NCCN Guidelines for Patients®
Adolescents and Young Adults with Cancer

Presented with support from:

Available online at NCCN.org/patients
LEARNING THAT YOU HAVE CANCER CAN BE OVERWHELMING.

The goal of this book is to help you get the best care plan for AYAs (adolescents and young adults) with cancer. It explains which cancer tests and treatments are recommended by experts on cancer in AYAs.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world’s leading cancer centers. Experts from NCCN have written guidelines for doctors who treat AYAs. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on cancer care for AYAs. Key points of the book are summarized in the related NCCN Quick Guide™. NCCN also offers patient resources on lymphoma, melanoma, breast and ovarian cancers, soft tissue sarcomas, leukemias, and other cancer types. Visit NCCN.org/patients for the full library of patient books, summaries, and other patient and caregiver resources.
NCCN Guidelines for Patients®

These patient guides to cancer care are produced by the National Comprehensive Cancer Network® (NCCN®). NCCN is an alliance of 27 of the leading cancer centers in the United States. The mission of NCCN is to improve cancer care so people can live better lives.

At the core of NCCN are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN Guidelines® contain information to help health workers plan the best cancer care. They list options for cancer care that are most likely to have the best results.

The NCCN Guidelines for Patients® present the information from the NCCN Guidelines in an easy-to-learn format.

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NCCN Foundation was founded by NCCN to raise funds for patient education based on the NCCN Guidelines. NCCN Foundation offers guidance to people with cancer and their caregivers at every step of their cancer journey. This is done by sharing key information from the world’s leading cancer experts. This information can be found in a library of NCCN Guidelines for Patients® and other patient education resources.

NCCN Foundation is also committed to advancing cancer treatment by funding the nation’s promising doctors at the center of cancer research, education, and progress of cancer therapies. For more information about NCCN Foundation, visit NCCNFoundation.org.

Sponsored and endorsed by LEUKEMIA AND LYMPHOMA SOCIETY (LLS) is dedicated to developing better outcomes for blood cancer patients through research education, and patient services, and is happy to have this comprehensive resource available to patients.

Endorsed by STUPID CANCER. Stupid Cancer proudly supports the NCCN Foundation’s mission to improve the care of patients with cancer.
Introduction

“Being a cancer patient is terrifying, but being myself is empowering.”

– Berenise
Acute Myeloid Leukemia Survivor
Age at diagnosis: 22
How to use this book

Who should read this book?
This book is designed for AYAs (adolescent and young adults) dealing with cancer. It may also be useful for caregivers, family, and friends. Reading this book at home may help you absorb what your doctors have said and prepare for treatment. As you read, you may find it helpful to create a list of questions to ask your doctor.

Feel free to skip over sections that don’t apply to you. And always, keep in mind that this book does not replace the knowledge and suggestions of your doctors. The first and most important rule of dealing with cancer is to talk honestly with your treatment team. They are there to help.

Where should I start reading?
This depends on what you need to know! Each topic is described at the start of Parts 1 through 9. Page numbers are listed so you can flip right to information you need. Your treatment team can also point out the sections that apply to you.

In this book, many medical words are included. These are words that you will likely hear from your treatment team. Most of these words may be new to you, and it may be a lot to learn.

Don’t be discouraged as you read. Keep reading and review the information. Don’t be shy to ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the Dictionary. Words in the Dictionary are underlined when first used on a page.

Acronyms are also defined when first used and in the Glossary. Acronyms are short words formed from the first letters of several words. One example is DNA for deoxyribonucleic acid.

Making sense of medical terms

Does the whole book apply to me?
According to the National Cancer Institute, an adolescent or young adult is anyone between the ages of 15 and 39. That’s a pretty big range, so not all of the information in this book is for you. For example, if you’re still in school you might not need information on how to deal with cancer in the workplace.

Feel free to skip over sections that don’t apply to you. And always, keep in mind that this book does not replace the knowledge and suggestions of your doctors. The first and most important rule of dealing with cancer is to talk honestly with your treatment team. They are there to help.

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But I'm too young to have cancer!

"YOU ARE SPEECHLESS WITH A DIAGNOSIS OF CANCER.

Constantly checking, crying as your mind runs wild with possibilities.

Allow yourself that time, but set an actual date and time to stop all of that and fight."

– Kimberly
Multiple Myeloma Survivor
Age at diagnosis: 37
You are not alone.

Part 1 shares what it means to be an AYA. Learn cancer basics and understand the special needs—and strengths—of AYAs with cancer.

Who is an AYA?

Finding out you have cancer is hard. It can be even harder for someone who is in school, just starting a career, or starting a family. But you are not alone and there are survivors out there just like you.

Every year in the U.S., more than 70,000 AYAs (adolescents and young adults)—people between 15 and 39 years old—are diagnosed with cancer. So if you’ve just been diagnosed, it is time to learn all you can and get the help you need—both physically and emotionally.

Dealing with cancer is different for AYAs. As a young person with cancer you may face challenges and bring special strengths to the fight to get well. You also need different kinds of support than older patients, whose bodies are no longer changing, and who are at a different stage of life.

To get the best possible treatment and support, it’s important to understand your type of cancer and what the options are. The information on the following pages is designed to help you understand what’s happening in your body and make it easier for you to take an active part in your treatment plan.

What is cancer?

Cancer is a disease that starts in the cells of your body. The human body contains trillions of cells that serve as the building blocks for everything from your brain to your toenails. Each of these cells has a purpose. Your DNA controls cells using instructions on what to do. The instructions are called genes and are found in the DNA. Genes tell cells what to become (for example, lung, heart, and skin) and what to do (make hormones, absorb nutrients, and kill germs). See Figure 1.
Normal cells grow and divide and repeat the process over and over again. The normal cells are supposed to die when they become old or damaged. If they don’t die and new cells start to form, the growth can get out of control. Then an abnormal growth forms that is called a tumor. Solid tumors can grow anywhere in the body. Abnormal cells can grow out of control in places like the bone marrow and blood. These cells can interrupt how the blood cells form but may not form a tumor. A solid tumor can form anywhere in the body. Tumors can be benign or malignant. See Figure 2.

What is the difference between benign and malignant tumors?

**Benign tumors** are not cancer.

- The cells are similar to normal cells.
- They do not spread to nearby tissues.
- They may be found in one area but can grow large in size.

Common forms of benign tumors include cysts (lumps filled with fluid), lipomas (lumps of fatty cells), and fibromas (lumps of fibrous or connective tissue cells). Some benign tumors are considered pre-cancerous, meaning that they may progress to cancer. Fortunately, once removed, most benign tumors do not come back.

**Malignant tumors** are cancer.

- The cells tend to be very different from normal cells.
- They can vary in size and be in more than one area in the body.
- They can invade nearby organs and spread (metastasize) to other parts of the body.
Cancer on the move
Normal cells typically stay where they are in the body. But cancer cells can escape from where they started and move to other parts of the body—a process called metastasis.

The ability to spread is what makes cancer so dangerous. Once cancer cells get loose, they can travel to distant parts of the body through the blood or lymphatic system. The lymphatic system is made up of lymph, lymph nodes, and lymph vessels. When cancer cells settle into new places in the body they can replace or damage healthy cells. In time, cancer cells can damage other tissues or organs.

- Cancer that has spread to a nearby body part is called a local metastasis.
- Cancer that has spread to a body part far from the original area it started is called a distant metastasis.

The cells that spread to other areas of the body are still called by the name of the original place it started. The original place the cancer started in the body is also referred to as the primary tumor. For example, when breast cancer cells spread to the lung it is not called lung cancer; instead it is called metastatic breast cancer.

Causes of cancer
Doctors are not completely sure what causes cancer. Many things can cause cancer or put someone at risk for the disease. Doctors do know that cancer gets its start when something goes wrong with the genes—a process called mutation. Mutations can be passed on from a parent and present before you are born (inherited) or caused by later genetic damage (acquired).

Inherited mutations are found in all of the body’s cells. People with inherited genetic mutations have a higher risk for certain cancers, but that doesn’t mean they will definitely develop cancer. Only a small number of cancers have an inherited mutation.

Acquired mutations, on the other hand, are found in every person with cancer. Unlike inherited mutations, which affect every cell in the body, acquired mutations happen in specific cells or types of cells.
Acquired mutations can happen because of:

- **Contact in the environment** – Ultraviolet rays from the sun or tanning bed, common carcinogens (cancer-causing substances) found in things like cigarettes and alcohol, and radiation.
- **Lifestyle choices** – For example, lack of exercise and being overweight.
- **Viruses** – Some viruses damage the genetic code in a way that makes infected cells more likely to become cancerous.
  - For example, HPV (human papillomavirus) is a sexually transmitted virus that is the leading cause of cervical cancer. It has also been linked to head and neck cancers in young adults.
- **Time** – Every time a cell divides, it has to make a copy of its original DNA. Sometimes the copies aren’t perfect and they contain genetic mutations that damage DNA. The damaged DNA is not repaired like it normally is and gets passed along every time the cells divide. Over time, the accumulated mutations may lead to cancer.

But I’m too young to have cancer! What is cancer?

At 24 you are invincible. You are healthy and young. Any ache or pain, is just simply an ache or a pain. You blame it on your job, your workouts, or your posture. You never think cancer. Until one day, you get a call from the doctor saying you have cancer. Yes, that is the last thing I expected to hear. But, what I can say after that one life changing day and having gone through everything, I am invincible after all. Nothing can hurt me.”

– Alyssa
Non-Hodgkin's Lymphoma Survivor
Age at diagnosis: 24
What should I know about AYAs?

It’s estimated that only 5 out of a 100 of cancer cases in the U.S. are diagnosed in people between 15 and 39 years of age. Yet cancer is the leading cause of death among AYAs (See Figure 3). While many of the cancers diagnosed in AYAs are treatable and even curable, survival rates for AYAs have not improved over time. The survival rates are better for young children and older adults with cancer.

Why?

1. One reason is that younger people may go to the doctor less often, so early signs of cancer are more likely to be missed. Teens and young adults who have little or no health insurance are unlikely to get regular health tests that might detect cancer before it has spread.

2. Doctors may not be familiar with treating AYA patients. AYAs bodies are still developing and this group needs special attention when it comes to cancer care. It is important that AYAs seek out a doctor that specializes in treating young adults.

3. A low number of AYAs participate in clinical trials. Clinical trials are research studies that can help find new or better ways to treat cancer. If more AYAs join clinical trials, there may be more advances in cancer treatment for this age group.

4. Both young adult males and females develop different types of cancer than older adults. These cancers often have different mutations and behave very differently than the same cancers in children and older patients.

For example:

- Women younger than age 40 who develop breast cancer are more likely to have a family history of the disease. These women are more likely than older women to develop tumors that do not respond to hormone therapy.
- Sun exposure is less likely to cause melanoma in young adults. It also tends to be less severe than melanoma in older people.
- Young adults with colorectal cancer are more likely to have inherited mutation and disease that grows or spreads quickly.

Cancer treatment in AYAs can be complicated by the fact that their bodies are still developing. Young adults are going through physical and hormonal changes that affect not only how cancer develops, but also how the body responds to cancer treatments.

On the plus side, younger patients often have fewer medical conditions, which means they can tolerate treatment that is more intense than usual (aggressive). Older patients may not be able to tolerate this intense treatment.

Treatment options will vary for young adults based on the unique needs of AYAs. In fact, young adults with cancer can join a clinical trial to learn more on how treat this age group. More on that topic in Part 5.
Figure 3. Common types of cancer affecting AYAs

* includes testicular cancer
** includes breast, cervical, colon, and other less prevalent cancers
*** includes malignant bone tumors and other less prevalent cancers

Review

- More than 70,000 AYAs—people between 15 and 39 years old—are diagnosed with cancer.
- Cancer is a disease that starts in the cells of your body.
- Cancer cells can spread to other body parts through the blood or lymphatic system.
- Doctors know that cancer gets its start when something goes wrong with the genes—a process called mutation.
- It’s estimated that only 5 out of a 100 of cancer cases in the U.S. are diagnosed in people between 15 and 39 years of age.
- Younger patients often have fewer medical conditions, which means they can tolerate more intense than usual (aggressive) treatment.
Dealing with the diagnosis

INITIALLY, WHEN YOU’RE DIAGNOSED AT 24 –

at a pinnacle moment in your life where you’re at the crossroads of figuring out your career path – you think the worst of your situation. That is, until you realize how fragile life is, and how incredibly lucky you are to have young age on your side in handling the side effects of chemotherapy. While I’ll never say it was an easy battle, maintaining a positive mindset and spirit makes the journey that much more tolerable. There’s a silver lining somewhere, you just need to find it.”

– Dayna
Hodgkin Lymphoma Survivor
Age at diagnosis: 24
Understanding your tests results.

Part 2 is a guide to common diagnostic tests and procedures and what the results mean.

How is cancer diagnosed?

Getting diagnosed with cancer is a process. It starts when you or your doctor notices something abnormal that wasn’t there before:

- a lump that can be felt
- a mole that changes shape or color
- a pain that can’t be explained

Your doctor will usually begin with asking you questions. He or she will then do some testing in order to get the most information about what is happening in your body. Very often your doctor will send you to a specialist who is more experienced in diagnosing and treating the type of cancer you have. Cancer doctors who specialize in treating cancer are called oncologists.

Medical history and physical exam

Details about your medical history and an exam of your body are two of the most basic tools of diagnosis.

- A medical history is just what it sounds like—a history of everything that has ever happened to you health-wise.

Your doctor will:

- Gather information about any health events that have happened in your life, including surgeries, accidents, and past illnesses.
- Find out about current problems and any medications you are taking.
  - It may help to make a list before you go to your appointment to make sure you don’t forget anything.
- Ask about the medical history of your family to check for disease such as cancer, heart disease, or diabetes.

When the doctor checks your body for signs of disease, it is called a physical exam. Doctors often perform a physical exam along with taking a medical history.
Your doctor will:

- Look in your eyes, ears, nose, and throat.
- Listen to your lungs, heart, and belly (abdomen).
- Feel and apply pressure to some parts of your body to see if organs are of normal size, are soft or hard, or cause pain when touched.

If something abnormal is found by you or your doctor, let’s say during a routine visit, you will need to have more testing done. These tests may include lab tests that collect blood, urine, or other fluids from your body.

**Blood tests**

Blood tests are an important part of cancer diagnosis and during the diagnosis phase, blood tests will be used to check your overall health and to look for signs that cancer is present.

Before blood tests can be run your doctor will need to get blood samples. This can be done at a doctor’s office, a laboratory, or in the hospital. The blood is collected by a nurse or a phlebotomist, a technician who specializes in taking blood samples.

The complete blood count

It’s likely that you’re going to have quite a few blood tests during the course of your diagnosis and treatment. One of the most common is the CBC (complete blood count). The CBC is a measure of the various types of cells found in the blood, including white blood cells, red blood cells, and platelets. After your blood is taken, it is checked to find the actual number of each cell type in the sample. These numbers are then compared to the normal range for those cells in a healthy person who is about your age.

**Blood chemistry tests**

In addition to the CBC, your doctors will probably order frequent blood chemistry tests to keep track of what’s happening in other parts of your body. Blood chemistry tests measure the levels of minerals, enzymes, and waste products that are normally found

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**Your medical history:**

What you share about your medical history will help determine what treatment is best for you. It’s important to be honest and tell the doctor everything you know.

Let the doctor know if you drink alcohol, use recreational drugs such as marijuana, or take over-the-counter medications, supplements, or natural treatments. Talk about your sexual history and habits. Remember, doctors aren’t there to judge you. They need to learn everything they can about you to make the best possible choices for your care.
in the blood. A blood chemistry panel may include more than a dozen different tests. Several measures will allow your doctor to track how your heart, liver, kidneys, and other organs are working.

**Imaging tests**

When a tumor is suspected, doctors want to get a look at exactly where it is and the size of it. Imaging tests are used to take pictures (images) of the inside of your body. Doctors can see the primary tumor and look for cancer in other parts of your body.

