use your retirement money early. Discuss how they may be affected by your decision.

Selling Real Property for Income

Real property is land and anything that is built, fixed or attached to it and passed on with the land when it is sold. Some people borrow against or sell the real property they own for extra income.

Some methods of selling real property may allow you to get income from the property while you continue to live there. Other methods require that you move. Be certain that you understand all of the ways selling property can affect you. Talk with loved ones about your options. The sale of the property may affect them.

Home loans, sales and rentals can be complicated. The laws that cover these are confusing and change often. Get help from an expert such as a banker, accountant or attorney. Compare



If you are thinking about taking money out of a retirement account:

- ☐ Think about whether your need for money now is greater than your need to save for retirement.
- ☐ Know what your retirement plan allows.
- ☐ Find out how taking money out of your account will affect you such as taxes and penalties.
- ☐ Think about the impact this will have on your loved ones.

your need for money to the benefits and risks involved with each option. This can help you make the right decision for your situation.

Using Credit

While you are in treatment for cancer, you may be tempted to use credit that is available to you. If possible, avoid running up debts on your credit card.

Living off credit cards is never ideal. Yet, if you are unable to work for a time or have no other resources, you may not have many other income options. If used wisely, credit can be a tool to help you get through a financial emergency.

Using credit can affect you and your loved ones in ways you might not expect. In some cases, it might create more problems than it solves. For example, paying cancer expenses with credit cards might make it hard to get financial help later. Ask a social worker or financial expert to help you look at the best options for paying medical bills.

DEALING WITH A FINANCIAL EMERGENCY

Reduce spending as much as possible during a financial emergency. However, always pay your rent or mortgage, utilities and taxes.

Contact your creditors to explain your situation. Tell your creditors that you intend to repay the debts. Do this before collection agencies get involved.

Some creditors may be willing to help you find a solution. For example, you might be able to make lower payments for a time. Some loans and credit card debts may qualify for a disability waiver if you are not able to work for a certain period.



Include the following steps as you look for ways to deal with a financial emergency:

- ☐ Evaluate the financial emergency and figure out how much it may cost.
- ☐ Think about possible sources of money and how you can add to your income.
- ☐ Talk with experts or those experienced in dealing with financial matters around cancer such as social workers.
- ☐ Identify the best way to begin to manage the financial emergency.

If you are not able to pay for health care, contact your local health and human services office or a hospital social worker. Find out if there are resources to help you. If you have a hospital bill, work with the hospital billing office and your insurance company to come up with a plan.

Act as soon as possible to handle financial problems. If you are not feeling well enough to do this on your own, ask a loved one, trusted friend or social worker to help you.

Consider all options to meet your health care needs such as:

- Community health care centers
- Hospital and medical center financial assistance programs
- Federal and state medical benefit programs
- Medical benefits for veterans
- Support services through local cancer programs

- Programs in the community for those who are disabled or aging
- Local churches or other faith-based organizations

You can also contact a nonprofit cancer organization to get help. For example, the Foundation partners with the **Patient Advocate Foundation** to offer assistance with financial and insurance concerns. Call 855.220.7777 or go to Livestrong.org/CancerSupport.

BANKRUPTCY

Certain situations can leave people deep in debt. It could become necessary to file for (or declare) bankruptcy. This is a legal method of dealing with debts that is overseen by the federal court system. Talk with a lawyer or nonprofit legal counseling service if you are considering this option. Find out about the current legal requirements to file for bankruptcy. It is important that you understand the best way to move forward for your situation.

Some people feel embarrassed about the need to file for bankruptcy. However, bankruptcy does not mean that anyone did anything wrong. For many survivors, the financial crisis could not have been avoided. No one plans to have cancer. In some cases, the costs that can come with cancer might be an unmanageable challenge. There is no need to feel guilty or ashamed if bankruptcy happens.

Dealing with financial matters can be a challenge, especially if you are not feeling well. A financial expert, trusted friend or loved one may be able to help you clearly define what you need. You can then choose the best way to meet your financial needs.



Livestrong means finding the best ways to meet the financial challenges of the cancer experience.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Keeping Important Records



Read more about living with cancer at Livestrong.org/WeCanHelp

- Assessing and Managing Your Financial Situation
- Converting Personal Assets Into Income
- Converting Retirement Accounts Into Income
- Planning Your Financial Future
- Credit for Survivors

Important Legal Documents

Some legal documents tell others what you want done during a health crisis or after death.

Four of the most important legal documents are:

- Advance health directives
- Power of attorney for financial decisions
- Will (also called last will and testament)
- Guardianship for children

The following is an overview of some important points about these documents. What you decide to do could affect the futures of your loved ones. Work with qualified professionals, such as an attorney who specializes in that area, to prepare these documents.

PREPARING ADVANCE HEALTH DIRECTIVES

Advance health directives inform your loved ones and the health care team of your choices for medical care. They provide direction about whether to start or stop certain types of treatment.

Each state has its own laws recognizing advance health directives.

Advance health directives act as a contract between you and your health care team. The document must be signed and witnessed. Ask your provider if he or she will honor your instructions. If not, you may want to transfer your case to the care of another health care provider who will. Without health directives, providers generally talk with family members about options. They then use their best judgment to make decisions about medical care.

The two most common types of advance health directives are the durable power of attorney for health care and the living will:

Durable Power of Attorney for Health Care

A durable power of attorney for health care is the best way to make certain that you get the type of medical care you want. This type

of legal document appoints another adult to speak for you. He or she will act as your agent or proxy. The document allows you to transfer your legal right to make decisions about health care to your agent. This power only applies when you do not have the ability to make decisions for yourself.

Most people choose a loved one or close friend to be their agent. It is important that your agent knows you well enough to make decisions that are in line with your wishes. Your agent's job is to ensure that your wishes are carried out.

Living Will

A living will tells your family and health care provider what you prefer in terms of medical treatment and care. It states what you want or do not want done to extend your life. For example, you might state that you do not want artificial feeding. A living will is not as effective as the durable power of attorney. A living will only states your health care preferences. The health care provider and family might make different decisions during a medical crisis.

They can decide based on their own medical or personal values.



Talk with loved ones before you start preparing important legal documents:

- ☐ Discuss what is important to you.
- ☐ Tell your loved ones what you want done.
- ☐ Ask loved ones how they feel about important matters.

PREPARING A WILL

A will is very important—no matter what your health, wealth or family status. It tells others how to handle financial and other legal matters after you die. Your will tells what valuables or assets are to be given to others. It also names the people you want to receive those assets (the beneficiaries). Your will can be rewritten as often as needed if your wishes or other things change. The laws in your state will determine how your assets are distributed if you do not have a will.

Before you start preparing your will, talk with loved ones and friends who will be affected. Discuss what is important to you. Tell them what you want to be done with your assets. This will help them in the future. It is also helpful to make certain that you know all the facts about the assets of other family members. For example, if you are married, you need to know specific information about the income, benefits, investments and debts of your spouse.

A will must be legally executed to be valid. This means it must meet certain conditions set by your state. It is best to prepare a will before a serious health crisis occurs. If a person is very ill or injured when the will is prepared, others could argue that medications or illness affected the ability to make decisions. This could result in a legal challenge to the will later.

CONSIDERING AN ATTORNEY TO CREATE YOUR WILL

It is often recommended that an attorney be used to create a will. An attorney who specializes in estate planning will know what state laws require. Tax attorneys, accountants and certified financial planners can also help with estate planning.

You need to have an attorney help you create your will if it includes complex matters such as:

- Guardianship arrangements
- Gifts for minor children
- Gifts of certain assets to specific individuals
- Estates of large value
- Real estate in a state other than your home state

- The “forgiving” (or cancellation) of debts others owe you
- A spouse who may need nursing home care
- A spouse who is not a citizen of this country

An attorney is also needed if you have:

- Made a major donation (or gift) within the past three years
- A plan to not include a living spouse or child under your will
- A need to make plans for individuals who are disabled or legally unable to care for themselves

If mistakes are made in preparing the will, there can be delays and expenses charged to the estate. This could mean that the will must go through probate. Probate is the legal process in your state that proves a will is valid. This process takes a long time and could cost the estate a lot of money.

You can legally write your own will. However, you need to know the legal requirements of your state. Create your own will only if family issues, finances and legal matters are not complicated. Some people use forms that are available in a “will kit.” This can be purchased through office supply stores, bookstores or online.

If a family member challenges your will, it could be declared as not valid. If this happens, the state might not follow your intentions. Property could then be distributed according to state probate laws. A will that is prepared by an attorney is more likely to withstand legal challenges.