Common imaging tests that take pictures of the inside of your body are:

- **X-rays** that use low-dose radiation to take one picture at a time.
- **Ultrasounds** that use high-energy sound waves to make pictures.
- **CT (computed tomography)** scans use x-rays to take pictures from many angles. You may be given dye (contrast material) for this type of scan. (Figure 4).
- **MRI (magnetic resonance imaging)** scans use radio waves and strong magnets to make detailed pictures.
- **PET (positron emission tomography)** scans use a tracer to detect disease and take 3-D pictures.

The pictures made during imaging tests will be reviewed by a radiologist, who will provide your doctor with a report on what the tests show. A radiologist is a doctor who’s an expert in reading imaging tests. It may take several days to get this report.

**Biopsies**

Blood tests and imaging studies can tell a doctor only so much about the possibility of cancer. The only way to be sure about what is going on is to look at the cells themselves. That means removing some suspicious tissue that can be looked at by a pathologist. The tissue will be tested for cancer cells. This removal of tissue is called a biopsy. A pathologist is a doctor who’s an expert in testing cells to find disease.

**Figure 4. CT scan**

A CT scan machine is large and has a tunnel in the middle. During the test, you will lie on a table that moves slowly through the tunnel.
Biopsies often include removal of tissue from nearby lymph nodes. The lymph nodes are groups of small round structures in the lymphatic system that help fight disease. By removing lymph nodes, your doctor can see if cancer has gone beyond the primary tumor. Once the biopsy is complete, a pathologist will look at the tissue sample—or samples—under a microscope to determine:

- Whether the tumor is benign or malignant.
- What kind of cancer it is.
- If—or how far—the cancer has spread.

The pathologist may also perform other tests to see if the cancer cells have specific genes (instructions for cells) or proteins. This can help in understanding how the cancer will act in the body and what treatment should be given.

Biopsies are usually done by a surgeon, a doctor specially trained in performing surgical procedures. Imaging scans can be used during a biopsy to guide the doctor when removing the tissue.

Biopsy techniques include:

- **Endoscopic biopsy** – a lighted scope is inserted into an opening in the body to remove tissue or cells through a tube.
- **Needle biopsy** – uses a needle to remove fluid or tissue in the body.
- **Incisional biopsy** – surgical removal of a sample of tumor tissue for testing.
- **Excisional biopsy** – surgical removal of the entire tumor for testing.

Biopsies are the final step in a cancer diagnosis. Ask your doctor or nurse to explain what biopsy you will have and what you can do to get ready.

The pathology report

The pathology report is written by a doctor for a doctor, which can make it hard for patients to understand. The report will cover everything from your name, age, and other details on who you are (check this carefully). It will have details on how the biopsy sample looks, how the cancer seems to be growing, and what it’s likely to do.

**Staging**

Once all of your tests are done, the doctor will tell you the stage of your disease. Staging tells the extent of cancer in the body. Your doctor will stage your disease to decide on a prognosis (the likely course the cancer will take) and to choose the best treatment for you.

The stage of the cancer may be expressed in several different ways.

- Carcinoma in situ is limited to the layer of cells where it began.
- Localized cancer is limited to the organ where it began.
- Regional cancer has spread to nearby lymph nodes or organs.
- Distant cancer has spread to distant parts of the body.
- Unknown means there’s not enough information to determine the cancer’s stage.

Tumors may also be described as stage 0 through IV:

- Stage 0 is a very early form of cancer that has not yet invaded other areas.
- Stage I–III indicates disease that is increasing as the stages go up. This can include larger tumor size and greater spread of cancer to nearby organs or lymph nodes.
- Stage IV indicates that the cancer has spread to distant parts of the body.
Some cancers are staged using the TNM system, which is based on the extent of the primary tumor (T), whether or not cancer was found in nearby/regional lymph nodes (N), and whether distant metastases are present (M). See Chart 1.

The blood cancers like lymphoma and leukemia use other ways to stage disease since they are not solid tumors. Brain tumors may not spread outside of the brain, so they also don’t use the TNM system. Each type of cancer has a slightly different staging system, so the letters and numbers can mean something different for someone with ovarian cancer than they do for someone with lymphoma.

When finding out a stage for cancer a doctor also looks at the tumor grade and tumor markers. The rating of how much cancer cells look like normal cells under a microscope is the tumor grade. This grade tells how quickly the cancer can grow or spread.

The doctor also tests for tumor markers that can be found at high levels in the blood or other bodily fluids. Certain tumor markers are used to check for certain types of cancer. For example, CA-125 may show in the blood at high levels for someone with ovarian cancer. This may mean cancer is present, but this marker is only one piece of the puzzle. Once your doctor puts all the pieces together, you will know more about your cancer diagnosis and how to fight this disease.

What do the test results mean?

Reviewing the test results marks the beginning of your cancer journey. The results from your blood tests, imaging studies, and biopsy will determine the treatment you get, so it is important you understand what they mean.

Of course, the shock of hearing that you have cancer can make it hard to absorb all the technical and scientific words. If you feel overwhelmed, follow a few simple rules to help prepare for your next steps:

<table>
<thead>
<tr>
<th>Primary tumor (T)</th>
<th>Regional lymph nodes (N)</th>
<th>Distant metastases (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>TX: unable to evaluate</td>
<td>NX: unable to evaluate</td>
<td>MX: unable to evaluate</td>
</tr>
<tr>
<td>T0: no evidence of primary tumor</td>
<td>N0: no cancer found in lymph nodes</td>
<td>M0: no distant metastases found</td>
</tr>
<tr>
<td>T1-T4: size of primary tumor</td>
<td>N1-N3: cancer in lymph nodes</td>
<td>M1: distant metastases found</td>
</tr>
</tbody>
</table>
Bring someone with you when meeting with doctors. You may also want to think about writing down or recording what you talk about so you can review it later.

Get copies of blood tests, imaging results, and reports about the specific type of cancer you have. It will be helpful when getting a 2nd opinion (more on that later).

Get organized since you can get a lot of paper such as insurance forms, medical records, and tests results. Make sure you have easy access to contact information for everyone on your treatment team.

Be prepared because cancer doctors are often on very tight schedules, so you’ll want to make the most of the time you have. Make a list of the questions or issues you want to talk about before you go to each doctor’s visit.

Most importantly, ask for help if you need it. You are anything but alone in this diagnosis.

What are my options?

When you’ve been diagnosed with cancer it’s perfectly natural to want to get the cancer out of your body right away. That being said, it is a good idea to start treatment within a few weeks of a diagnosis. You can take that time right after diagnosis to get a 2nd opinion.

Be sure you are working with doctors who understand the unique needs of AYAs with cancer. You also want to make sure they have experience treating patients with the same type of cancer you have.

Getting a 2nd opinion

Even if you like and trust your doctor, it is usually a good idea to get a 2nd opinion. Checking a biopsy sample requires skill and experience. It’s a possibility another doctor will see something the first pathologist missed. A cancer doctor (oncologist) may also bring a different view on the type of treatment that’s best for you. For example, a surgical oncologist may suggest that surgery is your best option, while a medical oncologist may suggest chemotherapy.

If nothing else, a 2nd opinion can confirm that your first doctor and pathologist got it right. Getting a 2nd opinion is common and important if:

- Your doctor has little knowledge about treating the type of cancer you have.
- Your test results were unclear and you need more tests done.
- You live in a rural area.
- You have a rare type of cancer.
- You want to join in a clinical trial.

Finding your 2nd opinion

The R.A. Bloch Cancer Foundation at www.blochcancer.org/resources-multidisciplinary-2nd-opinion-centers has a list of institutions across the country that offer 2nd opinions.

The Navigate Cancer Foundation at www.navigatecancerfoundation.org has experienced cancer nurses who can help you find a qualified doctor for a 2nd opinion.
Many insurance companies will pay for a 2nd opinion. Check with your insurance company about its rules on 2nd opinions. You want to know about out-of-pocket costs for doctors that are not part of your insurance plan.

Plan ahead
Make plans to have copies of all your records sent to the doctor you will see for your 2nd opinion. Do this well before your appointment! If you run into trouble having records sent, pick them up yourself and bring them with you.

If this doctor offers other advice, make an appointment with your first doctor to talk about the differences. If you're not sure what to do, get a 3rd or 4th opinion. Do whatever you need to feel confident about your diagnosis and treatment plan.

Review

- Cancer doctors who specialize in treating cancer are called oncologists.
- A medical history and physical exam are two of the most basic tools of diagnosis.
- If something abnormal is found by you or your doctor, tests will be done to collect blood, urine, or other fluids from your body.
- Imaging tests are used to take pictures (images) of the inside of your body.
- A pathologist is a doctor who's an expert in testing cells to find disease.
- Staging tells the extent of cancer in your body.
- You can take that time right after diagnosis to get a 2nd opinion.
Preparing for the future

“I WAS SUPPOSED TO LEAVE FOR COLLEGE THE WEEK I WAS DIAGNOSED.

Instead of going to parties at my new school that week, I had to decide if I wanted to freeze my eggs – which would delay treatment – or start treatment immediately so I could start college the next fall rather than winter. What 18-year old is prepared to make a decision about a future family in one week?”

– Connie
Hodgkin Lymphoma Survivor
Age at diagnosis: 18
Can I have children after cancer treatment?

Your fertility is important to think about after a cancer diagnosis. It may seem strange to start thinking about having children when you learn you have cancer. But now is the time to think about this possibility before treatment gets started. The fact that you are at an age when you are able to have children is one of the many things that sets you apart from most people with cancer. It’s important because cancer and its treatment can damage your reproductive organs and make it difficult or impossible to have children.

Up until recently most young cancer patients—and their doctors—didn’t think much about fertility. In 2006 the American Society of Clinical Oncology (ASCO) published guidelines recommending that cancer doctors talk with their AYA patients about fertility issues. Doctors are to inform them about options for preserving fertility, and provide referrals to fertility specialists when possible before starting treatment. This is also reflected in the clinical guidelines written by NCCN experts on cancer in AYAs. The NCCN experts recommend talking to your doctor at the very start of your cancer care about the risks of infertility and use of fertility preservation.

So even if you’ve never really thought much about being a parent, it is helpful to learn about fertility issues as soon as you’re diagnosed. Figure 5 outlines how fertility preservation can be worked into the process when you are finding out more about your diagnosis and treatment plan.
Figure 5. Steps to protecting your fertility

If your treatment plan includes medication or procedures that can have an effect on your fertility, work with your doctor and a reproductive specialist to:

- Limit the damage from treatment.
- Learn steps you can take so you can still have children in the future.
- Understand what your fertility options may be after treatment is complete.

Once you know what you want to do, let your doctor know what your plans are for children. Your doctor will take time to look into your case—including the risks of delaying treatment—to make a decision about the timing of fertility preservation.

Understanding the risks
The complete loss of the ability to have children is called infertility.

In men, infertility happens when the testicles can no longer make sperm (a condition known as azoospermia) or when the pathways that sperm travel through are blocked or damaged.

In women, infertility happens when:

- The ovaries can no longer make eggs, a condition called premature ovarian failure or early menopause.
- There is damage to the uterus (where babies grow during pregnancy) or other parts of the reproductive system so the eggs can’t get fertilized.
- There is damage to the uterus or other parts of the reproductive system so fertilized eggs can’t implant and grow inside the uterus.

The actual risk of infertility varies depending on the cancer, the treatment, treatment dose, and the age of the person getting cancer treatment. In general, the higher the dose and the older your age, the more likely you are to experience problems.

Treatments can harm the reproductive system. This depends on the area the treatment is given to and how much (the intensity or combination of drugs) are given. Treatments that affect the reproductive area may be:

- High-dose or targeted radiation to places like the pelvic area.
- Chemotherapy that includes a type referred to as alkylating agents.
- Surgery to remove tissue or organs from the reproductive area.

It is important for AYAs to think about fertility preservation early on. Still, today it is one of the least-thought-about services for AYAs. Sometimes it is not an option to look into fertility preservation early on due to an urgent need for treatment. If this is the case, you can still talk to your doctor about preservation after treatment starts.

“My wife is pregnant and I’ll be having my first child almost six years after I was first diagnosed. And it’s all because my doctor and I talked about fertility on day one.”

- Bret

Hodgkin Lymphoma Survivor
Age at diagnosis: 31
What do I need to know about fertility?

Fertility preservation is all about keeping your options open, whether you know you want to have children later in life or aren’t really sure at the moment. Reproductive specialists and the members of an oncofertility team can help you sort through what may work for you.

Depending on the type of cancer you have and the specialists available in your area, your oncofertility team may include:

- **Your oncologist** who should start the conversation about cancer-related infertility and help you understand your risks.
- **A nurse navigator** or case manager who will help you navigate the referral process, coordinate the various specialists involved in your care, and help deal with your insurance.
- **An endocrinologist/reproductive specialist** who specializes in fertility and cancer and can explain your fertility preservation options—including how they are done, success rates, timing, and costs. This specialist will carry out the fertility-sparing procedure.
- **A genetics counselor** who can assess your risk of passing on genetic abnormalities to your children. This is usually done within the 2 months of starting treatment.
- **A gynecologist (for women) or urologist (for men)** to assess your risk of infertility and guide you in addressing your fertility needs.
- **A gynecologic oncologist (for women)** who specializes in female cancers. This is usually a surgeon and may be the one to perform fertility-sparing surgery, if needed.
- **A family-planning specialist** who can offer information about many different options for becoming a parent.
- **An adoption professional** who can provide information and counseling on the process of becoming an adoptive parent. This can include criteria, timing, and costs.
- **A social worker or mental health counselor** who can give emotional support and counseling as you consider your fertility options.

Before you make a decision about how—or if—to preserve your fertility, you will need to think about what you need the most when it comes to becoming a parent. If you’re in a serious relationship, it may help to involve your partner in this discussion. If you’re younger and have never given much thought to having kids, you may want to talk with your parents or caregivers. Crucial questions to consider include:

- Have you always wanted children?
- How many children do you want to have? And when?
- How do you feel about adoption?
- How would you feel about using donor sperm or donor embryos?
- How would you feel about having a surrogate bear your child?
- Do you have any religious or moral concerns about technologies such as IVF (in vitro fertilization) or embryo transplantation?

You will also want to think about finances. All fertility preservation methods have an out-of-pocket cost, and many treatments are still being studied. You’ll need to check with your insurance company about what they will cover.

Fortunately, the LIVESTRONG Foundation’s Fertility section has an information guide on Fertility & Family Planning. It addresses things like money and insurance. It also offers financial assistance for fertility medication and other services for freezing embryos, eggs, and sperm. Visit https://www.livestrong.org/we-can-help/livestrong-fertility# to learn more.
What are my options?

Your fertility preservation options will vary depending on your age, gender, and type of cancer you have. Most techniques that can increase your chances of having children must be done before treatment starts. See Chart 2.

Before treatment
Fertility preservation methods that can be done before treatment fall into two basic groups: techniques that prevent damage from happening in the first place, and techniques that remove healthy cells (sperm, eggs, or embryos) and store them for later use.

Damage prevention
It’s sometimes possible to protect reproductive organs through fertility-sparing surgery. The surgeon removes only the cancerous tissue and leaves as much healthy tissue in place as possible. For example, the surgeon could leave the healthy ovary in place if you have early-stage ovarian cancer.

Exploring your choices
If you’ll be receiving radiation therapy, you can use a special lead shield to prevent radiation from reaching the ovaries or testicles. If you’re a woman, it may also be possible to surgically move the healthy ovary (or ovaries) out of the radiation field, a process called ovarian transposition.

There is also an experimental technique called ovarian suppression that uses a hormone-blocking drug to stop the ovaries from producing eggs. Although ovarian suppression is sometimes used in the treatment of breast cancer, there’s no research on how well it works for protecting fertility.

Banking healthy cells
The most well-established methods of fertility preservation are sperm banking for men and embryo freezing for women.

- Sperm banking is a fairly simple procedure that involves collecting and then freezing one or more samples of ejaculate. Men can find a local sperm bank or go online to look for a sperm banking kit.
- Embryo freezing is more complicated because it requires IVF, a process in which eggs are removed from the ovaries and fertilized in a lab. If you don’t have a partner, IVF can be done with a sperm donor.
  - Since IVF must be timed to your menstrual cycle and involves a series of hormone shots to prompt the ovaries to produce more than one egg, it could mean delaying treatment for several weeks.

Experimental options include:

- **Ovarian tissue freezing** – Surgical removal and freezing of a healthy ovary (or part of an ovary). When treatment is complete, the tissue is put back.
- **Egg freezing** – Use of hormones to make the ovaries produce multiple eggs, which are then taken out and frozen.
- **Testicular sperm extraction** – Removing a small portion of tissue from the testicle while under local anesthesia (a controlled loss of feeling in a small area of the body from drugs) to take out and freeze sperm cells.

After treatment
Even if you’ve already started or completed cancer treatment, you still have the opportunity to have a family. Sometimes the body recovers naturally from treatment-related damage. If it doesn’t, you can think about the following options:

- **Donor eggs or donor embryos** – Donor eggs are harvested from women who have volunteered to go through hormone treatment.
3 Preparing for the future  What are my options?

Chart 2. Fertility preservation methods

<table>
<thead>
<tr>
<th>Method</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>For women</strong></td>
<td></td>
</tr>
<tr>
<td>Radiation shielding</td>
<td>Use of lead shields to protect ovaries during radiation treatment</td>
</tr>
<tr>
<td>Embryo freezing</td>
<td>Use of hormonal treatment, egg extraction, and IVF to produce embryos that can be frozen for later implantation</td>
</tr>
<tr>
<td>Ovarian transposition</td>
<td>Surgical repositioning of healthy ovaries so they are out of the radiation field</td>
</tr>
<tr>
<td><strong>Experimental Options†</strong></td>
<td></td>
</tr>
<tr>
<td>Egg freezing</td>
<td>Extraction and storage of unfertilized eggs</td>
</tr>
<tr>
<td>Ovarian tissue freezing</td>
<td>Removal of healthy ovarian tissue (or whole ovary) for transplantation back into the body after treatment</td>
</tr>
<tr>
<td>Ovarian suppression</td>
<td>Medication to stop the ovaries from producing eggs during the treatment process</td>
</tr>
<tr>
<td><strong>For men</strong></td>
<td></td>
</tr>
<tr>
<td>Radiation shielding</td>
<td>Use of lead shields to protect testicles during radiation treatment</td>
</tr>
<tr>
<td>Sperm banking</td>
<td>Collection and storage of ejaculate</td>
</tr>
<tr>
<td><strong>Experimental Options†</strong></td>
<td></td>
</tr>
<tr>
<td>Testicular sperm extraction</td>
<td>Extraction of sperm from testicular tissue</td>
</tr>
</tbody>
</table>

† These techniques have not been proven to be effective and generally are not covered by insurance.

...to produce multiple eggs. The donor embryos are donated by couples who have chosen not to use their frozen embryos. Donor eggs are fertilized through IVF using a partner’s—or donor’s—sperm.

▶ **Adoption** – This is an option for anyone who wants to become a parent. Some adoption agencies may require that you be cancer-free and off treatment for a certain amount of time before adopting a child.

▶ **Surrogacy** – If treatment-related damage to the reproductive organs makes it impossible to carry a child, couples who have frozen embryos may consider using a surrogate. A surrogate is a woman who volunteers to have the embryos inserted into her uterus. She will then go through pregnancy and birth. Sometimes the surrogate is a relative or friend.
Review

- It is helpful to learn about fertility issues as soon as you’re diagnosed.
- Your treatment plan includes drugs or procedures that can have an effect on your fertility.
- The complete loss of the ability to have children is called infertility.
- Your fertility preservation options will vary depending on your age, gender, and type of cancer you have.
- The most well-established methods of fertility preservation are sperm banking for men and embryo freezing for women.
and told that you have cancer, it’s easy to play the ‘what if’ games about your future. Instead, I found tremendous comfort in focusing on the things that I could control, such as taking medications as directed, taking an active role in educating myself about my disease and my treatment plan, and ensuring I asked (and received) proper answers to all my questions.”

– Ryan
Chronic Myelogenous Leukemia Survivor
Age at diagnosis: 32
What you can expect during treatment.

Part 4 focuses on the treatment process and the different stages of care you will go through. Learn all you can about your treatment options. It’s important to stick with the treatment plan that you and your doctor decide to do.

Getting treated for cancer can be a strange journey. You know where you want to end up—healthy—but it’s not always clear how you’re going to get there or how long it will take. Depending on your diagnosis, the process can take a long time. It can be weeks, months, or even years for treatment that is followed by many more years of follow-up care. And all along the way you are a cancer survivor.

What are the stages of treatment?

Cancer treatment is rarely a one-shot deal. Most patients go through several rounds of treatment to make sure the cancer is either gone or under control. Although the specific therapies used during each stage will depend on your diagnosis, your treatment plan is likely to take you through several stages.

**Neoadjuvant or induction therapy**

Neoadjuvant or induction therapy is usually given to reduce the size of the cancer before cancer surgery. It can be helpful for a large primary tumor. Shrinking the tumor may make the surgery less complicated. Induction therapy may also be used to prepare the body for a stem cell transplant (or bone marrow transplant) in patients with leukemia or lymphoma. The transplant gives blood or bone marrow stem cells intravenously to restore cells that have been destroyed by cancer or its treatment.

Neoadjuvant therapy may include radiation therapy, chemotherapy, or a combination of several treatments. If the chosen treatment carries a risk of side effects such as nausea or being very tired and...
lacking energy (fatigue), the treatment team should also set up a supportive care plan to prevent or relieve these symptoms.

If the cancer does not change or continues to grow during neoadjuvant treatment, your doctor may try a different therapy such as a different chemotherapy drug. The doctor can also stop neoadjuvant therapy and move forward with surgery.

**Primary or first-line therapy**

Primary or first-line therapy is just what it sounds like—the first attempt to get rid of (or control) the cancer in your body. This can be done with local therapies that target just the areas where cancer has been found. It can also be systemic therapies that attack cancer cells throughout the body. Treatment can be delivered both locally or systematically or a combination of both.

- **Local therapies** include surgery and radiation therapy.
- **Systemic therapies** include chemotherapy, targeted therapy, and immunotherapy. For some patients, the best option for primary therapy may be a clinical trial of a new treatment.

After the primary therapy is complete, your doctor will run many of the same tests used during diagnosis to see whether the treatment worked in removing or controlling the cancer.

- If there are no signs of cancer, you may be declared to be in complete remission.
- If some, but not all, signs and symptoms of cancer have disappeared it may be called a partial remission.
- If the cancer has grown or spread to other places in your body, it means the cancer has progressed.

A complete remission is great news, but it doesn’t necessarily mean that every single cancer cell has been destroyed. This is why additional rounds of treatment are often given even after successful local or systemic treatments.

**Adjuvant therapy**

Adjuvant therapy is given after a tumor (or tumors) has been surgically removed or destroyed by radiation. It is given after the primary treatment. The goal is to get rid of any remaining cancer cells and prevent a possible recurrence of the cancer. Adjuvant therapy may include radiation therapy, chemotherapy, targeted therapy, or immunotherapy, either alone or in combination.

**2nd-line therapy (and beyond)**

If cancer does not respond to initial therapy—or reappears after a period of remission—it’s time for 2nd-line therapy. Some people may have many remissions and recurrences, and require 3rd, 4th, or even more lines of therapy. Treatment options in these situations may include another round of the first therapy that was given. This may be surgery, radiation therapy, immunotherapy, targeted therapy, chemotherapy, or a combination of all the above. Clinical trials are also an option for treatment at any stage of treatment.

**Supportive care**

Supportive care (also known as palliative care) is any treatment that relieves your symptoms and improves your quality of life. It can include everything from radiation to shrink a painful tumor, to anti-nausea and vomiting medication, to talking with a therapist about handling stress at work.

For years, supportive care was thought of as the treatment of last resort—something that was done only when everything else had failed. This is no longer true. Today’s clinical guidelines state that supportive care should be included in every stage of
cancer treatment. And this type of care can start early on in your cancer journey.

**Survivorship care**
When treatment leads to remission (or no evidence of disease) you are now moving into follow-up care. This is also known as survivorship care, although many patients refer to themselves as survivors from the time of diagnosis.

Life as a cancer survivor will not be quite the same as life before your diagnosis. Cancer and its treatment can’t help but leave their mark—on your body, and your mind. Dealing with these effects can be a challenge for any cancer survivor.

According to recommendations from the Institute of Medicine, every patient with cancer should have a survivorship care plan that includes guidelines for monitoring and maintaining health in the months and years after treatment. Part 8, *Moving Beyond Treatment*, has detailed information on survivorship issues.

**Recurrence (or relapse) vs. progression**
You may hear these words as you go through treatment. All of them mean that the cancer is growing in some way. Recurrence or relapse refers to cancer that shows up after the cancer has been in remission. Progression is when the cancer spreads or gets worse with no period of remission in between.

**End-of-life care**
Sometimes cancer keeps progressing despite everyone’s best efforts. When remission or cure is no longer possible, the next step is end-of-life care, which is designed to keep patients comfortable and help make the most of the time remaining.

Although it’s natural to want to avoid thinking about death, most cancer experts suggest completing an advance directive, to plan for end-of-life care, sooner rather than later. Doing this will give you one less thing to worry about. An advance directive does not mean you have given up. However, it ensures that your treatment team and your loved ones understand what you want.

### Who is on my treatment team?

To get the highest level of care possible, it’s helpful to work with a medical team that looks at the whole picture. It is good to find a doctor who will not only care for your physical health, but also can help you with the emotional effects of dealing with cancer.

Hospitals and cancer centers with AYA oncology programs typically have a team of specialists who can work with you to get the help you need. If you are being treated at a facility that does not offer support services, the following information can be helpful for building your own team of professionals. This team can help you during the treatment process.

Some members of your treatment team will be with you throughout the cancer journey, while others will only be there for parts of it. Key players are likely to be:

- **A primary care practitioner** (family doctor, internist, or general practitioner) handles medical care that isn’t related to the cancer. This person should be kept up-to-date on your cancer care and receive notes on your progress.

- **A medical oncologist or hematologist** specializes in the systemic treatment of cancer. This person will be the one who prescribes chemotherapy. Often, he or she will also lead the overall treatment team and keep track of tests and exams done by other specialists.
Navigating the treatment process

Who is on my treatment team?

- **Oncology nurses** will provide much of your hands-on care, like giving chemotherapy, managing your care, answering questions, and helping you cope with side effects.
- **Oncology nurse practitioners and physician assistants** may also perform health checks and physical exams. They can also order and review tests, prescribe medication, and order chemotherapy.
- **Social workers** provide counseling and also help with discharge planning and home care. They can also find local resources that offer support.
- **A patient navigator** can help with arranging financial support, transportation, and childcare during treatment. They can also coordinate care among several doctors.
- **A dietitian or nutritionist** can give nutritional advice and help you plan menus to meet your nutritional needs during cancer treatment.

Depending on your diagnosis your team may also have:

- **A surgical oncologist** who will perform any surgery.
- **Anesthesiologists** who will give anesthesia during surgery or procedures.
- **A radiation oncologist** who will prescribe and plan radiation therapy.
- **A pathologist** who reviews laboratory tests and evaluates cells, tissues, and organs removed during a biopsy or surgery.
- **A diagnostic radiologist** who reviews the results of x-rays and other imaging tests.
- **A psychiatrist or clinical psychologist** who can help you cope with the psychological and emotional effects of dealing with cancer.

- **Physical, occupational, speech, and respiratory therapists** who can help you with specific problems related to the cancer and recovery from treatment side effects.

The final and most crucial member of the treatment team is also the only one who will be there for every part of the process—you. And you know your body better than anyone. Help other team members understand:

- How you feel
- What you need
- What’s working and what is not

You should never wait to ask questions or seek other opinions. Let your treatment team know when you’re feeling overwhelmed or need to take a break.

Your team may get larger the further along you are in treatment. To keep track of everyone, think about putting together a list of names and contact information for each member of your treatment team. It will make it easier for you—and any loved ones involved in your care—to know who to contact when questions or problems come up.
**What does a treatment plan involve?**

A treatment plan is a written course of action that covers every stage of the treatment process, from the first treatment onward. It serves as a guide for everyone taking part in your care. It reminds everyone of decisions that have already been made and plans for the future.

If you’re in a relationship or still in your teens, your partner, parents, or caregivers will probably want to be involved in treatment planning. This can be a huge help, particularly when you may be overwhelmed and still in shock from the diagnosis. It’s important to keep in mind that you have a say in your treatment plan. Your loved ones can help you find information, take notes, ask questions, and talk through your options, but only you can decide if a treatment plan is right for you.

The specifics of your treatment plan will be based on many things like the kind of cancer you have and also your own personal needs and limits. As a young adult with cancer, you may have treatment options that children and older adults do not have.

For example:

- Depending on your diagnosis, you may do better with a pediatric treatment plan than one designed for adults.
- You can probably tolerate more intense treatment options than older adults.
- As a young, relatively healthy person (other than cancer) you’re an excellent candidate for a clinical trial.

Ask your treatment team to consider these factors as they weigh your treatment options—including suggestions from clinical guidelines related to the type of cancer you have.

Cancer treatment is always evolving, and it’s not always easy for doctors to keep up. That’s why organizations such as the American Cancer Society, the National Cancer Institute, and NCCN offer clinical guidelines for the treatment of specific cancers.

These guidelines are based on the best available science based evidence on cancer and its treatment. The guidelines are important tools for coming up with the right treatment plan for your diagnosis. You can access NCCN Guidelines on specific diagnosis. You can access NCCN Guidelines on specific cancers—and on other aspects of care of AYAs with cancer—on the NCCN website, www.NCCN.org.

> Accept help. Ask for help. Ask for resources. There are many people who want to support you, and it feels great.”

– Summer Colon Cancer Survivor Age at Diagnosis: 33
How can I learn more about treatment options?

Whether you go hunting for information yourself or hand the job over to a computer-savvy friend or relative, you should take some time to figure out what you'll be searching for. Start with the information you already have about the cancer. You'll want to look for information that fits the specific cancer you have, and weed out information that doesn’t.

The Internet can be an incredible resource, but it's also full of false information and scams. Websites can promote wrong or dangerous “alternative” therapies. Some of the most obvious “red flags” include:

- Claims that a certain treatment will work for every type of cancer.
- Treatments that are only available from one individual or facility, or that can only be purchased outside of the U.S.
- Claims that the government/pharmaceutical companies/medical establishment “don’t want you to know” about a certain treatment, doctor, or theory.
- Patient stories without any scientific backup.
- “References” from magazines or newspapers instead of recognized scientific journals.
- Offers of online diagnosis or treatment advice.
- Claims that the site is the “best” or “only” source of information on a particular topic.

In general, government-based (.gov) and university-based (.edu) websites are reliable sources of information. They are less likely to try and sell you something than commercial (.com) sites. Not-for-profit organizations (.org) also tend to be good sources, but it’s always a good idea to check who is funding the organization.

Other questions to consider when looking on a website are:

- Who’s checking the information? Reliable health websites will have an editorial or advisory board that reviews and approves the site's contents. The site should include the full names, credentials, and contact information for each member of the board.
- Where are the references? Medical claims and scientific information should always be supported by a reference from a scientific journal. (Think Lancet or The New England Journal of Medicine, not National Enquirer.) If the site is reference-free, there’s no way to check on the accuracy of the information.
- How current is the information? Since cancer research is always evolving, reliable sites will often update their content. The site will include a timestamp on every page with the date of the most recent update.

Forums, bulletin boards, and chat rooms are great places to share ideas and get support. Keep in mind, they may not be the best places to get medical information. Just because a treatment worked for one person on a cancer bulletin board doesn’t mean it will work for another.
How do I stay on track with my treatment plan?