Consider writing your own will only if you:

- Have limited assets registered in your name
- Want to leave your assets to only one or two people
- Have no major tax concerns to consider

If you write your own will, you may want to consider asking an attorney to review the document. He or she can oversee the execution of the will. The fee for this legal service should be less than if the attorney does all of the work.

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“I would really like to have everything decided so that I can decide for the people who will have to carry out those wishes. I would rather do it than leave it for them to struggle with.”

— BARBARA R.

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“I am not afraid to die anymore. As a single parent, I used to be really afraid: ‘What will become of my children? Who will take care of them?’ I have really done a whole lot of sorting out ... My children will be okay.” —SUSAN C.

GUARDIANSHIP FOR CHILDREN

Parents can name a legal guardian to care for their minor age child. A legal guardian takes care of the child and manages the estate during times when the parents cannot. No parent wants to think that there could be such a time, but all parents should consider this possibility.

There is peace of mind in knowing that your child will be well cared for if you are ever unable to do so. Preparing for this possibility is very important. Cancer or treatment might require hospital stays, out-of-town medical visits or other time away from your child. A legal guardian makes decisions about physical, educational and health matters.

There are different types of guardianship arrangements. Work with an attorney who specializes in this area. Guardianships must be set up according to the laws of the state in which you and your child live. If you live in more than one state or if the guardian you choose lives in another state, the guardianship must follow the laws of those states as well.

Planning allows you to name a guardian who respects your values and ideals. Make plans for the future care of your child. If you do not, the state court system could make decisions for your child without your input.

All parents should name a legal guardian for their child. The process can be an emotional experience. It can be helpful to talk with loved ones, friends or others who have already done this. A nonprofit cancer organization can also provide support and help you get started.

POWER OF ATTORNEY FOR FINANCIAL DECISIONS

A power of attorney can be set up for financial decisions. This legal document gives authority to a person you select (your agent). He or she can then pay bills and make financial decisions if you cannot do so. It is fairly simple and does not cost a lot to set up this legal process.



Livestrong means taking time to plan for the futures of your loved ones.

See the Livestrong Guidebook Planner and Journal pages:

During Treatment: Keeping Important Records



Read more about living with cancer at Livestrong.org/WeCanHelp

- Planning Your Medical Future
- Creating a Will
- Providing a Guardian for Your Children

Organizing and Keeping Important Records

There is a lot of important paperwork in the life of a cancer patient. You might think keeping track of this information will be difficult and not worth the effort. Yet organized records will make life easier for you and your loved ones. If you do not feel well enough to find and organize your records by yourself, ask a loved one or friend to help you.

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“I just bought a pair of shoes that will probably last me five years. Yet, while I am doing those things, I also updated my will and have made sure that everything is in place.”

—BETH S.

The Livestrong Guidebook Planner and Journal can help you get organized. Use it to keep track of medical reports, insurance records, correspondence and information about your type of cancer and treatment. You can carry this information with you to share with your health care team.

An organizing system can be simple. Some people use a filing cabinet. Others keep paperwork organized in a box. Still others keep important documents in a three-ring binder with dividers and plastic insert pages. Use the system that works best for you.

IMPORTANT RECORDS

Start by collecting and reviewing the documents and information that you already have including:

- Employment benefit records
- Insurance policies, receipts and other insurance records
- Social Security benefit records
- Health records including prescription receipts
- Personal financial records
- Advance medical care and financial directives
- Will, living trust and guardianship directives
- Copies of letters about your health care and insurance
- Records of telephone conversations that include dates, the name of the person you talked with and what was said

Request copies of the important documents that you do not have. Arrange them in order by categories and by date. That way you will be able to quickly find the information that is needed.

WHERE TO KEEP IMPORTANT DOCUMENTS

Give copies of important legal documents directly to the person who is responsible for seeing that your wishes are followed. If you do not want to do that, tell them where the copies are kept. Also, keep a copy of these documents for yourself.

Store your documents in a safe place. Make sure that trusted loved ones or friends know where these documents are. They may also need to have access to a key and know how they can get to the documents if they are ever needed.

The following provides a few suggestions about where to store some important documents:

Medical Directives

Give the original copy of all advance medical directives to your health care providers.

Copies of your advance medical directives should be kept by:

- Your hospital's medical records department
- You
- The person you have chosen to act on your behalf in a medical emergency

Will, Durable Power of Attorney, Advance Guardianship, Financial Directives

Give the original copy of each of the above types of documents to your attorney. He or she will store them for you and your loved ones.

Copies of these documents should be kept by:

- You (include a note with your copy that states where the original is stored)
- Others who might be involved later such as the legal guardian for your children

These types of documents should not be stored in your bank safe-deposit box. It would be difficult to get to them quickly in an emergency.

KEEPING MEDICAL RECORDS

Keep a copy of all of your medical records so that you will have accurate details about your medical treatment. Share this information with your physician and other health care team members. This will help you to get the best health care.

Your health information can also be used when you prepare tax returns. It will be useful as you complete forms for insurance claims. In addition, these records can be used to document the need to request changes in your work schedule or job.

MAKING A LIST OF INSTRUCTIONS

A list of instructions can serve as a guide to your home, health, family, legal and financial matters. A trusted friend or loved one can use this information to pay bills and take care of your household in case of an emergency.



Keep the following medical records and health information:

- ☐ Medical records and receipts, invoices and statements for prescriptions, medical equipment and health care provider and hospital visits
- ☐ All contact information for your current and past health care team members
- ☐ Information about prescription and over-the-counter medications and vitamins
- ☐ Your medical treatment history that lists dates, diagnoses and treating health care providers

Your list of instructions should include all that is needed to keep your home and finances in order. Include a guide to your filing and record-keeping system.

Some of the information in your list of instructions may be confidential. Keep the following types of information in a safe place so that only a person you trust can get to it:

- Banking and other financial information
- Credit card information
- PIN numbers
- Usernames and passwords to accounts
- Safe combination numbers

Just do as much as you can if developing your list of instructions becomes too tiring. You do not have to do it all at one time. Ask someone you trust to help you if it becomes too overwhelming.



Livestrong means finding ways to help yourself and your loved ones.

See the Livestrong Guidebook Planner and Journal pages:

During Treatment: Keeping Important Records



Read more about living with cancer at [Livestrong.org/WeCanHelp](https://www.livestrong.org/WeCanHelp)

- Important Records Survivors Should Keep
- How to Organize Important Records
- Planning Your Medical Future





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“We're three men in my family, and not to stereotype,
but I think men probably try to bite their lip and tough it out.”

—CHRISTOPHER W.



AFTER TREATMENT

This section includes information about the emotions and late effects that can occur after cancer treatment is done. It also provides information about developing a Survivorship Care Plan. It includes:

- Emotions After Cancer Treatment
- Late Effects of Cancer Treatment
- Developing a Survivorship Care Plan

Emotions After Cancer Treatment

Many cancer survivors experience a mix of reactions after treatment is done. Often the emotions are positive. Many feel good about personal strengths that were discovered during treatment.

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“I went through a lot of stages of fear and of joy when I found out I was in remission. When I was going through my treatments, I always tried to stay positive. Yet, there were still emotions running through me that I was suppressing — the fear, the anxiety. Why? What am I supposed to do with my life now? That is a question that I answer to this day. It is the reason I am here.”

—CHRIS C.

There may be deepened relationships with loved ones. Friends may be happy for you and expect you to return to life as it was before cancer.

Yet, survivors can also have feelings that are not always positive. Some describe the period after cancer treatment as one of the most emotional times of their lives. This can be confusing. Understanding these feelings can help you manage them.

Most cancer patients are not surprised by strong emotions during treatment. However, some survivors are surprised when new or old emotions occur after treatment is completed.

AFTER TREATMENT

When cancer treatment ends, you may feel excited about the future. There may be relief that treatment is over. You may be ready to move on with your life. The cancer journey may have brought positive changes. Some survivors report a sense of gratitude and renewed wonder about life. Others describe a deepened closeness to loved ones and friends. Often there is a desire to meet new goals and get the most out of life.

However, it can be a surprise to also discover uncomfortable feelings and unanswered questions. There is often more time to think about things that you did not have time to consider during treatment.

Some cancer survivors worry about the unknowns of the future. There may be mixed feelings about the

completion of treatment. Others may feel concerned that they are no longer receiving treatment to get rid of cancer cells. Sometimes survivors feel anger about having had cancer. There may be financial concerns or regrets about having had to rely on others for help and support.

Loved ones, friends and even your health care team may be ready to celebrate your victory of beating cancer. It may seem that others do not understand the emotional stress that completing treatment can bring. You may feel that others now expect you to get on with your life. Dealing with these types of feelings when those close to you are celebrating your success can be confusing to you and others. Talk with them about how you are feeling. You can help them better understand your experience.