Research has shown that treatment can give AYAs with cancer a good chance of living for a very long time. But getting there means sticking with the treatment plan—a task that many AYAs find difficult. Many AYAs can stray from their treatment plan at one time or another—whether it’s not taking medicine as prescribed, not showing up for treatment, or taking recreational drugs that can harm treatment effects.

Cancer treatment can be tough. But there are things you can do to make it easier to stick with your plan.

- **Take all of your medicine as prescribed.** That means taking it in the right amounts, at the right time. Skipping or delaying doses may change the drug’s effects. If you’re having trouble paying for your medicine, ask your treatment team for help. They may be able to refer you for financial aid or tell you about special drug company programs that help people who cannot afford cancer treatment.

- **Talk to your treatment team.** If you’re having trouble coping with the treatment plan, let them know. They can give you a hand with getting psychological, financial, and practical help for sticking with treatment while living your life.

- **Stick with your appointments.** Although your team will try to be flexible when timing your appointments, most cancer facilities have tight or full schedules. If you miss a scheduled appointment, it may not be possible to get a new one right away—which could delay treatment by days or longer.

- **Be honest.** Your treatment team can’t help you if they don’t know what’s going on.

Review

- Most patients go through several rounds of treatment to make sure the cancer is either gone or under control.

- Supportive care (also known as palliative care) is any treatment that relieves your symptoms and improves your quality of life.

- When treatment leads to remission (or no evidence of disease) you are now moving into follow-up care.

- Recurrence or relapse refers to cancer that shows up after the cancer has been in remission.

- Progression is when the cancer spreads or gets worse with no period of remission in between.

- Most cancer experts suggest completing an advance directive, to plan for end-of-life care, sooner rather than later.

- A treatment plan is a written course of action that covers every stage of the treatment process, from the first treatment onward.
Understanding your treatment options

YOU HAVE TO BE AN ACTIVE PARTICIPANT IN YOUR TREATMENT.

In my experience the best doctors are the busiest, so important details get lost in the process. However, the best doctors also make you feel like the captain of the ship. It’s too easy to forget that they’re working for you. Ask questions. Know your drugs. Research journals. Know the clinical trials. Close down your hospital’s medical library. Oh, and most importantly, find your social worker. There is nothing worse than realizing there was a better option for your care that you just didn’t know about.”

– Bret
Hodgkin Lymphoma Survivor
Age at diagnosis: 31
Learn about treatment options.

Part 5 goes over clinical trials for cancer treatment and commonly used treatments that may be offered to you. You can also get the facts about complementary and alternative therapies.

If you had been diagnosed with cancer a decade ago, your treatment options were less than they are today. Thanks to technical advances and research on how and why cancer develops, doctors can now prescribe many therapies that target cancer with greater accuracy than ever before. Understanding these therapies can help you work with your treatment team. You can make informed decisions about your treatment plan.

What are clinical trials?

A clinical trial is a type of research study that people chose to take part in. Clinical trials help learn how to prevent, diagnose, and treat a disease like cancer. Because of clinical trials, doctors find safe and helpful ways to improve your cancer care. This guide has many of those tests and treatments used to help young people with cancer.

Clinical trials go through levels or phases of testing. These phases help move the research along to find out what works best for people with cancer.

- Phase I looks at how much and how to give the treatment.
- Phase II tests for side effects and how it works on the cancer type.
- Phase III compares the treatment (or new use of treatment) to what is commonly used.
- Phase IV follows late side effects and if the treatment still works after a long period of time.
All clinical trials have a plan and are carefully led by your medical team. People in a clinical trial are often alike with their cancer type and general health. You can join a clinical trial when you meet certain terms (eligibility criteria).

If you decide to join a clinical trial, you will need to review and sign a paper called an informed consent form. This form describes the clinical trial in detail, including the benefits and risks. Even after you sign consent, you can stop taking part in a clinical trial at any time.

Some benefits:

- You’ll have access to the most current cancer care.
- You will be closely watched by your medical team.
- You may help other people with cancer.

Some risks:

- Like any test or treatment, there may be side effects.
- New tests or treatments may not work.
- You may have to visit the hospital more often.

Ask your doctor or nurse if a clinical trial may be an option for you. There may be clinical trials where you’re getting treatment or at other treatment centers nearby. You can also find clinical trials through the websites listed in Part 10, Resources.

The National Cancer Institute’s Cancer Information Service can also provide information on clinical trials. The service is available in English and Spanish, Monday through Friday 8:00 AM to 8:00 PM ET at 800.4.CANCeR (800.422.6237).

What are local treatments?

Local treatments remove or destroy individual tumors or cancerous tissues. This type of treatment can be surgery or radiation. It is aimed at treating a specific area and does not travel through the body.

Surgery

Surgery is a local form of treatment. It can be done in many ways depending on where the cancer is in the body. The type of doctor who performs surgery is called a surgeon. Surgery can be done alone for cancer treatment with a plan to cure the disease (remove it all) or take out a section (debulk) the cancer because the surgeon can’t remove the whole area. It can also be done to provide supportive care (relieve pain or discomfort).
Surgery can be:

- Open where the **surgeon** makes a large incision and takes out the tumor and some surrounding tissues or **lymph nodes**.
- Minimally invasive where small cuts are made rather than a large one. A thin, lighted scope (laparoscope) is inserted and the surgeon uses tools for the surgery.

Other surgery done before or after treatment:

- Restorative (or reconstructive) surgery to repair damage caused by other cancer treatments. The most familiar example of this kind of surgery is breast reconstruction, in which a surgeon restores the appearance of the breast after the removal of breast cancer.
- Preventive (or prophylactic) surgery to remove tissue that carries a high risk of becoming cancer, such as precancerous polyps in the colon. Preventive surgery can also be done for people with **genetic mutations** that put them at risk for certain cancers.
  - For example, a woman with cancer in one breast who has the gene mutation associated with a high risk for breast cancer may choose to have her healthy breast removed (prophylactic mastectomy).

Many techniques are used for surgery and can be talked about with a surgeon. Each surgery is carefully planned by your surgical team, which includes the surgeon, anesthesiologist, and nurses. A patient having surgery has a risk of infection and may experience pain. The medical team takes time to plan ahead and give support after surgery. Follow-up care is necessary for healing. You need to know when you can return to normal activities and your diet.

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**Radiation therapy**

**Radiation therapy** uses high-energy particles or rays to kill cancer **cells**. It can also damage the cells’ DNA so they can no longer grow or divide. Radiation is given over a certain period of time planned by the radiation treatment team. This type of treatment is given to cure cancer and as a supportive treatment to help ease discomfort or pain. It can also be given before, during, or after surgery to treat or slow the growth of cancer.

There are two main kinds of radiation treatment:

**External beam radiation** uses a machine outside of the body to aim radiation at the cancer. It is planned to treat a certain area of the body where cancer can be found.

**Internal radiation** is when radiation is placed inside the body as a solid like seeds or capsules, or it can be given in liquid form.

- The solid form is called brachytherapy and would be placed in a specific area in or around the cancer.
- The liquid radiation can be given through an IV (intravenous) into a vein to find cancer cells in the body. This would be a systemic form of treatment.

The **radiation oncologist** and other treatment staff take time to plan the treatment that is right for you. Even with planning, the radiation can harm healthy tissue near the cancer. **Side effects** like fatigue or skin irritation can happen.

Radiation is given at different doses and schedules. **External radiation** can be given once, for days, or even weeks, so planning time off from work or school is important. Any concern about the schedule or side effects can be discussed with your doctor before you start.
What are systemic treatments?

Systemic treatments are a big part of the cancer therapy world. They are drugs used to treat cancer. Some go after rapidly dividing cells in the body (chemotherapy), some zero in on particular characteristics of cancer cells (targeted therapy), and some recruit your body’s natural defenses to recognize and destroy cancer (immunotherapy).

Because systemic therapies go after cancer in many different ways, doctors will often use combinations of cancer drugs to get the biggest treatment effect. This increases the chances of getting rid of the cancer, but it also puts healthy cells at risk for damage. This damage can lead to side effects that may make it necessary to stop or delay treatment, or change the treatment approach.

Chemotherapy

Chemotherapy, or chemo, is a main systemic treatment. All chemotherapy drugs affect the genetic make-up that cells use to grow and divide. Some damage DNA directly; others get in the way of processes that help cancer cells build DNA.

This kind of treatment can be given in many ways depending on what the doctor prescribes. You can get it in cream form (topical), pill form, or a needle (injection). Most often chemotherapy drugs are given as liquids through:

- **IV (intravenous)** – thin device that goes right into the vein.
- **Catheter** – thin, long tube that is often placed in the chest. This goes into a large vein and stays there until treatment is done. Medical staff can also take blood from a catheter.
- **Port** – small, round disc that is usually placed in the chest where a catheter delivers the chemotherapy. Minor surgery is done to place the port and it stays in the body for days or weeks until treatment is complete.
- **Pump** – this is attached to a port or catheter and allows chemotherapy to be given outside of the hospital. The pump is set to give certain amounts of the drug at a time.

Chemotherapy is often given in cycles of treatment days followed by days of rest. These cycles vary in length depending on which drugs are used.

**Chart 3. Chemotherapy drugs**

<table>
<thead>
<tr>
<th>Drug Class</th>
<th>What They Do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alkylating agents</td>
<td>Damage DNA so cancer cells can’t multiply</td>
</tr>
<tr>
<td>Antimetabolites</td>
<td>Kill cancer cells by getting in the way of the “building blocks” of DNA</td>
</tr>
<tr>
<td>Anticancer antibiotics</td>
<td>Interfere with enzymes that help cancer cells build DNA</td>
</tr>
<tr>
<td>Plant alkaloids</td>
<td>Block mechanisms that help cancer cells to divide</td>
</tr>
</tbody>
</table>
For example, the cycles can be 14, 21, or 28 days long. These cycles, including days of rest, giving the body a chance to heal in between treatments.

**Immunotherapy**

The immune system usually does a pretty good job of defending your body against germs, viruses, and parasites (as well as the occasional grain of pollen). In theory, it should recognize cancer cells as abnormal and attack them in the same way. But cancer cells have ways of getting around the immune system’s defenses.

Immunotherapies are designed to boost immune activity. They help the immune system find and attack cancer cells. Many immunotherapies are now available and others are being studied to find new ways to fight cancer using our immune system. Here are a few examples of commonly used therapies:

- **Cytokines** (for example, interleukins or interferons) boosts the activity of normal proteins that control our immune system’s response to cancer.
- **Monoclonal antibodies**—called MABs—(for example, ipilimumab or rituximab) are man-made types of proteins that attach to the surface of cancer cells (kind of like a key fitting into a lock). Once MABs link up with the cancer cell, other immune cells are able to recognize and attack the cancer.
- **Cancer vaccines** (for example, Sipuleucel-T) act in the same way as vaccines do against the flu or chicken pox. They teach the immune system to recognize cancer cells so the immune system can defend itself against the cancer.

**Targeted therapy**

Unlike chemotherapies, which go after just about any fast-dividing cell, targeted therapies seek out how cancer cells grow, divide, and move in the body. Targeted therapies are usually grouped on the basis of what they do or the part of the cell they target.

- **Hormone modifiers** (for example, tamoxifen or anastrozole) block the making or the activity of estrogen. This is a hormone that some cancers of the breast and uterus need to survive.
- **Enzyme inhibitors and growth factor inhibitors** (for example, trastuzumab or erlotinib) block specific enzymes and growth factors that cancer cells need to grow and spread. These drugs may also be called small-molecule drugs or signal transduction inhibitors.
- **Apoptosis-inducing drugs** (for example, bortezomib or pralatrexate) change parts of the cancer cell that control survival and death, causing the cell to kill itself. Apoptosis is natural cell death.
- **Angiogenesis inhibitors** (for example, bevacizumab or sunitinib) target growth factors that allow cancer cells to build new blood vessels. This cuts off the tumor’s blood supply and basically starves it to death.
- **Antibody-drug conjugates** (for example, ibritumomab tiuxetan) are a combination of a MAB and a toxin or radioactive substance (radiopharmaceutical) that enters and kills the cell after the MAB latches on.

Because these drugs zero in on molecular targets found mostly in cancer cells, targeted therapies are less likely to damage healthy cells and cause side effects.
Some targeted therapies are given as pills and others must be given into a vein. Some IV medication can be given in the outpatient clinic, while others require admission to the hospital. Intravenous methods include:

- An IV push, in which the drug is injected quickly over a few minutes.
- An IV infusion that can last from 30 minutes to several hours. The medication flows through a tube that is attached to the catheter. The flow may be controlled by a machine called an IV pump.
- A continuous infusion that can last days. Continuous infusions are always controlled by electronic IV pumps.

Corticosteroids (for example, prednisone, prednisolone, methylprednisolone, and dexamethasone) are man-made versions of hormones made by the adrenal glands. The adrenal glands are small structures found just above the kidneys, which help regulate blood pressure and reduce inflammation. Corticosteroids are not the same thing as the steroids used by some athletes.

**A word on corticosteroids**

Corticosteroids can be given as a pill or a liquid. You can get it through an IV, cream, or by injection. They may be used as an anticancer treatment or most often in combination with chemotherapy. This medication also relieves side effects of treatment, such as:

- Nausea
- Swelling
- Allergic reactions
- Poor appetite

Corticosteroids can be very helpful, but they do have side effects like:

- Indigestion or heartburn
- Swollen hands, feet, or ankles
- Increased risk of infection
- Changes in blood sugar levels with high-dose or long-term treatment
- Changes in mood
- Difficulty sleeping

If your doctor gives you corticosteroids, be sure to take them exactly as prescribed.

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**How can I learn more about complementary and alternative medicine (CAM)?**

Even though they are often lumped together, complementary medicine and alternative medicine are not really the same thing.

- **Complementary therapies** are meant to be used alongside standard therapies, most often to prevent or reduce side effects. They can be helpful for dealing with side effects such as pain or nausea.
Alternative therapies are treatments and techniques that are used instead of standard treatments such as chemotherapy or radiation. Some medicine is sold as a cure even though it hasn’t been proven to work. If there was solid scientific proof that an alternative treatment or technique was effective against cancer, it would be included in this guideline.

It’s important to tell your treatment team if you are using—or thinking about using—any complementary treatments, especially nutritional supplements, vitamins, or herbs. These therapies can interfere with some cancer drugs. Your team can tell you which treatments might be helpful and which can be dangerous.

Review

- A clinical trial is a type of research that studies a test or treatment.
- Surgery is a local form a treatment.
- Radiation therapy uses high-energy particles or rays to kill cancer cells.
- Chemotherapy, or chemo, is a main systemic cancer treatment.
- Immune therapies are designed to boost immune activity.
- Targeted therapies seek out how cancer cells grow, divide, and move in the body.
- Complementary therapies are meant to be used alongside standard therapies.
- Alternative therapies are treatments and techniques that are used instead of standard treatments such as chemotherapy or radiation.
Coping with side effects

I REMEMBER FEELING CONSCIOUS AND FULLY AWARE OF EVERY SENSATION, every needle, every heartbeat, and every smile – the trauma of my situation was causing those I loved agony, and I remember thinking, “I’m still alive, I’m still alive, I’m still alive.”

– Ron
Acute Myeloid Leukemia Survivor
Age at diagnosis: 36
## Side effects can happen.

Part 6 talks about things you can do to cope with common side effects or prevent them from happening. As always, talk to your doctor or nurse if you need to know more about side effects.

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### Why do side effects happen?

Most side effects happen because healthy cells get damaged in the battle to rid your body of cancer. Radiation that kills cancer cells will also damage nearby normal cells. **Chemotherapy** drugs that attack fast-dividing cancer cells can also damage normal cells that divide rapidly.