The following is a list of common emotions that can occur after treatment and ways to deal with them:

Fear of recurrence

It is common for survivors to feel fearful that cancer could come back. This may be a serious concern if symptoms or aftereffects from treatment continue. There can be concerns about whether your health care team is watching your medical condition as closely now that treatment is done. Talk with your health care provider about your concerns. Ask him or her to schedule you for regular follow-up health care and screenings.

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“I deal with my fear of recurrence by getting involved. I am involved with a group of young breast cancer survivors, and I try to be there for newly diagnosed people.”

—AUDRA O.

Anxiety

Some survivors experience worry or anxiety right after treatment ends. This is a time when there may be many questions. You may have concerns about how cancer could affect your future. Talk with loved ones and members of your health care team about your concerns. If needed, ask for a referral to a licensed social worker or counselor to help you deal with your worries.

Concerns about physical appearance

Physical changes during treatment may bring concerns about the way you look. There may be worries about what other people might think. There can be a change in how you see yourself as you are adjusting to life after treatment. If you are worried about physical changes, talk with your health care provider about your concerns and what can be done to make things better.

Sadness

Sadness is a very common response after treatment ends. This is often the time when cancer survivors have time to think about the changes that have happened.

It is normal for survivors to feel sad as they adjust to the changes that have occurred. However, sadness should not last for a long time. Talk to loved ones and your health care team if sadness begins to feel overwhelming. Tell your health care provider about sadness that does not go away.

Depression

Change and loss can result in stress that begins to feel overwhelming. Long-term stressful situations can bring depression. So can sadness that goes on for too long. Depression is a serious condition. It can be caused by or made worse by chemical changes in the brain.

People who are depressed may need medical treatment to get better. Treatment can include medication and counseling. If you think you may be depressed, talk with your physician

or another member of your health care team right away. There is no need for you and your loved ones to suffer with depression.

Grief

Grief is a natural response to loss that can last for quite some time. It generally comes with losing someone or something that has been important to you. In addition to a deep sadness, the grieving process may also include stages of denial and anger before one is able to reach a full acceptance of the loss. Many cancer survivors find comfort in talking with someone they trust such as a loved one, friend or faith-based counselor. A support group, licensed social worker or counselor can also help survivors and their loved ones deal with loss and grief that does not go away.

Guilt

Some survivors have feelings of guilt following completion of cancer treatment. Guilt comes from thinking that you are to blame for something. Some may think that they did something that caused the cancer. Others might feel guilt because they survived while others did not. Still others may worry that too much of a burden was placed on loved ones. Whatever the cause, guilt is a complicated emotion.

Cancer survivors do not need to carry the burden of guilt. If you have these feelings, start by acknowledging them. This can be the first step towards letting guilt go. Talk with loved ones and others you trust about how you feel. A social worker or other licensed counselor can help you release these feelings and move forward with your life.

Uncertainty

Cancer can leave you feeling unsure about the future condition of your health. Most cancer survivors live with some feelings of uncertainty. For example, you may feel nervous before medical follow-up appointments. An important



date, such as the date of diagnosis or the date you completed treatment, might bring these feelings out.

Ask your health care provider to help you develop a follow-up health care plan. A care plan may lessen feelings of uncertainty and help you know what to expect. Some survivors find that staying focused on the present is helpful. Living this way can help you avoid worrying about things that may never happen.

Anger

Anger can range from mild irritation or frustration to rage. Some survivors may feel angry about how cancer affected their lives. They might have

new physical, financial or emotional challenges. A certain amount of anger is normal. Yet some survivors may need help to get past strong feelings of anger. Talk with your health care provider if such feelings do not go away. Ask for a referral to a licensed social worker or counselor to help you get through anger.

Emotional numbness

The cancer experience can leave you feeling numb or without feelings. After the stress of treatment, you may feel unable to take on anything more. Some survivors protect themselves by shutting down their feelings for a while. If you find yourself thinking that you no

longer care, you may be experiencing emotional numbness. Your health care team and loved ones may be able to help you sort out these feelings. Working with a social worker or other counselor can provide support and guidance during this process.

Spiritual distress

A belief system that helps you make sense out of the experiences of life is important to your well-being. A new search for meaning can begin when cancer is diagnosed. It may continue for many years after cancer treatment is over.

Spiritual distress can begin if life becomes very different from the way you thought it would be or should be. Some survivors may redefine values and goals during such a time. A search for what now gives life quality and meaning can take place. Talking with a loved one, clergyperson or hospital chaplain can be helpful as you go through this process.

Adjusting to emotions

Some survivors need help adjusting to strong emotions after they complete cancer treatment. Each person will react in his or her own way. In time, it generally becomes easier to deal with emotions. Other life events may begin to require more attention. Often, less time needs to be focused on the cancer experience. This can help one adjust more quickly.



Tell your health care provider if you have any of the following symptoms of depression:

- ☐ Long-lasting changes in eating habits (not wanting to eat or eating too much)
- ☐ Loss of interest in activities you usually enjoy
- ☐ Crying spells
- ☐ Fatigue or problems sleeping
- ☐ Feelings of hopelessness, helplessness or despair
- ☐ Inability to experience joy
- ☐ Problems with concentration
- ☐ Suicidal feelings
- ☐ Unexpected changes in weight (loss or gain)



Livestrong means dealing with emotions during the cancer journey.

See the Livestrong Guidebook Planner and Journal pages:

Just Diagnosed: Finding Support



Read more about living with cancer at Livestrong.org/WeCanHelp

- Emotional Support
- Finding a Counselor
- Meeting Other Survivors

Late Effects of Cancer Treatment

The day that cancer treatment ends, a new life chapter begins. Some survivors may leave cancer behind and continue life with few or no health problems. Others might have ongoing physical challenges. Some of these might be due to aftereffects or the late effects of cancer treatment.

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“A survivor is someone who takes what they have been dealt and tries to make the most out of it.”

—SUSAN C.

Not all cancer survivors will experience late effects. If you do, they may appear soon after treatment or up to years after treatment ends. Let your loved ones know that this can happen. In most cases, the earlier these late effects are identified, the easier they are to treat.

Ask your health care team about what late effects could occur. This will help you and those close to you know what to watch for. For example, fatigue is a common side effect. It may have a number of causes, such as pain, stress, depression or anemia. Your provider can help you get the right treatment.

Late effects vary from one cancer survivor to the next. They can range from very mild to serious. Medical experts cannot always predict if or when they will occur. Some effects might improve or go away with time such as anemia. Others might be permanent such as certain types of nerve damage. If late effects of treatment do occur, it does not mean that your health care team did anything wrong. In most cases, the effects could not have been avoided.

Be sure to report any signs or symptoms to your health care team right away. Early medical attention can often reduce problems that can come from late effects.

OVERVIEW OF POSSIBLE AFTEREFFECTS

The following is a brief overview of the common types of cancer treatment and the late effects that can occur:

Surgery

The aftereffects of surgery depend on the area of the body (or site) where the surgery is performed. Risks have been lessened by new and improved surgical methods but late effects may still occur.

A tumor may affect healthy tissue as it grows if it damages or kills normal cells. Damage can also occur if the healthy tissue around a tumor is removed during surgery. This might be done to make certain that all of the cancer cells are removed and thus may be necessary for appropriate cancer treatment.

Aftereffects of surgery could include:

- Scarring at the surgical site
- Problems fighting infection
- Lymphedema or swelling of arms or legs
- Nutritional problems
- Cognitive problems such as trouble focusing or memory loss
- Changes in sexual function or fertility
- Pain that may be chronic or long term
- Difficulty with speech or swallowing

Physical changes can also bring emotional aftereffects. This can happen even if others cannot see the changes. For example, a survivor could feel self-conscious about a scar, even if it is hidden by clothing. There may be concerns about body image.

Chemotherapy

Chemotherapy medicines interfere with the rapidly growing cells of the body. These cells can include those related to hair, skin, fingernails or the stomach lining. This is why chemotherapy can cause temporary side effects. These include mouth sores, upset stomach, hair loss or skin rashes. Side effects usually improve as the normal (or non-cancer) tissues repair themselves.

Not all chemotherapy medicines have the same late effects. A lot depends on the kind of medicines used. The dosage and whether chemotherapy was done with another type of treatment are also important. If an organ is damaged, a lot depends on whether it can repair itself. Before starting treatment, ask your health care provider about the possible after-effects of all the medications you will receive.

Aftereffects of chemotherapy could include:

- Fatigue
- Difficulty with focused thinking (sometimes called chemo brain)
- Early menopause
- Heart problems
- Reduced lung capacity
- Kidney and urinary problems
- Nerve problems such as numbness and tingling
- Bone and joint problems
- Muscle weakness
- Secondary cancers

Radiation therapy

Radiation therapy is applied to the areas of the body that are affected by cancer. Aftereffects occur only in the area that was treated. In some cases, treatment may also include healthy tissue. This is to make certain that all of the cancer is treated.

Newer methods of radiation therapy help minimize damage to normal tissue. Treatment is directed to the same area each time. Yet, radiation rays sometimes scatter. Tissues and organs near the cancer site might receive small doses of radiation if this happens.

Aftereffects of radiation could include:

- Cataracts
- Fatigue



When you talk with your health care provider, ask him or her:

- What are the best resources for information about late effects for my type of cancer?
- What are the possible aftereffects of the medications I have been taking?
- What is the best way to manage aftereffects?
- Will you provide me with a treatment plan summary now that I have completed cancer treatment?
- Which provider should I see if symptoms or problems develop?
- Which provider should I contact with other medical needs?
- What is the best way to explain after-effects to my employer?

- Dry mouth
- Permanent hair loss
- Problems with thyroid or adrenal glands
- Infertility
- Slowed or halted bone growth in children
- Decreased range of motion in the treated area
- Skin sensitivity to sun exposure
- Problems with memory or ability to learn
- Secondary cancers such as skin cancer

Cancer treatment and fatigue

Fatigue or feeling physically exhausted is a very common aftereffect of cancer and treatment. Fatigue can affect you mentally and emotionally. You may have no energy to do things that are important to you. Yet fatigue can usually be successfully managed medically.

The causes of fatigue can include physical problems such as pain, stress, anemia or the side effects of treatment. Sometimes the cause is emotional such as depression. Other times, the cause might not be clear.

Be certain to talk with your health care team if you are fatigued. Describe your level of fatigue by using terms like mild, moderate or severe. Your team will try to find out what is causing the fatigue so they can provide the best treatment.

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“This diagnosis was not scary because I have lived with cancer for 22 years. A second diagnosis is not nearly as frightening as the first. I am back at work — telecommuting and flying across the country, full time. No cancer can get us down.”

— MARK K.

AFTEREFFECTS AND DAY-TO-DAY CHALLENGES

In the past, treatments for many types of cancer were more severe than today. If you received cancer treatment many years ago, you may already be living with aftereffects.

Aftereffects of treatment can affect day-to-day life activities. Some problems start during treatment and continue after treatment is done. Other late effects may not appear for months after treatment has been completed.

Keep track of unexplained symptoms and problems. This will help you talk with your health care team and loved ones. Work with your health care team to develop a health care follow-up plan that will be part of your Survivorship Care Plan.

Examples of day-to-day challenges might include:

- Difficulty working due to physical or emotional issues
- Changes in relationships with loved ones, friends or coworkers
- Impact on self-esteem
- Difficulty getting health or life insurance
- Difficulty communicating concerns to others
- Financial stress

TREATING AFTEREFFECTS

Talk with your health care team about what aftereffects you might expect for your type of cancer and treatment. Ask your provider to describe possible symptoms. Find out how to get treatment early.

It may also be helpful to talk with other cancer survivors. There are likely to be others who have been through similar experiences. Sharing information might help you find new ways to manage challenges.

Your oncology team will probably continue to see you for a period after treatment is done. Your health care will then be returned to your primary care physician for most matters. However, many providers are not trained in the aftereffects of cancer. Contact your oncology provider if you begin to have problems that may be related to cancer or its treatment.



Livestrong means taking an active role in your own health care.

See the Livestrong Guidebook Planner and Journal pages:
After Treatment



Read more about living with cancer at Livestrong.org/WeCanHelp

- Aftereffects of Cancer Treatment
- Communicate With Your Health Care Team
- Body Image

Developing a Survivorship Care Plan

Every day there are increasing numbers of cancer survivors. Advances in medicine and health care technology have made this possible. Many survivors live full and healthy lives after cancer treatment is done. However, cancer can become a chronic (or long-term) condition for some.

Chronic conditions may include an increased risk for a recurrence of cancer or a high risk of developing a new type. There might also be concerns about long-term emotional issues, physical limitations or cognitive changes such as memory loss.

Survivorship after treatment is an important phase of cancer care. The Institute of Medicine's (IOM) report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, recommends that each cancer patient receive a "Survivorship Care Plan." This plan for wellness can help you continue to receive the best health care for your situation. The information in this section is based on the general recommendations of the IOM.

A Survivorship Care Plan should include the following items:

- Record of your medical history
- Summary of your cancer diagnosis and treatment
- Follow-up plan for health care

Cancer survivors deserve quality health care for as long as it is needed. However, some primary care physicians and other health care providers who have not specialized in cancer care may not understand all that is needed after treatment is done.

Work with your oncology team and primary care providers to develop a Survivorship Care Plan that includes:

- Specific information about your cancer diagnosis and treatment
- Information about possible late effects and signs of a recurrence or new cancer
- A schedule for follow-up health care including screening tests
- Tips on cancer prevention and suggestions for maintaining a healthy lifestyle

- How to find quality health care and other support services

Work with your health care team to take the following steps to create your Survivorship Care Plan:

STEP 1 — CREATE A RECORD OF YOUR MEDICAL HISTORY.

A record of your medical history is helpful to loved ones and to health care providers. It should include all medical issues with dates, symptoms, treatments received and side effects. Include facts from as far back as possible.

Include the following information in your **medical history**:

- Types of **vaccinations and immunizations** you have had
- Information about **ongoing health problems** including dental issues
- List of the **prescribed and over-the-counter medicines** you take (dates taken, name of medication, dosage and name of the prescribing health care providers)
- Notes about **side effects or reactions** you had to medicines or treatments
- History of **pain problems** including treatments and results
- Information about specific **cancer treatments and side effects**
- List of **allergies** and sensitivities
- List of **past injuries and surgeries** with treatments and results
- Information about **diet and nutritional concerns**
- Facts about your **family's medical history** including cancer, diabetes, heart conditions, stroke and other issues



STEP 2 — GET A CANCER TREATMENT PLAN SUMMARY FROM YOUR HEALTH CARE TEAM.

After your treatment is done, ask your oncology providers to provide you with a written cancer treatment plan summary. This document should contain information that can be shared with your primary care provider. It will also help future health care providers.

A cancer treatment plan summary (updated and completed after all of your treatment is done) can help ensure that you get the best possible future health care. Ask your provider to update your summary if there are new treatments.

To save time for your health care provider, fill in what you can on a treatment summary form such as the one in the Livestrong Planner and Journal. Take this form to the provider and ask him or her to complete what you could not.

Be certain that you, the oncology providers and your primary care provider keep a copy of your

cancer treatment summary. This can help you get the best care and support in the future.

Include the following information in your **cancer treatment plan summary**:

- Description of **diagnostic tests**, dates and results
- Your specific **cancer diagnosis** including the type of cancer, date of diagnosis, where it occurred, stage, grade, hormonal status and markers
- **History of your cancer treatments** and hospital stays including dates, dosages of medications and the agents that were used
- Information about your **cancer treatment responses, reactions and side effects**
- **Other health care services** that were provided such as physical therapy, psychosocial counseling and nutritional services
- **Names and contact information for the health care team members** who were involved in your cancer treatment

- **Future cancer care recommendations** including prevention methods and a schedule for ongoing screening tests
- **Future cancer care provider recommendations** for follow-up care including names, specialties and contact information

STEP 3 — GET A HEALTH CARE FOLLOW-UP PLAN.

When treatment is done, your health care provider should provide you with a health care follow-up plan. This plan tells you what you need to do to stay physically and emotionally healthy. Your follow-up plan should include the specific types of health care you will need in the near and distant future.

A health care follow-up plan should tell you:

- What needs to be done in terms of future health care
- When it needs to happen
- Where you can get help including referrals to providers

Include the following information in your health care follow-up plan:

- Possible late and long-term effects of treatment including symptoms
- Signs and symptoms of cancer recurrence and other types of cancers
- Information about social and emotional support including support groups and counseling resources
- Recommendations for healthy living including information about risks and prevention
- Recommended schedule for medical tests, cancer screening and specific types of exams
- Referrals to specific health care providers for follow-up care
- Contact information for nonprofit cancer services and other resources

The OncoLife Survivorship Care Plan was created to help you develop a personalized plan for post-treatment care. It is a free online tool to help

you work with your oncology team and primary care provider to address the medical, emotional and social challenges that may arise after cancer treatment is completed. By answering some questions related to your cancer treatment, you will receive information about your follow-up care. The information includes symptoms to watch for in the future and steps you can take to stay healthy. You can find the OncoLife Survivorship Care Plan at <https://www.oncolink.org/oncolife/>.