Most side effects tend to be worst in the days right after treatment is given and get better once treatment is complete. But some damage does not heal when treatment is over, leading to long-term problems such as early **menopause** and infertility. There is a risk of later health problems, even some forms of **leukemia**. Since you may be living for many, many years after treatment is over, your doctor will carefully think about the risk of long-term side effects from treatment.

The side effects you’re likely to face will depend on your treatment plan. Some chemotherapies tend to cause more side effects than drugs designed to zero in on cancer cells, such as **targeted therapy** drugs and **immunotherapy** drugs. Higher doses may also cause more severe side effects.

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### Side effects are a fact of life when you’re being treated for cancer.

With some treatments, side effects are mild and don’t interfere much with day-to-day life. With others, side effects can make it hard to do much of anything—at least in the days right after treatment.

Fortunately, a better understanding of just why side effects happen has made it easier to prevent side effects and to treat such problems when they come up. Also, newer drugs and improved technology are making it easier to target cancer cells with less harm to healthy tissues. These new treatments can help prevent side effects from even happening.
How do I prevent or take care of my side effects?

Taking good care of yourself is the first and most important thing you can do to get ready for treatment. The healthier you are before and during treatment, the easier it will be to recover from unwanted side effects. So if you’re already fairly active and a fan of fruits, vegetables, and other healthy foods, you’ll want to continue those healthy habits.

Feed yourself well
Keeping yourself well-fed can help keep up your energy so you can bounce back when treatment is done. If your treatment team doesn’t already include a nutritionist or dietitian, ask for one. Then set up a meeting to work out a diet plan that includes your unique needs. Make a plan that fits:

▷ Your lifestyle that can include work, school, or other daily needs.
▷ Your living situation and if you need help cooking or food shopping.
▷ Your personal taste or liking for certain kinds of food and drinks.
▷ The types of side effects you’re likely to have.

Nutritional counseling is important because it’s likely everyone is going to have an opinion about what you should eat. But when it comes to cancer, the usual nutritional advice may not apply. If you’re dealing with nausea, mouth sores, or feel tired it’s good to keep up your energy and a healthy weight. This may mean eating lots of rich, high-calorie items and staying away from foods that are not good for you right now. So listen to your body, your doctors, and your dietitian or nutritionist and do what works for you.

Drink fluids
Your body is mostly made of water, and it needs a steady supply to function at its best. Getting enough fluids (staying hydrated) is even more important during cancer treatment. Side effects such as vomiting and diarrhea leave your body in need of fluids. Drinking plenty of fluids will also help prevent constipation (difficulty going to the bathroom), protect your bladder and kidneys from the damage of systemic therapy, and help flush out the chemical waste from your treatment.

Your treatment team can guide you on exactly how much fluids you should be drinking every day. The general rule is to get at least 64 ounces (2 liters) of noncaffeineated liquids every day. It is best to stick with noncaffeineated liquids but a little caffeine is okay. Keep in mind that it has dehydrating effects.

Keeping a water bottle with you at all times will make it easier to track how much you’re drinking during the day. Fluids can also come from other things listed below.

▷ Watermelon
▷ Ice pops or sherbets
▷ Sports drinks
▷ Juices
▷ Jell-O
▷ Soups or broths
▷ Fruit smoothies
▷ Caffeine-free herbal teas
▷ Caffeine-free sodas (like ginger ale)
There is now a great deal of research data linking regular alcohol intake to the risk for multiple forms of cancer. Based on research, both men and women are affected and advised to drink only small amounts of alcohol, or no alcohol at all. Regular drinking of alcohol has shown to increase the risk for cancers of the breast, esophagus, stomach, colon, rectum, liver, pancreas, lung, bladder, and kidney. All types of alcoholic beverages, including wine, can put someone at risk.

**Keep moving**

Staying active is one of the best ways to keep up your energy. Exercise can also help boost your appetite and help you sleep better at night. And you don’t need to be running in a marathon. Even a short walk can go a long way toward making you feel better.

Pay attention to your body. When your energy level is good, do something you already enjoy. Ask your treatment team about exercise programs available through the hospital or center where you are getting treatment. Many large cancer centers offer yoga and other exercise programs designed for people being treated for cancer.

**Get enough sleep**

Sleep gives your body and mind a chance to rest and recover from stress. As you may know, dealing with cancer and its treatment is pretty stressful, which can make sleep a challenge. Over time, missing sleep can mess with your mood, your relationships, and your day-to-day routine.

Your treatment team can help if you’re having trouble sleeping—and can even refer you to a sleep specialist if problems are keeping you up at night. There are also a few simple steps you can take that may make it easier to sleep:

- **Set a sleep schedule.** Many people find it easier to sleep when they go to bed and get up at around the same time every day.
- **Nap when you need to** but try to limit naps to less than an hour so you can still fall asleep at night.
- **Exercise during the day.** Improved sleep is just one of the many benefits of physical activity. Try to exercise at least three hours before bedtime so you’re not too revved up to sleep.
- **Relax in the evening.** Give yourself some time to wind down and relax before trying to sleep. Limit screen time. Take a bath. Listen to music. Read a good book. Do whatever works to slow you down.
6 Coping with side effects

How do I prevent or take care of my side effects?

Steer clear of caffeine and alcohol at the end of the day, both of which can make it more difficult to fall—and stay—asleep.

Make use of your team
Your treatment team has a wealth of experience and information. This is particularly true if you are being treated at a center that has an AYA cancer program. The program should have lots of resources to help you deal with the physical, emotional, and day-to-day challenges of cancer treatment.

Many cancer centers also have complementary or integrative medicine programs that offer acupuncture, hypnotherapy, reflexology, yoga, and other types of complementary therapy that can prevent or help you cope with side effects.

Your team will want to watch for the side effects you have, how severe they are, and how they affect your overall health and well-being. You may be asked to keep a diary tracking your side effects and things like your temperature or blood pressure. Be honest about what you’re feeling—this isn’t the time to put on a brave face or keep quiet about what is going on. If the side effects are too much or if they put you at risk for long-term problems, the team may consider changing your treatment plan or parts of it.

When dealing with treatment side effects, don’t be afraid to reach out to the unofficial members of your team—family and friends who want to lend a hand. If someone wants to pick up your groceries (or your homework, or your kids) when you’re tired and it’s hard to do much of anything, let them. If someone wants to make you a batch of homemade chicken soup or ginger cookies, let them. If someone wants to give you a lift to yoga class, let them. After all, you’d do the same if they needed help.

“ When I was diagnosed I thought the hardest part of cancer would be the actual having cancer part. Chemo and all its lovely side effects: the needles and constant invasion of my body, and losing my hair. What I didn’t realize is that the fight against cancer doesn’t end when your scans are clear, your port is removed, your hair grows back, and your scars heal. The fight against cancer rages on within. The emotional and mental wounds needed to heal as well. You just have to find your new normal and not punish yourself if it is different from before.”

- Ashley
Hodgkin Lymphoma Survivor
Age at diagnosis: 20
How do I cope with side effects?

There are some side effects that occur with many types of cancer treatment. Although a full list is beyond the scope of this book, the following pages offer tips for coping with some of the most common side effects.

Nausea and vomiting

Why it happens
The nausea and vomiting that happens during cancer treatment has more to do with your brain than with your stomach. Cancer treatment can wake up a section of the brain called the CTZ (chemoreceptor trigger zone), which helps the body recognize and get rid of toxic or dangerous substances. (If you’ve ever had food poisoning or felt queasy, you’ve experienced the CTZ in action.) Since most cancer treatments are toxic, they tend to trigger the CTZ.

What you can do
The basic rule of dealing with nausea is to stay ahead of it. It’s a lot easier to prevent vomiting than it is to stop vomiting once you’ve started. So be sure to let your treatment team know if you have nausea or vomiting right before treatment—a condition known as anticipatory nausea.

Medicine can be given to prevent the “puke now” signals from reaching the CTZ. This can include: ondansetron, granisetron, dolasetron, prochlorperazine, promethazine, metoclopramide, and aprepitant. When given before chemotherapy, they can prevent nausea for up to 24 hours.

Other medicine that can help prevent or ease nausea and vomiting include:

- Steroids such as dexamethasone
- Tranquilizers such as lorazepam
- Antihistamines such as diphenhydramine
- Antacids

If the medicine isn’t working, you might want to consider asking your doctor to prescribe medical marijuana. The active substance in marijuana—a chemical called THC (tetrahydrocannabinol)—can relieve nausea and get the appetite going.

There are also some natural and complementary therapies used to prevent and calm nausea and vomiting. They can be used with anti-nausea and vomiting medicine, including acupuncture and ginger root (as candy or tea). Staying well hydrated and eating frequent, small meals can also help.

Hair, skin, and nail changes

Why it happens
Because the cells of your hair follicles, skin, and nails divide quickly, they can be damaged by some chemotherapy drugs. In addition to the classic cancer side effect of hair loss (alopecia), cancer treatment can cause changes in the appearance of your nails and leave them weak and brittle. It can also cause skin problems such as dryness and, rarely, painful inflammation of the palms and soles of the feet called hand-foot syndrome.

What you can do
If your treatment can cause hair loss, you’ll want to make plans on how to deal with it before treatment starts. Some people find it helpful to shave their heads or cut their hair short. If you’d rather save as much of your hair for as long as possible, be gentle with it—baby shampoo, no harsh chemicals or blow drying.

Being gentle is equally important when caring for your nails and skin. As your nails may be much more likely to catch and tear, consider keeping them short and well-trimmed and steer clear of fake nails and tips.
Some basic skin care tips that can help:

- Use warm, not hot, water when bathing.
- Stick with mild, unscented soaps and moisturizers.
- Use soft washcloths rather than loofahs and pat yourself dry with soft towels.
- Keep your skin well moisturized with hypoallergenic, unscented, water-based products.
- Avoid using products with alcohol in them.
- Try a rich skin lubricant such as Bag Balm® or Udderly Smooth® right after bathing to help with severe dryness or hand-foot syndrome.
- Wear soft, loose clothing next to your skin to prevent the irritation of sensitive areas.

If you have severe skin reactions, your treatment team may try prescription drugs or creams. They can also change the treatment schedule to give your skin time to recover.

For more information on hair loss, skin care, and other appearance-related issues, check out:

- Wigs for Cancer Patients at the Cancer and Careers Website at www.cancerandcareers.org/en/at-work/Managing-Treatment-Side-Effects/Wigs-for-Cancer-Patients
- The American Cancer Society’s “tlc”™ Tender Loving Care catalog at www.tlcdirect.org
- Look Good Feel Better at www.lookgoodfeelbetter.org

**Mucositis and stomatitis**

**Why it happens**

The tube-like organs that go from your mouth right through to the other end is called the GI tract (gastrointestinal tract). It is lined with cells that are always dividing and replacing themselves, which makes them likely to being damaged by chemotherapy. Cancer treatment can lead the GI tract to become inflamed (mucositis)—often with pain and diarrhea—and sores in the mouth (oral mucositis or stomatitis).

**What you can do**

Be kind to your mouth and the rest of your GI tract. Keep your mouth clean and wet. Avoid products and foods that can irritate the mouth and open sores.

- Suck on ice chips or ice pops (not citrus) before and during chemotherapy to help prevent oral mucositis from developing.
- Switch to a soft toothbrush, and brush your teeth after every meal. If your mouth is very sensitive, try a sponge-tipped swab.
- Avoid products that contain alcohol that can irritate and dry your mouth.
Try a specialty toothpaste—such as Biotene®—that does not contain sodium lauryl sulfate.

Rinse your mouth regularly with a special mouthwash (such as Biotene®) or mix baking soda and warm water to make a rinse.

Stay away from spicy or acidic foods (such as chili and lemonade).

If you’re experiencing diarrhea, be sure to get more fluids to make up for what you’re losing. To prevent diarrhea, try the following:

- Eat several small meals a day.
- Have easy-to-digest foods such as bananas, white rice, and applesauce.
- Avoid high-fiber foods such as whole grains or raw fruits and vegetables, and gassy foods like broccoli.
- Avoid spicy, fried, greasy, or rich foods, like dairy products.

Let your treatment team know if you have more bowel movements than usual or severe diarrhea for two or more days in a row. If you become dehydrated, you may need fluids given by IV.

**Fatigue**

**Why it happens**

Fatigue can be the result of many things. It can be from the treatment’s effects on the red blood cells that carry oxygen to your tissue (anemia), side effects of other medicine, pain, dehydration, stress, sleeplessness, your diet, or any combination of the above. If you have fatigue, you may find that it is worse right after treatment.

**What you can do**

How your fatigue is managed will depend on what is causing it. If you have anemia, you may get a transfusion of red blood cells. If your fatigue can be traced to factors such as pain, sleeplessness, or diet you may be referred to specialists in those areas.

Pay attention to when fatigue tends to start and take it easy. If you tend to feel wiped out the days following treatment, avoid doing too much during those times. When you do have energy, take your time doing things. Feel free to change or cancel plans if you’re just not up to it.
Infection and low white blood cells

**Why it happens**
Cancer itself and cancer treatment can put you at risk for infection by lowering the number of white blood cells (neutrophils). A severe drop in the neutrophils is known as neutropenia. These white blood cells help you fight infection. An infection is caused by germs like bacteria, viruses, or fungi that enter the body and grow out of control. Other things like lack of sleep, stress, and poor diet can also lower your immune system’s ability to fight an infection.

**What you can do**
Be aware of what your body is feeling. Frustrating though it may be, you really need to protect yourself from germs that your system just isn’t ready to fight. After all, the last thing you need while battling cancer is a severe case of the flu. Below are things you can do to protect yourself.

- Buy a good thermometer. Taking your temperature can help find infections before they get serious.
- When your counts are at their lowest, stay away from young children or sick people. Tell people to be extra careful about hand washing and covering their sneezes and coughs around you.
- Wash your hands. Carry hand sanitizer and try to use it whenever you touch certain surfaces like doorknobs. You may want to avoid shaking people’s hands.
- Avoid salad bars and buffets.
- Ask friends and family to stay away if they’re feeling sick, or if they’ve been around a sick person.
- If your white blood cell count is low, ask your doctor if you should stay home from work or school. If you can’t stay home, be sure to wash your hands often.
- Get a flu shot every Fall. Talk about when you should get the shot with your treatment team.

Nerve damage (neuropathy)

**Why it happens**
Many common chemotherapy drugs can cause damage to nerve cells that affect normal nerve signals (neuropathy). Peripheral neuropathy affects the hands and feet and can begin as sensitivity to cold, pain, burning, and numbness. It is also said to cause that feeling of “pins and needles.”

Neuropathy can also affect nerves in the ear, leading to hearing loss, ringing in the ears, and problems with balance and coordination. Central neuropathy can cause problems with concentration and memory that are common in people receiving chemotherapy (chemobrain).

Neuropathy usually stops once treatment is over, but sometimes the neuropathy does not go away. Your treatment team will want watch for these side effects very closely.

**What you can do**
Your treatment team may try to limit your risk by reducing or skipping one or more doses of a cancer drug that cause neuropathy.

If you have neuropathy, there is medicine and complementary therapies you can use:

- Doctors can prescribe medicine like gabapentin—a drug to prevent convulsions—can ease the symptoms of peripheral neuropathy.
- Antidepressants such as amitriptyline and venlafaxine can alter the level of brain chemicals that control pain signals.
- Over-the-counter pain relievers such as acetaminophen and ibuprofen can relieve the pain of neuropathy.
- Things like acupuncture, massage, and physical therapy can help as well.
Review

- Most side effects happen because healthy cells get damaged in the battle to rid your body of cancer.
- Newer drugs and improved technology are making it easier to target cancer cells with less harm to healthy tissues.
- Keep yourself well-fed. Your treatment team should include a nutritionist or dietitian.
- Getting enough fluids (staying hydrated) is even more important during cancer treatment.
- Staying active is one of the best ways to keep up your energy.
- Your team will want to watch for side effects you have, how severe they are, and how they affect your overall health and well-being.
Living your life

“BE YOUR OWN ADVOCATE.”