STEP 4 — GET INFORMATION FROM YOUR HEALTH CARE TEAM TO HANDLE YOUR CONCERNS.

Life after cancer treatment can be different. Your life might have changed in many ways. You may have developed a strong interest in making even more changes in your life.

Talk with your health care providers about specific areas of concern in your life. You may have medical questions, relationship issues and day-to-day concerns. Your provider or other members of your health care team can help you find answers. Talk with them as you work to develop your health care follow-up plan.

Here are examples of questions that you may have about life after cancer treatment:

Medical Concerns

Ask your oncology providers questions about medical concerns such as:

- Can the cancer come back?
- Could a new type of cancer develop?
- What are symptoms and signs of recurrence or new cancer?
- What aftereffects of treatment are possible?
- How can aftereffects be treated?
- What can I do to stay healthy and prevent future health problems?
- Will I need ongoing therapies such as physical therapy?
- Will you provide a schedule for follow-up exam, screening and other medical tests?

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“It begins to be about how you redefine yourself as a person, drawing on all those things that you have experienced ... making yourself into the new person that you want to be.”

— AMY D.

- Where can I find information about genetic testing and counseling?
- What prescriptions and over-the-counter medications will I need?
- Will you refer me to health care specialists for follow-up care?
- What do you recommend about screening or testing for family members?

Relationship Issues

Ask your health care team questions about relationship concerns such as:

- Where can I find help with relationship problems?
- Where can I find support groups or counseling services?
- Will you give me a referral for sexuality or fertility concerns?
- Where can I find help with parenting or caregiving concerns?

Day-to-Day Concerns

Ask your social worker or other patient advocate questions about day-to-day concerns such as:

- What types of changes could be made at work for my situation?
- Where can I find help with legal and financial issues?
- How can I find resources and information to help me with future insurance and health care benefits?

STEP 5 — KEEP YOUR HEALTH CARE TEAM INFORMED, BOTH NOW AND IN THE FUTURE.

Talk with your health care provider if you have health concerns. Discuss symptoms that might be related to cancer. There could be a need to make an appointment to go back to your oncology team for further evaluation or health care.

Keep your health care team informed about problems you experience such as:

- Pain concerns
- Signs and symptoms of possible cancer (recurrence or new type)
- Information about medications, supplements or other treatments you are taking
- Emotional concerns such as depression or anxiety
- Physical concerns including fatigue, memory changes and sleep problems
- Relationship concerns



Livestrong means planning for your survivorship.

See the Livestrong Guidebook Planner and Journal pages:

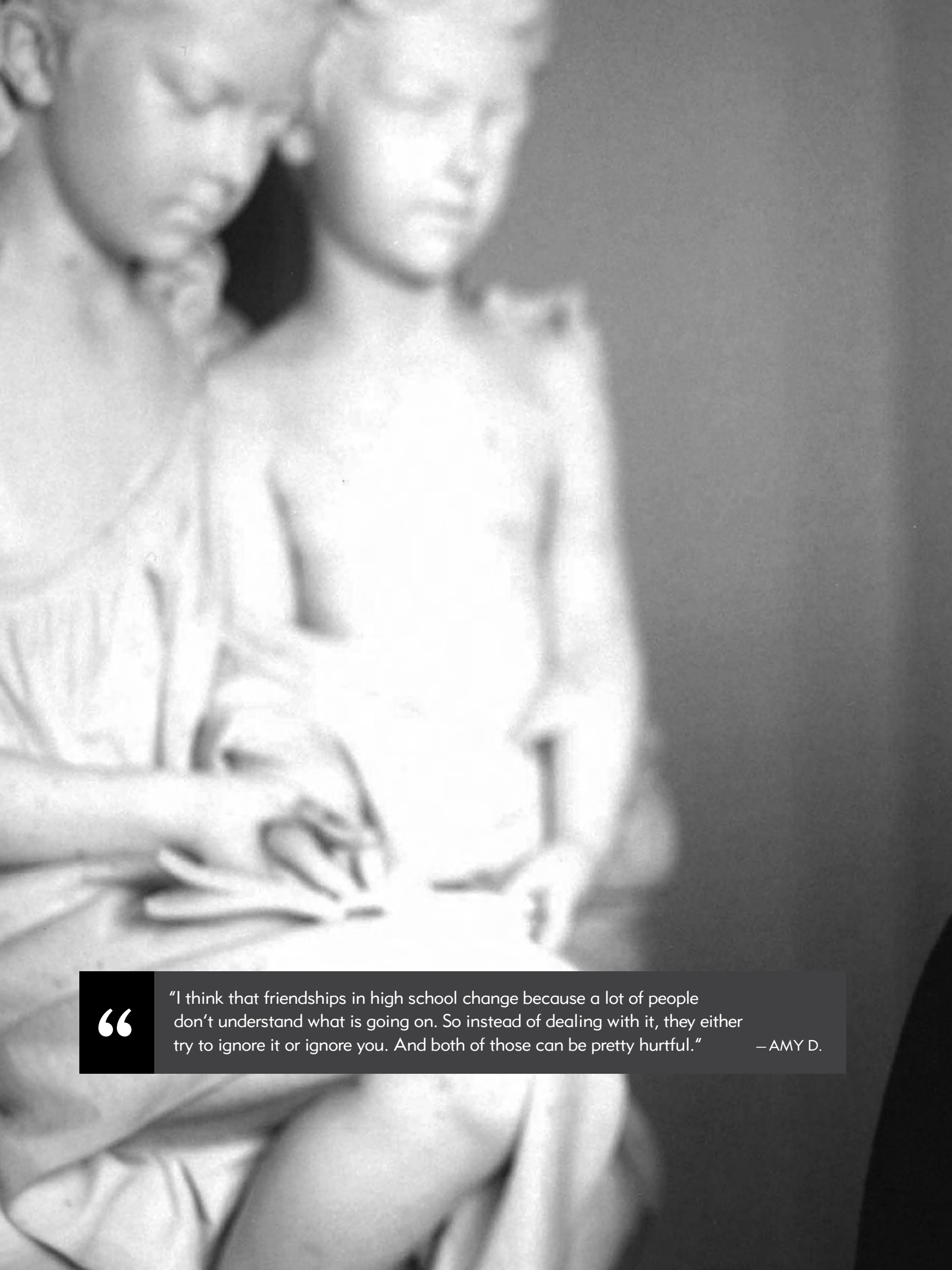
After Treatment: After-Cancer Treatment Plan Summary



Read more about living with cancer at Livestrong.org/WeCanHelp

- Aftereffects of Cancer Treatment
- Communicate With Your Health Care Team
- Meeting Other Survivors





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“I think that friendships in high school change because a lot of people don't understand what is going on. So instead of dealing with it, they either try to ignore it or ignore you. And both of those can be pretty hurtful.”

—AMY D.





HEALTHY LIVING

This section includes information about things you can do to contribute to a healthy life. It includes:

- Health Care Follow-Up and Screening
- Reducing Risk for Cancer
- Planning for Healthy Living

Health Care Follow-Up and Screening

Most survivors continue to have concerns about their health after cancer. It is common to be worried about the possibility of cancer returning. Feeling this way is normal. There are steps you can take to reduce your worry. Health care follow-up and screening will help ensure that any future problems are discovered early. Discuss specific questions and fears you have with your health care team.

YOUR HEALTH CARE FOLLOW-UP PLAN

All cancer survivors need good ongoing health care. Your cancer care team should have provided you with a plan for health care follow-up when cancer treatment was completed. This type of plan will help you continue to get quality care. It can also provide referrals to specific health care providers for your follow-up care.

Future follow-up health care appointments might include one or more of the following:

- Screening tests
- Physical exam
- Laboratory tests
- X-rays
- Imaging scans such as CT, PET, MRI or ultrasound scans

If you do not already have a health care follow-up plan, ask your health care provider to help you develop one. Your plan should include information about possible cancer treatment aftereffects. It should provide a schedule of medical exams and cancer screening tests you will need. It needs to include information about cancer risks, prevention and healthy living options.

GETTING FOLLOW-UP CARE

The provider you see for your follow-up health care should have experience with your type of cancer. If he or she does not, find out if you can return to your oncology provider for follow-up cancer care appointments. If you can, return to the oncology provider who treated your cancer. If you are not able to do this, ask to be referred to a medical care center that provides specialized care for cancer survivors.