Do your research. Talk to someone who has gone through the same thing as you. Ask a lot of questions, even the ones you are afraid to ask. You have to protect yourself and ensure you make the best decisions for you, and get the best care for your particular situation.”

– Anjali
Papillary Thyroid Carcinoma Survivor
Age at diagnosis: 27
Life can change when you have cancer.

Part 7 talks about life with cancer and how it affects your loved ones. You can find ways to deal with the day-to-day living and ask for help. Financial challenges may also come up, so here you will find resources you can use.

For the next year or more, a lot of your time is going to be focused on cancer. The plans you made before your diagnosis can change. You will have tests, treatments, insurance issues, and try to hold it together. This doesn’t mean that you have to do it alone. You can get support and do some planning to keep things moving forward.

What happens now that I have cancer?

Coping with moving back home
If getting cancer also means moving back in with your parents or other family members, the shock of your diagnosis may be mixed with a lot of other feelings. You may feel frustration at losing your independence or relief to be back where you grew up. It can be a strange mix of feelings.

Although the love and support of your family can be at the top of your list, it’s important that they—and you—know that you have the final decision when it comes to treatment. Parents and other family members can help you with research, support you during doctor visits, and offer their opinions. But you have the right to lead the way or decide to let others do this for you.

Maintaining a sense of control
A cancer diagnosis and treatment can lead to feelings of fear and loss of control. You can do things to help maintain a sense of control after a cancer diagnosis.

- Get organized. You’ll be dealing with a LOT of paper and information on your cancer journey.
7   Living your life

Staying on top of it from the very start can save you from feeling overwhelmed and help maintain a sense of control.

- Maintain a sense of independence. It may be an adjustment to spend more time at home, especially if you haven’t lived at home for a while or if you have mixed feelings about being home. If possible, try to create an environment and a routine that is comfortable for you.
- Set your priorities. This is a good time to think about what’s really important to you and where you want to put your time and energy. What gives you satisfaction? Makes you happy? Makes you laugh? Is there anything you’ve always wanted to do, but haven’t because you were always on the go? Make these things a priority as you plan the days, weeks, and months ahead.
- Set some goals. Although your plans for the future can change because you’re being treated for cancer it is possible, and important, to set goals for yourself. Try setting some short-term goals that you can work toward during the treatment phase. Whether it is writing in your journal every day, watching your favorite show, or reading that book that everyone’s been talking about.

Dealing with doubts

No matter how good you are at trying to stay positive, there will be moments when doubts creep in and you find yourself losing faith. When this happens:

- Give yourself permission to have negative thoughts and feelings. Cancer stinks. You have every right to feel scared or angry.
- Talk about it. Keeping negative feelings inside may not be good for you. Let friends and family know when you’re feeling down or scared. If you don’t want to talk about how you feel, you can try other things like writing in a journal, listening to music, or exercising.
- Work with a professional. If doubts and fears become difficult to manage, reach out to a social worker or psychologist. They can help you work find ways to cope. If you’d prefer, you can also talk to a minister, rabbi, or other clergyperson you trust. Your treatment team can also refer you to a psychiatrist if you feel that it will be helpful.
- Connect with others who are in the same situation. There are some things only another person with cancer can really understand. If your hospital or community doesn’t have support groups for young adults with cancer, check out the online communities like Stupid Cancer at www.stupidcancer.org. For more one-on-one support, try Imerman Angels at www.imermanangels.org. This organization matches and pairs you with a person touched by cancer (a cancer fighter or survivor) with someone who has fought and survived the same type of cancer.

The Cancer101 website offers a planner that can get you started. It includes sections for test results, insurance information, symptom tracking, appointments, and more. You can order the planner at www.Cancer101.org or by calling 646.638.2202.
Hanging out with friends...  
Having a social life can be difficult while being treated for cancer. Some of your relationships with friends can grow stronger, while others may be challenged. Take time to decide what is right for you when it comes to your social life.

- **Tell your friends what they need to know.** Share whatever information will help friends understand your new needs and limits. Let them help you out if you are feeling sick or down.
- **Keep your plans flexible.** It may be hard to know how you’ll be feeling from one day to the next. Let friends know that all plans are based on how you’re feeling on any given day.
- **Be selective.** When your energy is limited, it makes sense to spend it on events and activities that you feel up to doing.
- **Expand your horizons.** Consider putting stress-reducing activities into your social life. Ask friends to join you for yoga class and brunch instead of a night out.
- **Don’t be afraid to change your mind.** It’s better to opt out of a planned activity than to push yourself when you’re not feeling well.
- **Be aware of your risks.** If your treatment plan includes drugs that suppress your immune system, you’ll want to avoid large group situations that can expose you to germs. Be sure to check with your doctor on when you may be able to participate in large group activities.
- **Think before you drink or smoke.** Alcohol and other drugs may interact with your cancer treatment and cause serious side effects. Be sure to talk to your treatment team about whether—or how much—alcohol is safe for you, and about the risks of other recreational drugs. Keep your treatment team informed of how much you are drinking, smoking, or using.

Helping those around you know what to do  
Lori Hope’s *Help Me Live: 20 Things People with Cancer Want You to Know* (Berkeley, CA: Celestial Arts, 2011) is a terrific resource for friends who aren’t sure what to say—or do—to help.
Will my relationships change?

Friends and family can react to a cancer diagnosis in different ways. Some find the perfect balance of support and normalcy. Others are unsure of what to say and may distance themselves from you. Still others can become very focused on helping you each step of the way.

Navigating your relationships with friends and family members requires a mix of honesty, patience, and self-protection. You might feel like you are telling the same story over and over again. To let people know what is going on, consider one or all of the following options:

➤ Ask a friend or family member to serve as information central, keeping people updated on your condition, and fielding questions and messages, so you don’t get overwhelmed.
➤ Start a blog. The website www.familypatient.com or www.carepages.com is a free service that you or your information central person can use to post updates on your health.
➤ Use e-mail or social media to send messages on how you’re doing and what you need.

*An important note of caution: what you post online or through social media may exist on the internet indefinitely. Be mindful about what you post now and how you may feel about this information in the future.

Talking with your partner

If you’re married or in a relationship, it’s important to be open with your partner about the details of your treatment plan and its likely effect on your sex life. Side effects of treatment such as fatigue, vaginal dryness, hair loss, skin problems, and scarring can sometimes make sex stressful and downright painful.

Before you begin treatment, sit down with your partner and your doctor to discuss what side effects you can expect. It’s good to think about the side effects and the impact on your sexuality.

Talk to your doctor about your sexual health to find out if there is anything that can be done to help. As you go through treatment, be honest with your partner about what you are going through physically and emotionally. Even if sexual intercourse is not possible, you can maintain your physical intimacy by continuing to caress, hold, and kiss one another.

Talking with children

If you’re a parent, telling your children about your cancer can be one of the most challenging things about the disease. It may be tempting to put on a brave face and try to protect them from the news. But kids are very aware, and they’re likely to know that something is wrong whether you tell them or not.

Books that can help


7 Living your life

Will my daily life change?

There's plenty of information out there on how to talk to children about cancer and help them cope with a parent’s illness. The website Telling Kids About Cancer at www.tellingkidsaboutcancer.com offers a wealth of age-appropriate tips and resources for parents. Some helpful tips for talking with children:

- Use age-appropriate language.
- Be honest and accurate in describing your illness. Call cancer by its name.
- Tell your child that the cancer is not contagious and that he or she did not cause your illness.
- Explain what kind of treatment you will be receiving and the side effects you may have.
- Reassure your child that he or she will be taken care of no matter what happens, and that you and other family members are there to listen and to answer any questions.

If you need more guidance on talking to your children about cancer, seek help from a social worker. They can also refer you to local support services. You can also reach out to Cancer Care, an organization where oncology social workers provide free counseling and referrals for assistance. You can visit the website at www.cancercare.org or call 800.813.HOPE (4673) for more information.

Will my daily life change?

If you’re living on your own or caring for a family, managing your home life and treatment can be a struggle. Staying on top of things like laundry, cleaning the bathroom, or grocery shopping gets hard when you have side effects. This is an excellent time to accept any offers from others that want to help you.

If friends and family members want to rally to your aid, suggest that they check out the My Lifeline at www.mylifeline.org or Lotsa Helping Hands at www.lotsahelpinghands.com. These free services are designed to help friends and family organize support efforts. They include features such as a help calendar to schedule and sign up for specific support activities for things like shopping or appointments, as well as a message board for sharing information.

Being in school

The combination of cancer and the social part of school can be challenging. In addition to constantly being exposed to the germs in classrooms, locker rooms, and shared bathrooms, side effects like fatigue and chemobrain can make it harder to keep up with your school work.

No matter how much you may want to keep your condition quiet, it’s good to let your teachers/professors and school counselor know what is going on. Have a talk with each teacher soon after your diagnosis and at the beginning of each semester. Let them know about the side effects you’re likely to experience and how they may affect your ability to attend class or meet deadlines. Discuss how—and when—you should request more time to do your work, if needed.

Working during treatment

Since cancer treatment can last for months to years, you might be working while you are being treated. You may want make time to talk with your boss before treatment begins. Get a clear understanding of your company’s policies on things like flex time, telecommuting, qualifying for Family Medical Leave Act benefits, and short- and long-term disability.

If you have other questions, check out Cancer and Careers at www.cancerandcareers.org, a one-stop-shop for all things cancer- and work-related. This site aims to stop the fear and uncertainty for working people with cancer. It has expert advice on everything from selecting a wig to disability law. The site has
interactive tools and educational events on how people with cancer can thrive in the workplace.

Start preparing your workplace as soon as you know your treatment plan and its likely side effects. Ensure that your chair is comfortable, and that you have a place to keep snacks, drinks, and other supplies for relieving side effects such as dry mouth and nausea.

You may also want to prepare your coworkers. Let close colleagues know how treatment may be affecting your work schedule, and keep them updated on your needs and limitations as treatment progresses.

What are the financial challenges?

Financial problems are unfortunate and can happen to AYAs with cancer. You may face financial stresses such as unemployment or lack of health insurance. In addition, medical co-pays can add up. The cost of transportation to and from the hospital, as well as lodging, can also add to your bills. Talk with your team’s social worker, patient navigators, and hospital financial services about getting financial support.

An excellent source of support and information is the not-for-profit Patient Advocate Foundation. This Foundation provides professional case managers who serve as advocates for patients dealing with insurance companies, employers, and/or creditors. To contact a case manager go to www.patientadvocate.org or call 800.532.5274.

Pharmaceutical companies often have patient assistance programs, which provide free or discounted medications to patients in financial need. Search online databases at Rx Assist at www.rxassist.org/patients or Needy Meds at www.needymeds.org.

Other sources for help with medication costs include:

- The Patient Access Network Foundation at www.panfoundation.org or 866.316.7263. This foundation provides help to underinsured patients for out-of-pocket expenses for life-saving medication. Patients must complete an application and meet certain insurance and income criteria to qualify for aid.
- The Patient Advocate Foundation’s Co-Pay Relief Program at www.copays.org provides direct financial support for pharmaceutical co-payments to insured patients who financially and medically qualify.
- NCCN hosts a Virtual Reimbursement Resource Room at www.nccn.org/reimbursement_resource_room/default.aspx. You can download a free reimbursement app or resource guide that lists reimbursement or payment assistance programs.
Review

- Navigating your relationships with friends and family members requires a mix of honesty, patience, and self-protection.
- Talk to your partner and children about your cancer diagnosis and treatment plan.
- You can find services that help with financial stresses such as unemployment, inadequate health insurance, and other added costs.
- Communication with your friends, family, and treatment team is key to get help with the life changes you experience.
Moving beyond treatment

“ALTHOUGH FIGHTING CANCER HAS PHYSICALLY AND EMOTIONALLY BEEN THE HARDEST EXPERIENCE OF MY LIFE, I am so thankful for the new perspective I have because of it. Now that I have beaten cancer, I feel as though I can face all other life obstacles with more confidence and with the knowledge that I am strong and capable of anything.”

– Courtney
Non-Hodgkin's Lymphoma Survivor
Age at diagnosis: 22
Getting back to a normal routine after treatment takes time.

Part 8 gives you information on going from treatment to survivorship care. Life can change, but it is good to prepare for your next steps and focus on your health.

Finishing treatment is a major milestone in your cancer journey. It’s a time to say goodbye to the cycle of treatments and get back to normal or make a new routine. But the “normal” of post-treatment life may not be the same as life before your diagnosis. Things can change, so it’s helpful to find a routine that works for you.

Some people have described survivorship as “being disease free, but not free of disease.” As a cancer survivor, you have a new perspective, new worries, and new strengths that will influence every day of your life. Adjusting to this “new normal” isn’t always easy. Preparation and planning can help you make the most of this next phase of the journey.

You will hear the term cancer survivor, a lot during your journey. This section refers to the time after treatment. In this phase you will be in follow-up care. This care centers on checking your health at certain time points like months or years after treatment. These time points can be found in the NCCN clinical guidelines for the treatment of specific cancers at www.nccn.org.

What happens after treatment?

During treatment, your treatment team, family, and friends were likely a main source of information and support. You’ll still need many of these supports as you continue along the road of cancer survivorship.

After months of spending a lot of time with various medical people, you may want to take a break from doctors’ visits. That is understandable, but regular follow-up is critical to protecting your long-term health. Your doctor will probably want to check for a cancer recurrence and other medical problems every 1–3 months for the first year or so. If all goes well, it may change to once a year.
Follow-up is important because treatment-induced damage can cause health problems that last long after treatment is over. Survivorship may include things like:

- Pain
- Dry mouth
- Difficulty swallowing
- Difficulties with memory or concentration
- Neuropathy (pain/numbness in hands and feet)
- Lymphedema (swelling in arms or legs)
- Menopause symptoms (hot flashes, sleep difficulties, mood swings, or vaginal dryness)

In addition, many cancer treatments have been linked to late effects that may not become obvious until years after you’ve finished treatment. This can include:

- Secondary cancers
- Heart problems
- Lung problems
- Hearing problems
- Cataracts
- Stroke
- Kidney problems
- Osteoporosis

Cancer leaves its mark in other ways, as well. You may find that you have worries or doubts about the future. You may also have concerns about school, work, and your relationships. Dealing with these effects will take time, patience, and plenty of support. So instead of a cancer treatment team, you will now need a cancer survivorship team.

To prepare, you’ll want to make sure you have all your medical information as well as access to doctors, therapists, and other professionals who can be part of your survivorship team. To begin, make sure you have complete records of your overall medical history. This will include:

- Your family medical history.
- All vaccinations and immunizations you have had.
- Any past injuries or surgeries—including details on the treatment and results.
- Information on any ongoing health problems you have other than cancer, including dental issues.
- A complete list of all medications you are currently taking, including over-the-counter drugs. The list should specify drug names, doses, and the name of the prescribing doctor.
- Notes about any side effects or reactions you have had to medication or medical treatments.
- History of pain problems including treatments and results.
- Information about specific cancer treatments and side effects.
- A list of allergies and sensitivities.

Step two is getting a summary of everything that was done during your cancer treatment, including:

- A record of diagnostic tests and their results.
- The specifics of your diagnosis, including the type and location of the cancer, stage, grade, hormonal status, and markers.
- History of your cancer treatments and hospital stays including dates, cancer drugs given, doses used, treatment response, and any reactions or side effects.
- Records of any other health care services you received such as physical therapy, psychosocial counseling, and nutritional services.
- Names and contact information for all health professionals involved in your treatment.
This summary of information can be used to develop a survivorship care plan for the days, months, and years ahead.

What is a survivorship care plan?

The goal of a treatment plan is to completely get rid of or control the cancer. The goals of a survivorship care plan are different. There are 3 areas in the plan.

- **Supportive care** (palliation or relief) of any ongoing symptoms or side effects.
- **Prevention** of late effects of cancer treatment, including secondary cancers.
- **Promotion** of overall good health and well-being.