Some survivors experience emotional distress after completing cancer treatment. This can make it hard to focus on follow-up care. Talk with your health care team if this happens to you. A referral to an oncology social worker or another licensed counselor can be very helpful in dealing with emotional issues after cancer treatment.

FOLLOW-UP HEALTH CARE SCHEDULE

Your provider can tell what type of follow-up health care you will need. This will depend on the type of cancer and treatment you had. He or she will also take into account your overall health after cancer treatment.

Follow-up health care is likely to include a review of your medical history and a physical exam. There may also be tests such as X-rays, blood work and other lab work. It is common for cancer survivors to return to their health care provider for follow-up care every three to four months for the first two to three years after treatment. Your follow-up care may drop to once a year after that, if you have no further problems.

SCREENING TESTS AND EXAMS

Screening tests and exams check for diseases or problems. They can identify health issues before there are signs or symptoms. Treatment may then be started early.

Ask your health care provider about recommendations for screening tests. Find out when to begin each type of screening testing he or she recommends. Find out how often you will need to be tested. Screening recommendations for survivors might be different from those who have not had cancer.



“I feel much more developed after I got cancer than I did before.
I feel like I am experiencing life tenfold.”

—CHRIS O.

Commonly used screening tests include:

- Mammograms to detect breast cancer
- Pap smears and HPV testing for cervical cancer
- Blood tests to detect high cholesterol, diabetes and thyroid disorders
- Blood pressure readings for hypertension
- Fecal occult blood tests and colonoscopies for colon cancer
- Bone density tests for osteoporosis
- Testing for HIV and sexually transmitted infections
- Imaging studies

RECOMMENDATIONS FOR HEALTH SCREENING

The Centers for Disease Control and Prevention (CDC) currently supports screening for breast, cervical and colorectal (colon) cancers. Your provider can refer you for screening tests.

The CDC reports that there is not yet enough evidence to determine whether there are definite screening benefits for some types of cancers. Talk to your health care provider to learn more about how this affects your situation.

Screening tests also exist for other health problems. These may be done as part of a general health exam. Tests may screen for cholesterol problems, high blood pressure, diabetes, depression and osteoporosis (or bone density).

CONCERNS ABOUT CANCER RECURRENCE

There is no easy way to know whether cancer will return. There are not always symptoms such as pain or a growth. In some cases, there are no signs. For these reasons, regular medical follow-up care and screening tests are important.

Pay attention to your feelings and experiences. See your health care provider right away if you:

- Think that something has changed
- Feel there is something wrong
- Experience unusual pain
- Have problems breathing



Livestrong means knowing about and using the tools available to stay healthy.

See the Livestrong Guidebook Planner and Journal pages:
After Treatment: Follow-Up Health Care Plan



Read more about living with cancer at Livestrong.org/WeCanHelp

- Aftereffects of Cancer Treatment
- Communicate With Your Health Care Team
- Meeting Other Survivors

Reducing Risk for Cancer

There are no guarantees for perfect health. Yet some lifestyle changes can help you stay healthy and reduce your risk for cancer in the future. Talk with your health care team about specific things you can do. Healthy habits and screening can reduce the risk of new cancers. These may also reduce risks for other conditions such as high blood pressure and heart disease.

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“Survivorship means having a second chance. The more you realize how lucky you are...you develop a passion for not wasting time.”

— BRIAN H.

ACTIONS TO TAKE TO REDUCE RISK

Some cancer survivors have special dietary or other needs after cancer treatments. Ask your health care provider if there are things you can do to prevent further health problems. Find out about current recommendations for diet, weight and physical activity. Let your provider know you want to do what is possible to stay healthy. Tell your provider what you are doing to be healthy on your own.

Consider the following things you can do to build prevention into your choices for healthy living:

Avoid Tobacco

Tobacco products increase the risk of cancer. Research shows that tobacco contributes to the development of many types of cancer. These include lung, throat, mouth, esophagus and kidney cancer. Tobacco smoke can also cause other health problems. Tobacco use also contributes to health problems including heart disease and emphysema. There are now many programs that support people to stop using tobacco. If you use tobacco products, talk with your health care team about getting help to quit.

Be Physically Active

Experts say that exercising even three times a week may improve health. Physical activity can reduce stress, increase energy and help maintain a healthy weight. Exercise can range from gentle stretching to being very active. There may be physical activities you can do even while you are dealing with cancer. Ask your health care provider what he or she recommends for your situation.

Eat Healthy Foods

Your health may be affected by what you eat.

Some research suggests there may be a connection between eating certain types of foods and certain diseases, including cancer. General recommendations are to reduce fat intake and eat a diet that includes fruits, vegetables, nuts, beans and whole grains. Talk with your health care team or a nutritionist to find out what is best for your situation.

Maintain a Healthy Weight

Being overweight can increase the risk of health problems. These risks include diabetes, heart disease, stroke and certain cancers. Exercise burns calories. It is recommended that you exercise regularly. Also, avoid a diet that is high in calories or fat. You may need to increase physical activity and reduce calories to avoid gaining weight as you age.

Protect Your Skin and Eyes

Protect yourself from too much ultraviolet (UV) radiation. This can come from the sun, sunlamps or tanning booths. UV damage can also come from reflections off other surfaces such as pavement or snow. UV exposure can damage your skin and eyes. It can also cause early aging. This can lead to cancer and other problems.

Skin cancer is very common. In many cases, it can be prevented by avoiding UV exposure. Use sunscreen that blocks both UV-A and UV-B radiations with a sun protective factor (SPF) of at least

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“I was bound and determined to keep exercising. It made me feel better, and I knew I could probably recover faster if I continued to exercise.”

— ANGIE M.

15. Also, wear protective clothing and a hat when you are outdoors. UV damage occurs most during the mid-morning to late afternoon hours. Also, protect your eyes by wearing sunglasses that block 99–100 percent of UV-A and UV-B radiations.

Avoid Known Risks

Research has shown that certain risks can increase the possibility of developing cancer. Many people have experienced one or more risk factors. Some individuals may be more sensitive to risks than others.

It is recommended that you avoid exposure to risk factors such as:

- Exposure to certain chemicals and harmful substances such as benzene, asbestos, nickel, cadmium and others
- Environmental exposure such as radon gas
- Certain hormone treatments
- Use of tobacco products and exposure to tobacco smoke
- Excessive use of alcohol, especially combined with tobacco use
- Risk of exposure to viruses, such as HIV and HPV, through unprotected sex

Know About Family Genetic Factors

Research shows that certain types of cancer may be more common to some families than other types are. These types include melanoma,

breast, ovarian, prostate and colon cancers.

Talk with your health care providers if a specific type of cancer appears in your family. There may be things you can do to try to reduce your risk including screening tests or exams.

If a certain pattern of cancer appears to exist in your family, your health care provider may suggest genetic testing. These tests check for gene changes. Finding a change does not mean that you will develop cancer. However, it may mean that there is a higher-than-average possibility of developing the disease. The provider may then recommend steps to take to reduce your risk. He or she might also increase the frequency of screening for these diseases.

Take Care of Yourself

There are things you can do to make the most of your health such as:

- Limiting the amount of alcohol that is regularly consumed
- Taking prescription and preventive medicines
- Having needed immunizations
- Getting regular dental checkups and care
- Getting vision and hearing checked regularly
- Asking your provider about flu shots and other vaccinations
- Exercising according to your health care team's recommendation



Livestrong means making positive choices for healthy living.

See the Livestrong Guidebook Planner and Journal pages:

After Treatment



Read more about living with cancer at Livestrong.org/WeCanHelp

• Reducing Your Risk for Cancer

Planning for Healthy Living

Good nutrition, exercise and other healthy behaviors may help your body heal. A good plan for healthy living may improve your quality of life. It might also lower your risk for future illnesses such as other cancers and heart disease.

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“As a long-term survivor of a life-threatening illness, I have become stronger and yet more vulnerable. I let a whole lot of stuff slide off my back. I choose my battles differently. I am a different person because of it.” —SUSAN C.

Work with your health care team to develop a plan for a healthy lifestyle. Consider your entire medical history. Include any new goals you have set for yourself such as:

Physical activity

- Breathing exercises
- Walking, running or cycling
- Gardening and outdoor work
- Activities you enjoy such as swimming
- Dance or movement classes
- Yoga, tai chi or other types of stretching exercises

Diet and nutritional recommendations

- Eating five to nine servings daily of fruits and vegetables free of pesticides
- Including plenty of fiber in your diet
- Drinking eight to ten glasses of water per day
- Avoiding salted, pickled or smoked foods
- Not eating a lot of red meat or processed meats such as bacon, sausage and hot dogs
- Limited alcohol consumption

Reducing stress

- Doing things you find fun and that make you laugh
- Doing things that make you feel relaxed such as hobbies or massages
- Taking classes such as music or painting
- Writing in a journal
- Listening to music
- Attending support groups or counseling
- Praying and meditating

Medical care

- Taking medications as directed
- Having regular health care follow-up appointments
- Having recommended screening tests
- Knowing what symptoms to look for
- Avoiding health risks such as tobacco
- Contacting your health care team with questions and concerns



Develop a plan for healthy living with your health care team that includes:

- ☐ Physical activity
- ☐ Diet and nutritional recommendations
- ☐ Reducing stress
- ☐ Good medical care

A plan for healthy living can help you make healthy behaviors part of your life. Start by doing things you enjoy. Expand your efforts as you can over time. There can also be comfort in knowing you are doing what you can to reduce your risk for cancer and other health problems.



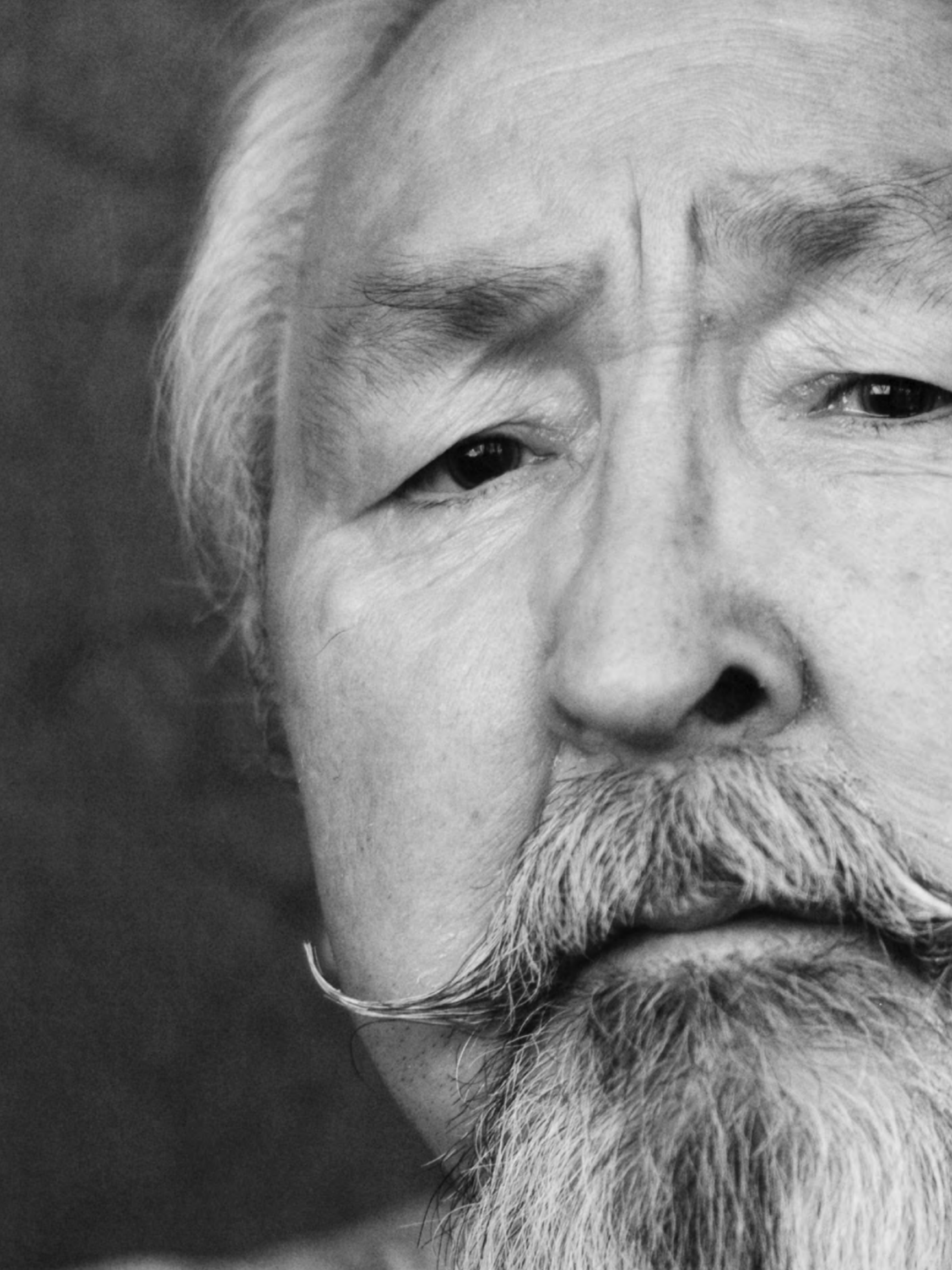
Livestrong means making positive choices for healthy living.

See the Livestrong Guidebook Planner and Journal pages:
After Treatment



Read more about living with cancer at Livestrong.org/WeCanHelp

• Reducing Your Risk for Cancer





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“I probably need to go back and fully grieve, because I don't think that's actually happened yet. ... Some people grieve early, and some people, it takes a while, and some people, they just suppress it. I don't know what the best way is, but we all deal with it in our own way.” —CHRISTOPHER W.



ADVANCED CANCER

This section may be helpful if it becomes necessary to make decisions related to advanced cancer. It includes the following information:

➤ Advanced Cancer Decisions

Advanced Cancer Decisions

Cancer that has grown and spread to vital organs is called advanced or metastatic cancer. Making decisions related to advanced cancer can be difficult. It is often hard to talk with others about these types of matters. Yet sharing this information will help you and your loved ones make the best decisions for the situation.

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“There are choices in how I respond to different things, but I have a faith that life is what it is. ... In some things, we really don't have a choice. Hope for me really means hope for the future of treatments for these kinds of illnesses. Hope is broader for me—it's for the whole universe.”

—SUSAN C.

Making advanced care decisions can be a very emotional experience. A member of your health care team, a loved one or trusted friend might be able to help. A social worker, member of the clergy or a faith-based advisor can also provide support. There is no need to make challenging decisions alone.

TREATMENT OPTIONS FOR ADVANCED CANCER

Cancer may have already spread or metastasized at the time of diagnosis. It can also happen during treatment or even years after. Cancer that has spread does not mean that you or your medical team made a wrong choice or did anything wrong.

Many clinical trials are working on developing new treatments for metastatic cancer. Ask your health care provider if he or she knows about any treatments or clinical trials for your type and stage of cancer. You may want to seek other medical opinions about the best care options as well.

A navigator from the Foundation's cancer navigation services can also help you find information about treatment options including matching to clinical trials. Other free services include counseling and help with insurance issues. Call toll-free 855.220.7777 or go to Livestrong.org/CancerSupport.

Survivors with metastatic cancer often have prolonged and productive lives. However, learning that cancer has spread can bring strong feelings. These may include anxiety and depression. Ask your health care provider to refer you or your loved ones for help dealing with worries and stressors.

If you have advanced cancer, discuss your preferences for future care with the people you love. It is time to prepare advance medical directives if you have not already done so. It is also time to prepare legal documents such as a living will. Taking care of legal matters does not mean you are giving up. This is an important part of life planning that everyone needs to do. It is also something you can do that will help your loved ones in the event of a medical crisis.

SUPPORTIVE CARE DURING ADVANCED CANCER

Advanced cancer can bring sleep problems, confusion, depression or physical challenges. Many of these symptoms can be relieved. Discuss specific care concerns with members of your health care team.

There is hope during advanced cancer. There are many amazing stories about recovery when no one seemed to think it could be possible. Yet, the focus of care might change from cure to comfort care if there are no new treatment options. Comfort care means providing the best ways of caring for pain and symptoms.

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“Survivorship means to me that there is life continuously, all the time.” — ALECIA H.

Comfort care finds ways to:

- Relieve suffering and provide support for the survivor
- Prevent, evaluate and treat pain
- Address other physical, emotional and spiritual concerns
- Respect the cycle of life including end of life
- Assist with grief issues

Managing pain is very important. It affects quality of life. The **National Hospice and Palliative Care Organization** offers information about pain management, hospice care and caregiving. Call 703.837.1500 or visit nhpco.org.

PLANNING FOR END-OF-LIFE AND HOSPICE CARE

Sometimes it is necessary to plan for end-of-life care. Start by talking with loved ones about preferences. Let your health care team know if there is no one who can act as a primary caregiver. A social worker can help arrange for the best level of end-of-life care.