The U.S. Institute of Medicine has recommended that all cancer patients be given a survivorship care plan. This plan should spell out who you will be seeing to monitor your health, when you should be seeing them, and what they should be doing. Essential components of such a plan include:

- A summary of your cancer treatment history. This will ensure that other doctors you work with have a complete understanding of your case. **See page 67.**
- Detailed recommendations for follow-up care, which include:
  - Names and contact information for follow-up doctors.
  - A schedule for follow-up visits with an oncology specialist.
  - Tests that should be done to check for recurrence like blood tests, imaging tests, and an echocardiogram to check your heart.
  - Recommendations for identifying and managing long-term and late effects.
- Information on available resources that can help you deal with survivorship challenges like:
  - Physical problems
  - Psychological and emotional stress
  - Financial concerns
  - Insurance issues

For more on long-term and late effects of cancer treatment, check out:

- Cancer.Net’s “Late Effects” at [www.cancer.net/survivorship/late-effects](http://www.cancer.net/survivorship/late-effects).

Ideally, your treatment team will take the lead in putting together a survivorship care plan before you’re even finished with treatment. If you want to start your plan, the LIVESTRONG Foundation has partnered with OncoLink (from Penn Medicine) to provide the LIVESTRONG Care Plan at [www.livestrongcareplan.org](http://www.livestrongcareplan.org). This interactive website uses your answers to a brief questionnaire to create a basic individualized care plan. The resulting care plan can then be shared with your oncology team and used as a start for putting together your survivorship care plan.
Many large cancer centers offer survivorship programs to help people make the transition from patient to survivor. If your treatment center is one of them, take advantage of as many survivorship resources as possible.

**Life changes**
Being a cancer survivor can add new layers of complexity to your personal life and relationships. You may question who to tell about your history, how much they need to know, and when you should tell them. People may not realize how long it can take to recover from the effects of cancer treatment. Survivors may take on too much. Friends and family may not realize their support is still needed. Romantic partners may have trouble adjusting to sex after cancer.

Surviving cancer can also give you a whole new point of view on life and what you want from it. You may find new ways to take advantage of what life brings your way or set new goals for your future.

**At school**
Problems with concentration and memory can make it hard to get back to your school life. If you continue to experience chemobrain, try cutting back on your course load and scheduling more time to study and to complete assignments. If any treatment-related side effects are making it hard to keep up, let your doctors know.

Neuropsychological testing can identify your limits, and your doctors can work with your school to create a plan to help with them as much as possible. You can also talk with your teachers/professors or school counselor about changing your schedule and adjusting deadlines.

If you’re facing financial challenges, consider applying for some of the many scholarships and grants that are available to students who are cancer survivors. Learn about the SAMFund Support for Young Adult Cancer Survivors at [www.thesamfund.org](http://www.thesamfund.org). You can find a list of cancer-related scholarships on the website FinAid! The SmartStudent Guide to Financial Aid™ at [www.finaid.org/scholarships/cancer.phtml](http://www.finaid.org/scholarships/cancer.phtml).

**At work**
Cancer survivors can still be productive in the work place. You may worry about what others think of you returning to work. It’s even possible that you have some concern about how you’ll cope when going back to full-time work.

If you were able to keep working during your treatment, the transition may come easily. If you’re moving into a new job or will be working with people who don’t know about your illness, keep in mind that you have no legal obligation to talk about your cancer history unless it directly affects your work.
If you feel that letting coworkers know you are recovering from cancer treatment will be helpful, tell them. The choice is up to you.

That being said, you can talk to your employer if you need to adjust things at work because of ongoing side effects. Under Federal law, employers are required to make reasonable accommodation to help you do your job during or after cancer treatment. Reasonable accommodation is loosely defined as changes in work arrangements (schedule, office location, etc.) that will allow a qualified person to continue to do his or her job without causing a significant hardship for the employer.

**In your relationship**

Sex has a way of falling by the wayside when you’re being treated for cancer. Sexual side effects such as reduced libido (interest in sex), vaginal dryness, and difficulties getting or maintaining an erection can happen. Physical effects such as hair loss or scarring can leave cancer patients feeling damaged and undesirable. So even if you have a supportive partner, it may take a little time to re-create a comfortable sexual intimacy once treatment is over. And if you’re single, re-entering the dating world can feel overwhelming.

Getting back in touch with your sexual self is a process. Physical problems can often be helped with medication. Emotional barriers such as fragile self-esteem can be overcome by being open and honest with your partner so you can both work through your concerns about sex after treatment.

If you’re currently single, try not to put too much pressure on yourself to date. Give yourself space and time to figure out what you want in a relationship. When you do start dating, wait until you have a sense of trust and connection with the other person before telling him or her about your cancer.

For more information on laws related to survivorship and the workplace:


Both sites include a wealth of information on getting back to work after cancer treatment. You will also find current information on legal and insurance issues.

For more on sexual issues during survivorship:


Late effects on fertility
Many cancer treatments damage cells in the testicles and ovaries and can lead to problems with fertility. In men, treatment-related infertility is often temporary. That is rarely the case with women. In fact, women may develop premature ovarian failure months or years after treatment is over.

These uncertainties make it important that you get regular checkups to determine if you are still fertile, and that you use birth control if you don’t want a child in the near future. If you’re a woman and are still having periods, you may want to ask your doctor whether the treatment you received is associated with an increased risk of delayed premature failure. See Part 3.

Will the cancer come back?
Sometimes a few cancer cells manage to survive despite everyone’s best efforts to destroy them. Over time, these cells can divide and spread, leading to a return (recurrence) of the cancer. Recurrences can happen in:

- The same place as the original cancer (local recurrence).
- The same general area as the original cancer (regional recurrence).
- A completely different part of the body (distant recurrence or metastasis).

Recurrences are scary and frustrating but you do have options. Advances in cancer treatment have made it possible to cure many local and regional recurrences, and even a distant recurrence can sometimes be successfully treated or kept in check for years. The exact treatment for the recurrence will be based on the same factors that were considered after your first diagnosis, including clinical trials.

Give yourself permission to express your feelings and reach out for help. Above all, use your valuable time and energy to move forward not backward. This time around you have quite a few advantages that you didn’t have when you first were diagnosed.

- You know more. The first time out, everything was a surprise. Now, you have experience.
- You’ve built relationships. If you’re being seen by the same treatment team, you also have the advantage of working with people you already know and trust.
- You know what works for you. Instead of trial and error, you can draw on your first experience when making decisions about dealing with side effects, planning your life, and making use of support services.

Use the lessons learned during your first round of cancer to help with decision making and take control of the situation.

For more on navigating life after treatment, check out:


- Written by psychologist and cancer survivor Michael Feuerstein and social worker Patricia Findley, *The Cancer Survivor’s Guide* offers 7 distinct steps to help survivors chart the course of their post-treatment life.
Review

- Finishing treatment is a major milestone in your cancer journey.
- Regular follow-up is critical to protecting your long-term health.
- Instead of a cancer treatment team, you will now need a cancer survivorship team.
- The U.S. Institute of Medicine has recommended that all cancer patients be given a survivorship care plan.
- Being a cancer survivor can add new layers of complexity to your personal life and relationships.
- You may worry the cancer will come back and you will have to start over with treatment.
Thinking about the unthinkable

"When you have cancer, you experience many different emotions and feelings. But there are two that you will never forget: The feeling you have when you were first diagnosed and the feeling you have when you decided to become your own hero."

- Jessica
Hodgkin Lymphoma Survivor
Age at diagnosis: 27
Part 9 looks at advance care planning and preparing your loved ones to cope with the possibility of advanced cancer or even death. Hospice care for incurable disease is all about the quality of life.

Most people with cancer go into treatment determined to “beat this thing.” And lots of them do—at any given time there are millions of cancer survivors in the U.S. alone. But sometimes beating cancer isn’t an option. When cancer is diagnosed very late or keeps progressing despite all treatment efforts, it may be time to set some new goals. If it becomes clear that cure is not possible, treatment becomes about making the most of your time and assuring that you can meet death on your own terms.

What is advance care planning?

Advance care planning is all about making sure that your wishes are understood and respected. The focus is on you receiving the best possible care at the end of your life. Patients with incurable cancer can set up an advance care plan early on to be prepared to cope with their condition and the paths it can take.

The advance care planning process starts with an open and honest discussion with your doctor about your prognosis—what you may experience in the coming months—and the medications or therapies that may give you the best quality of life. This discussion should include your partner and/or other family members who love you and are likely to be with you at the end. It’s important that everyone understand the goals of your care and your personal wishes about what should—and should not—be done.

Once you’ve made these decisions, you will fill out a legal document that lays out what you want done if you aren’t able to tell the doctors yourself. This document is called an advance directive.
Doctors are required to follow the care instructions in an advance directive when you are too ill to give instructions about your care.

- The advance directive will include information on how much you want your doctors to do if your heart or lungs stop working or if you are no longer able to eat.
- Many advance directives include DNAR (Do Not Attempt Resuscitation) or DNI (Do Not Intubate) orders, which do not allow medical providers to revive you with CPR (cardiopulmonary resuscitation) or hook you up to a breathing machine.
- It will be important to keep your advance directive on hand because without these papers, health care providers are legally required to do everything possible to keep your heart beating and lungs breathing.

Make sure everyone on your team—and in your family—knows about your advance directive and its contents.

This doesn’t mean that you have to choose not to attempt resuscitation. The advance directive should reflect your wishes—not what you think your parents or partner would want. And keep in mind that the advance directive isn’t written in stone. If your thoughts on feeding tubes or respirators change, you can always make changes.

Your advance directive should also identify a person who is authorized to make decisions on your behalf (health care proxy) if you can’t communicate. This person may one day have to make some very tough decisions, so you should think carefully when selecting your proxy.

Researchers from the National Institutes of Health developed the Voice My Choices: A Planning Guide for Adolescents & Young Adults at www.agingwithdignity.org/voicing-my-choices.php. This is a simple but complete template for laying out your end-of-life wishes. You can find forms for selecting your health care proxy and your instructions regarding life support and resuscitation.

In addition to making plans about your care, organizing your personal and financial affairs can lessen the burden on family and friends when you are gone. This leaves you free to focus on other things in the time you have left.

- Clear up any insurance questions. Find out which end-of-life services your provider will cover and clarify any limitations in the coverage (such as a cap on the number of visits by a nurse or health aide).
- Organize your financial records like bank accounts, insurance policies, and mortgage to make sure your family knows where everything is. The National Cancer Institute’s book, Coping with Advanced Cancer at www.cancer.gov/cancertopics/coping/advancedcancer.pdf has a detailed worksheet you can use.
- Think about making the arrangements for a funeral or memorial service in advance.
What can I do to cope when time is limited?

Realizing that your time on this earth is limited can be hard to accept. You may feel devastated yet free at the same time. Some patients with incurable cancer note that the loss of the future can give back the present, letting you to focus on activities that bring you the most joy and satisfaction.

Use the times when you are feeling well to pursue the hopes and dreams that are still within your reach. Enjoy the company of the people you love and build positive memories that will last when you are gone. Some people use this time to prepare something special that they can leave behind for their loved ones by:

- Organizing and labeling family photos
- Putting together a family tree
- Writing letters to loved ones
- Giving meaningful objects to people they care about
- Gathering favorite recipes into a cookbook

These kinds of activities are particularly helpful if you have young children. Creating a video diary or journal will allow you to share meaningful messages with your child even if you cannot physically be there.

This can also be a time to reflect and work through painful emotions for those people you love and are leaving behind. If your treatment center doesn’t have an end-of-life program, ask for a referral to a counselor with experience in end-of-life issues or to a support group for patients who are dealing with incurable disease. Having a safe place to vent your fear, guilt, grief, sadness, and anger will make it easier to talk about these issues with family and friends.
What is hospice care?

Hospice is a type of care designed to provide medical, psychological, and spiritual support to terminally ill patients and the people who love them. The goal is comfort, not a cure. Many insurance plans will only cover hospice services if your doctor has said that your are likely to live 6 months or less and you will not be receiving treatment designed to cure cancer.

Of note, some forms of treatment may still be covered if they are being prescribed to relieve pain or symptoms. Be sure to talk with your doctor and your insurance company to clear up these issues before making your decision.

Hospice care is all about your quality of life. Services can be provided in your home, a hospice facility, or even in the hospital. A major goal is to keep you pain-free and make sure that you can leave this world comfortably and with dignity. Hospice doctors, nurses, social workers, and chaplains are experts in helping patients work through the spiritual and emotional challenges of coping with the end of life.

Because hospice care is focused on making you as comfortable as possible, the hospice team may stop medicines that aren’t adding anything to your overall quality of life. The goal is to ensure that you don’t have to take any more pills or injections than are absolutely necessary.

Providing support for family members is a major part of the hospice approach to end-of-life care. Most programs offer counseling and support groups for family members, including support after the patient has died. This is referred to as bereavement. It can be enormously comforting to know that your loved ones will have that kind of support after you are gone.

Review

- Advance care planning is all about making sure that your end-of-life wishes are understood and respected.
- You will fill out a legal document that lays out what you want done if you aren’t able to tell the doctors yourself (advance directive).
- Your advance directive should also identify a person who is authorized to make decisions on your behalf (health care proxy) if you can’t communicate.
- People find different ways to cope when their time is limited.
- Hospice is a type of care designed to provide medical, psychological, and spiritual support to terminally ill patients and the people who love them.
- Providing support for family members is a major part of the hospice approach to end-of-life care.
PEOPLE ASSUME THAT WHEN TREATMENT IS FINISHED, CANCER IS FINISHED.

It's not that simple. The people around you return to their normal routines, but your life is forever changed. Treatment might be over, but the doctor's appointments, the side effects, the medical expenses aren't over. It wasn't until I was finished with treatment that I could even process what had happened to me. It became difficult emotionally in a whole new way. Since I was no longer fighting for my life, now I had the time to process what had just happened in my life.”

- Lauren
Hodgkin Lymphoma Survivor
Age at diagnosis: 28
10 Resources

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Learn all you can about cancer.

Parts 1 through 9 of this book are meant to guide you through the different phases of your cancer care. Part 10 will focus on resources available for people with cancer and their loved ones.

When you are ready, learn more about cancer and support services for AYAs. You can get more facts on the cancer you have, find emotional support online or in the community, or find out about financial services.
Questions to ask your doctors

You may meet with experts from many fields of medicine during this time. Make it a goal to have helpful talks with each person along the way. Get your questions ready before your visit and repeat back what you hear. You can also record your talks and get copies of your medical records. It may be helpful to have a family member or friend with you at these visits. A patient advocate or navigator might also be able to come.

The questions below are suggestions for the many topics you read about in this book. Feel free to use these questions or come up with your own personal questions to ask your doctor and other members of your treatment team.

Testing and the results

1. What tests will I have?
2. Where and when will the tests take place?
3. How long will they take?
4. What are the risks?
5. How do I prepare for testing?
6. How soon will I know the results and who will explain them to me?
7. What type of cancer do I have?
8. Have any cancer cells spread to other parts of my body?
9. Were any of the results unclear?
10. What is the stage of cancer?
Fertility

1. Will the treatment affect my ability to have children?
2. Are there other ways to treat this cancer that will not affect my fertility?
3. How will I know if I am fertile when treatment is over? Are there tests that I can take?
4. Is there anything that can be done during treatment to protect my fertility?
5. Where can I find support for coping with fertility issues?