Include the following while planning for care near the end of life:

Living arrangements

Consider options for living arrangements. Think about comfort and trust issues. Care might be provided in your own home or that of a loved one. Other options might be an assisted living facility, nursing home or hospice program.

Caregivers

Caregivers may be loved ones, friends or professionals brought in to help. Consider when and how caregivers will be found. Identify whom could help with daily care needs. Needs might include bathing, dressing, feeding and assistance going to the bathroom. Caregivers must be trustworthy and dependable. There must be someone to cover all of the times when care will be needed.

THE CAREGIVER ROLE

Being a caregiver for a loved one who has advanced cancer may be very different than caring for someone who has a chronic (or ongoing) illness. A person with advanced cancer usually has a variety of symptoms and needs that caregivers try to manage. In most cases, the needs of a loved one in hospice are expected to increase slowly over time.

Caregivers may be involved in activities such as:

Physical care

- Organizing and giving medication
- Monitoring symptoms and discussing treatments with loved ones and hospice staff
- Providing assistance with personal care

Emotional care

- Listening, talking, reading or playing music
- Providing companionship and love
- Helping loved ones and friends understand what is needed

Practical care

- Handling insurance and other financial matters
- Paying bills
- Coordinating communication and visits from loved ones, friends and hospice staff
- Making certain that last wishes are carried out



Talk with loved ones about end-of-life planning:

- ☐ Get planning help from your health care team members.
- ☐ Identify living arrangements where care can be provided.
- ☐ Consider when and how caregivers will be found.
- ☐ Look into advance directives for health care.
- ☐ Learn about hospice care.
- ☐ Seek support to deal with grief and loss issues.

If you are a caregiver, remember to also take care of yourself. This will help you to remain physically, mentally and emotionally able to care for someone else. If you do not care for yourself, you may not be able to continue to care for your loved one.

Caregivers need occasional breaks to avoid physical and emotional exhaustion. This allows you to take time to also focus on your own life. Consider joining a support group for caregivers. Respite care is a hospice benefit that allows a caregiver to take a break for up to five days per month. During this time, hospice benefits generally pay for the loved one to be cared for outside the home such as at a hospice or other residential care facility.

You can always visit your loved one during the time you are taking a respite break. Talk with the hospice staff to make arrangements. Try to plan ahead because it could take some time to arrange the details of respite care. Also, consider:

Medical support

Advance directives are used if a patient becomes unable to communicate about his or her health care. These documents name the person who is to make care decisions. They also specify the types of medical support that are wanted such as the use of feeding tubes and breathing machines. Ask the health care team to work with you to prepare these types of documents.

Hospice care

Hospice care is for people with life-limiting illnesses. It helps people focus the rest of life on quality of life. Hospice care offers care with compassion for the patient and for loved ones. It allows loved ones, friends and caregivers the chance to spend more quality time with the patient.

Hospice services may include:

- Medical and physical care
- Best pain-control treatments available
- Emotional and spiritual support for the patient
- Support for the patient's loved ones

- Practical care assistance
- Help getting personal and legal affairs in order

Hospice care allows one to make meaningful choices and to have those choices respected. Yet, some are afraid to ask about hospice care for themselves or a loved one. There may be a concern that thinking about hospice support means giving up. However, this type of support is not about giving up. Hospice support allows the patient to focus his or her energy on quality of life.

Care services may begin as soon as the health care provider makes a referral for hospice care. The referral will generally state that the patient's life expectancy is six months or less. Contact the hospice program as soon as the referral is made.

A hospice patient may still be quite active, able to carry on with daily life and travel. In fact, some patients improve under the care of this type of program. A hospice patient could return to long-term care if his or her health improves.

Talk with local hospice providers about the specific services they offer. Choose the provider that can meet your needs. Hospice benefits will vary by insurer, so find out what your insurance plan allows. Some plans may allow hospice services to continue longer than the original estimate of six months provided by the health care provider.

The Centers for Medicare and Medicaid Services (CMS) have developed a list of rights for hospice patients ([cms.hhs.gov](https://www.cms.hhs.gov)). Hospice programs must meet these rules for Medicare patients. The rules specify the right to have concerns about quality of life met. They allow the patient to make choices about his or her life. They also ensure the right of a patient to have a say about how end-of-life care is provided.

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“I did do funeral planning ... [while doing] things that told myself, ‘I’m going to live.’ I take care of business things so that my sister won’t have to do it. It is not particularly sad for me, but it is an interesting sort of balance that I do. I have to pay attention and plan for a time when I may not be here. ... But I am looking forward to years, if I can have them.”

—BETH S.



There are also CMS hospice rules about assessing patients, reviewing drug therapies and contracting for other services. Check with the Medicare program in your state to learn more about the rules for hospice care in your area.

FUNERAL OR MEMORIAL SERVICE PREPLANNING

Some people want to be involved with end-of-life planning. Others do not want to think about this. Do what is right for you.

Planning a funeral or memorial service in advance can be an important thing to do with or for loved ones.

Some think of funeral planning as part of making preparations for their estate. It can provide an opportunity to talk with loved ones about certain matters. For example, some may want to assure loved ones that expressing love and respect has nothing to do with high funeral costs.

Preplanning may also help relieve some of the stress that comes at a time of loss. It can help avoid the need to make decisions during a difficult time. There may be comfort in knowing that the services are carried out according to the wishes of a loved one.

If you decide to do preplanning, write down the information and make sure that the right people know where it is kept. Do not include this information in a

will because it will not be read soon enough. Also, it should not be stored in a safe deposit box because the contents will not be available in a timely manner.

Consider the following as you do the preplanning:

- Cultural traditions
- Faith-based practices
- Cost
- Location
- Individual preferences such as a traditional service or more personal style
- Sharing plans with loved ones

Ask for help if advance planning seems too hard to do alone. A loved one, friend or an attorney can assist you. Let others do the planning if thinking about a funeral or memorial service is too difficult.

GRIEF

Grief is a natural response to loss. People grieve after the loss of someone or something that was important to them. Some losses are more difficult than others. When a loss is especially important, grief is more than simple sadness. Finding ways to express your grief can help you adjust to the loss.

Grief is a process that happens over a long period of time. It can include a wide range of thoughts and feelings. Even though these feelings and reactions can be painful, it is important to remember that grief is a normal, healthy response to loss.

Anyone who has been involved in the life of another may experience loss and grief. This can include loved ones, friends and caregivers. Talk with your health care provider if grief becomes too much to handle. You can ask for a referral to a licensed social worker, counselor or a hospital chaplain for help dealing with your loss. Some people find the support they need through their faith-based organizations or support groups.

Important losses that are not grieved are difficult to heal. Unresolved grief can rob you of energy and joy and prevent you from moving forward in life

again. Some individuals come to understand grief on their own. For others, it may be difficult to share feelings of loss and grief. However, many people find that talking with others helps them:

- Recognize losses
- Express emotions
- Connect feelings and reactions to the experience of loss
- Understand loss and grief feelings and reactions as normal
- Find ways to cope
- Adjust more quickly to life after loss
- Feel stronger and more capable than before

In some cases, it may seem that certain individuals do not recognize your loss or that you are grieving. It may be that they feel unable to deal with the intense feelings that they have about loss and grief.

Some friends or loved ones might act like they do not want to talk to you about your feelings. They may really want to help you, but do not know what to say. They might not understand how important it is for you to be able to talk about your loss. If this happens, try explaining that you need someone to support you by listening. Let them know you do not expect them to make everything better.

Children need the support of both family and teachers as they grieve. The Foundation has developed a fact sheet to help adults understand how to support school-aged children through difficult times. Go to [Livestrong.org/what-we-do/program/livestrong-at-schoolforfreeonlinelessons\(K-12\)andotherimportantinformation](http://Livestrong.org/what-we-do/program/livestrong-at-schoolforfreeonlinelessons(K-12)andotherimportantinformation).

The pain of grief generally subsides as it is shared. Good listeners may be found among loved ones, friends and members of your health care team such as a hospital chaplain or an oncology social worker. You can also share with members of faith-based organizations or in-person and online support groups.



Livestrong means making difficult decisions in a way that is best for you.

See the Livestrong Guidebook Planner and Journal pages:
During Treatment: Keeping Important Records



Read more about living with cancer at Livestrong.org/WeCanHelp

- What Hospice Care Means for Survivors
- What Hospice Care Means for Caregivers
- Quality of Life and Palliative Care
- Funeral and Memorial Service Preplanning

The Livestrong Foundation thanks
the cancer survivors who allowed us to share
their quotes and photographs for this resource.

Thank you and Livestrong.