For women:

6. After my treatments are over, how long will it take for my periods to begin again?
7. If I am not having periods, should I still use contraceptives?
8. Is pregnancy safe for me after treatment? If so, how long should I wait after treatment to become pregnant?
Fertility preservation

1. Is there anything I can do after treatment to preserve my fertility?
2. What are my fertility preservation options?
3. Will any of the options affect the cancer treatment?
4. Will using one of these options delay cancer treatment? If so, for how long?
5. Will fertility treatments increase the risk that the cancer may return?
6. How much will these fertility preservation options cost?
7. Are any of these fertility preservation options covered by insurance?
8. Can you refer me to a specialist who can help preserve my fertility?
Clinical trials

1. What clinical trial is right for me?
2. How many people will be on the clinical trial?
3. What are the tests and treatments for this study? And how often will they be?
4. How long will I be part of the clinical trial?
5. Will I be able to get other treatment if this doesn’t work?
6. How will you know the treatment is working?
7. Who will help me understand the costs of the clinical trial?
8. What are my other options besides a clinical trial?
Treatment options

1. What is the best treatment for this cancer when it occurs in someone my age?
2. Does this hospital (or center) offer the best treatment for me?
3. Is a pediatric or adult treatment plan better for me?
4. Is it better for me to be treated at a pediatric or an adult facility?
5. Can you provide me with the research that supports this treatment plan?
6. How often will I get treatment and will I need more than one?
7. How much time do I have to think about my options or get a 2nd opinion?
Side effects

1. What are the side effects?
2. When can they start?
3. How long will the side effects last?
4. When should I call the doctor about my side effects?
5. Are there any medications that can prevent or relieve these side effects?
6. Are there any complementary therapies that might help?
7. Are there any long-term effects from this treatment?
Survivorship

1. What happens now that treatment is over?
2. What are the chances that my cancer will come back or that I will get another type of cancer?
3. How often should I see my doctor? And who do I see for follow-up care?
4. What tests, if any, should I have to monitor my health?
5. Can you refer me to any support groups or other resources that can help me with survivorship issues?
End-of-life care

1. What symptoms will I have as the cancer progresses?
2. How will it affect my ability to do things and get around?
3. Will I have any pain?
4. What can I take to stop the pain?
5. Are there any complementary treatments that can help? If so, can you refer me to a practitioner who has worked with cancer patients?
6. Am I eligible for hospice care? Will it be covered by my insurance?
7. Does this hospital have an end-of-life support program for people my age? If not, can you refer me to a counselor or support group?
General information on cancer in AYAs

Web Resources

The 15-40 Connection
www.15-40.org
Not-for-profit organization dedicated to motivating AYAs to take their health and medical care seriously, to take action when they notice changes in their health, and to be strong self-advocates when their instincts tell them something is wrong.

Seventy K: Survival Up
www.seventyk.org
Not-for-profit organization dedicated to improving cancer care by educating patients, families, and their health care providers about age-appropriate treatment and the unique needs of AYA cancer patients.

Stupid Cancer (The I’m Too Young for This! Cancer Foundation, i[2]y)
www.stupidcancer.org
The nation’s largest online support community for AYAs affected by cancer.

Teens Living With Cancer
www.teenslivingwithcancer.org
National non-profit organization dedicated to helping teens live with cancer. This site contains teen-oriented resources designed to help teens cope with their disease and treatment and connect with other teens on the same ride.

Ulman Cancer Fund for Young Adults
www.ulmanfund.org/
Grassroots organization dedicated to supporting, educating, connecting, and empowering AYA cancer patients and survivors.

Print Resources


Written by cancer survivor Kris Carr (with an introduction by Sheryl Crow), Crazy, Sexy Cancer Tips is a rambling, very personal, often funny, and incredibly useful assortment of tips from Ms. Carr and her “cancer posse” of patients and survivors. Includes tips on everything from picking out a wig and a “cancer wardrobe” to how to select a good cut of meat.


Written by a health care advocate and cancer survivor, Everything Changes uses the stories of 26 AYAs with cancer (including the author) to provide perspective, advice, and plenty of information and useful resources for patients facing the challenge of cancer and survivorship.


Written by the same team that developed the Planet Cancer website, this book is a truly comprehensive guide to dealing with cancer, from diagnosis to treatment and beyond. Filled with first-person stories, humor (“Top 10 Worst Ways for An Oncologist to Break the Bad News”), and information on everything from dealing with insurance companies to maintaining your sex life, Planet Cancer is a must-read for any young adult with cancer.
Cancer diagnosis and treatment

Web Resources

American Cancer Society

Understanding your diagnosis
http://www.cancer.org/treatment/understandingyourdiagnosis/index

Cancer surgery

Chemotherapy
http://www.cancer.org/treatment/treatmentsandsideeffects/treatmenttypes/chemotherapy/index

Radiation therapy
http://www.cancer.org/treatment/treatmentsandsideeffects/treatmenttypes/radiation/index

Immunotherapy
http://www.cancer.org/treatment/treatmentsandsideeffects/treatmenttypes/immunotherapy/index

Targeted therapy
www.cancer.org/treatment/treatmentsandsideeffects/treatmenttypes/targetedtherapy/index

Leukemia & Lymphoma Society
http://www.lls.org

LIVESTRONG Foundation
Claustrophobia tips
http://www.livestrong.com/article/94950-claustrphobia-tips/

MyCancerGenome.org
Overview on Targeted Therapies for Cancer
www.mycancergenome.org/content/other/molecular-pathology/overview-on-targeted-therapies-for-cancer

National Cancer Institute
Fact Sheets

Bone Marrow Transplantation and Peripheral Blood Transplantation

How to Find a Doctor or Treatment Facility if You Have Cancer

Targeted Cancer Therapies
www.cancer.gov/cancertopics/factsheet/therapy/targeted

National Center for Complementary and Integrative Medicine
https://nccih.nih.gov/

National Comprehensive Cancer Network
Cancer Staging Guide
www.nccn.com/understanding-cancer/cancer-staging.html

Navigate Cancer Foundation
www.navigatecancerfoundation.org/
5448 Apex Peakway #328
Apex, NC 27502-3924
Toll Free: 866.391.1121

This free, online program provides consultation services by experienced cancer nurses who can translate pathology reports, scans, and medical documents and help patients find a qualified doctor for a 2nd opinion.
Stupid Cancer
Stupid Cancer & Bristol-Myers Squibb “I Am Not a Trial”
Hear from real young adults about their experience being on a clinical trial.

U.S. National Institutes of Health
Registry and results database of publicly and privately supported clinical studies
http://www.clinicaltrials.gov/

Print Resources


Free subscriptions to a quarterly magazine for patients with cancer and their caregivers. For the CURE magazine subscribe at: www.curetoday.com/subscription. For Cancer Fighters Thrive go to www.cancerfightersthrive.com/subscribe/.

Fertility issues

Web Resources
American Society of Clinical Oncology (ASCO)
What to Know: ASCO’s Guideline on Fertility Preservation
www.cancer.net/publications-and-resources/what-know-ascos-guidelines/what-know-ascos-guideline-fertility-preservation

Hope for Two…The Pregnant with Cancer Network
https://www.hopefortwo.org
Free support for women diagnosed with cancer while pregnant.

LIVESTRONG Foundation
https://www.livestrong.org/we-can-help/livestrong-fertility
LIVESTRONG has information on “Becoming a parent after cancer” dedicated to providing reproductive information, family building support, and assistance to cancer patients and survivors whose medical treatments present the risk of infertility.

MyOncofertility.org
www.myoncofertility.org
Patient education resource provided by the Oncofertility Consortium.

The Oncofertility Consortium
www.oncofertility.northwestern.edu
Research group dedicated to exploring the relationships between health, disease, survivorship, and fertility preservation in young cancer patients. Site includes information on fertility options and a map of oncofertility centers across the U.S.

Verna’s Purse
http://www.vernaspurse.org
Financial assistance program for those in need of fertility services.
Print Resources


Managing side effects

Web Resources

**American Cancer Society**
Chemotherapy Side Effects Worksheet

Nutrition for the Person with Cancer During Treatment: A Guide for Patients and Families

“tlc™ Tender Loving Care catalog
[www.tlcdirect.org](http://www.tlcdirect.org)

**American Society for Clinical Oncology (ASCO)**
Moving Forward Video Series for Young Adults with Cancer:

Body changes video

Print Resources

Diet and exercise

Managing pain

**National Cancer Institute**
Coping with Cancer: Managing Physical Effects
[www.cancer.gov/cancertopics/cop Ing/physicaleffects](http://www.cancer.gov/cancertopics/physicaleffects)

**National Institute of Health (NIH)**
Sleep Hygiene Guide

**University of California San Francisco Medical Center**
Diet for Cancer Treatment Side Effects

Nutrition and Coping with Cancer Symptoms
[www.ucsfhealth.org/education/nutrition_and_coping_with_cancer_symptoms/index.htm](http://www.ucsfhealth.org/education/nutrition_and_coping_with_cancer_symptoms/index.htm)

**Print Resources**


Navigating life (during and after treatment)

Web Resources

**American Cancer Society Road to Recovery Program:**
Cancer in Our Family
Guide that helps parents teach children about the diagnosis, treatment, potential recurrences of the illness, and terminal illness

Provides free ground transportation to patients receiving treatment; volunteers available based on zip code.

**American Society of Clinical Oncology (ASCO):**
Family life

**Cancer101**
[www.cancer101.org](http://www.cancer101.org)
CANCER101 helps cancer patients and their loved ones function as active partners in their care. The site offers tools such as the Cancer101 Planner that can help patients navigate their cancer journey.

**Caregiver Action Network**
Provides resources for family and caregivers, such as education and peer support.

**Cancer and Careers**
[www.cancerandcareers.org](http://www.cancerandcareers.org)
Empowers and educates people with cancer to thrive in the workplace by providing expert advice, interactive tools, and educational events.

**Wigs for Cancer Patients**

**Look Good, Feel Better**
[www.lookgoodfeelbetter.org](http://www.lookgoodfeelbetter.org) (for women)
[www.lookgoodfeelbetterformen.org](http://www.lookgoodfeelbetterformen.org) (for men)
Program dedicated to improving the self-esteem and quality of life of people undergoing cancer treatment. Includes information on how to manage the appearance-related side effects of treatment.

**Cancer Care**
[www.cancercare.org](http://www.cancercare.org)
Provides free professional support services to anyone affected by cancer. All services—including counseling and support groups, education, financial assistance, and practical help—are provided by professional oncology social workers and are completely free of charge.

**Cancer Legal Resource Center (CLRC)**
Telephone assistance line for cancer patients looking for legal information or assistance.

**Cancer.Net**
Late Effects
[www.cancer.net/survivorship/late-effects](http://www.cancer.net/survivorship/late-effects)

**CaringBridge.org**
[www.caringbridge.org](http://www.caringbridge.org)
Online space where cancer patients and their friends and family can connect, share, and receive support—
kind of like a personalized social network. Available 24/7 to anyone, anywhere at no cost.

**Family Patient Online Patient Update Reports**  
[www.familypatient.com](http://www.familypatient.com)  
Website that allows family members to post up-to-date information about the condition of their loved ones.

**FinAid! The SmartStudent Guide To Financial Aid™**  
[Cancer Scholarships](http://www.finaid.org/scholarships/cancer.phtml)  
Information about scholarships for cancer patients, cancer survivors, children of a cancer patient or survivor, students who lost a parent to cancer, and students pursuing careers in cancer treatment.

**First Descents**  
[http://firstdescents.org/](http://firstdescents.org/)  
Provides free outdoor experiences for young adults with cancer. Helps participants to find support, face fears, and heal.

**Imerman Angels**  
[www.imermanangels.org](http://www.imermanangels.org)  
Pairs individuals touched by cancer with other people who have fought and survived the same type of cancer (a Mentor Angel). These one-on-one relationships inspire hope and offer support from someone who is uniquely familiar with the experience of cancer.

**Job Accommodation Network**  
[www.jan.wvu.edu](http://www.jan.wvu.edu)  
Offers tools to help patients understand the types of workplace adjustments that may help them continue working during and after cancer treatment.

**LIVESTRONG Foundation Resources**  
[www.livestrong.org](http://www.livestrong.org)  
LIVESTRONG Navigation Services provide free, confidential support through education, referrals, and counseling services at any point in your cancer experience. Call toll free 1.855.220.7777 or complete the online intake form at [www.livestrong.org/Get-Help/Get-One-On-One-Support](http://www.livestrong.org/Get-Help/Get-One-On-One-Support)

**LIVESTRONG Care Plan**  
[www.livestrongcareplan.org](http://www.livestrongcareplan.org)  
Interactive program that uses answers to a brief questionnaire to produce a basic survivorship care plan. The LIVESTRONG Care Plan is meant to be shared with the oncology team and used as a start for putting together a personal survivorship care plan.

**Lotsa Helping Hands**  
[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)  
Free service designed to help friends and family organize support efforts. Includes a help calendar to schedule and sign up for specific report activities (shopping, rides to medical appointments, meal preparation, etc.) as well as a message board for sharing information.

**MyLifeLine.org**  
[www.mylifeline.org](http://www.mylifeline.org)  
Non-profit organization that encourages cancer patients and caregivers to create free, customized websites to build an online support community of family and friends.

**National Cancer Institute**  
Adolescents and Young Adults with Cancer: Survivorship  
[www.cancer.gov/cancertopics/aya/survivorship](http://www.cancer.gov/cancertopics/aya/survivorship)  
Facing Forward: Life after Cancer Treatment  

**National Coalition for Cancer Survivorship**  
[www.canceradvocacy.org](http://www.canceradvocacy.org)
877.NCCS.YES (622.7937)  
The oldest survivor-led cancer advocacy organization in the country, advocating for quality cancer care for all Americans and empowering cancer survivors.

**Needy Meds**  
www.needymeds.org/indices/pap.htm  
Searchable online database of pharmaceutical companies’ patient assistance programs.

**The Patient Access Network Foundation**  
www.panfoundation.org  
866.316.7263, 9:00 AM to 5:00 PM, ET  
Provides help to underinsured patients for out-of-pocket expenses for life-saving medications. Patients must complete an application and meet certain insurance and income criteria to qualify for aid.

**Patient Advocate Foundation Co-Pay Relief Program**  
www.copays.org  
Provides direct financial support for pharmaceutical co-payments to insured patients who financially and medically qualify.

**Patient Advocate Foundation**  
www.patientadvocate.org  
800.532.5274  
Provides professional case managers who serve as advocates for patients in dealing with insurance companies, employers, and/or creditors.

**Rx Assist**  
www.rxassist.org/patients  
Searchable online database of pharmaceutical companies’ patient assistance programs.

**The SAMFund Support for Young Adult Cancer Survivors**  
www.thesamfund.org  
Non-profit organization that helps young adult survivors of cancer with a successful transition into their post-treatment life, by providing financial support through the distribution of grants and scholarships.

**Telling Kids About Cancer**  
www.tellingkidsaboutcancer.com  
Comprehensive, user-friendly site with a wealth of age-appropriate tips and resources for parents.

**The Young Adult Cancer Alliance**  
Critical Mass “Mission Control”  
http://criticalmass.org/missioncontrol/  
Comprehensive database to help you find the most up-to-date information on resources that best suit your needs, specific to your diagnosis and location.

**Young Survival Coalition**  
www.youngsurvival.org  
Network of breast cancer survivors and supporters dedicated to the concerns and issues that are unique to young women and breast cancer.

**Print Resources**


End-of-life issues

Web Resources

**American Cancer Society**
Nearing The End Of Life
[www.cancer.org/treatment/nearingtheendoflife/nearingtheendoflife/index](http://www.cancer.org/treatment/nearingtheendoflife/nearingtheendoflife/index)

**Caring Connections**
[www.caringinfo.org/i4a/pages/index.cfm?pageid=1](http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1)
Provides free resources and information to help people make decisions about end-of-life care and services.

**National Cancer Institute**
Advance Directives

Coping with Advanced Cancer

End-of-Life Care for People Who Have Cancer

Hospice

Last Days of Life (PDQ®)

**Voicing My Choices Planning Guide for Adolescents and Young Adults**
Planning tool designed to help young people living with a serious illness to communicate their preferences to friends, family, and caregivers.

Print Resources


abdomen
The belly area between the chest and pelvis.

acquired mutation
A mutation that happens after conception.

alkylating agent
A cancer drug that damages coded instructions in cells by adding a chemical to them.

angiogenesis
The growth of new blood vessels.

apoptosis
The natural death of cells. Also called programmed cell death.

alternative medicine
Treatments used in place of ones usually given by doctors. Also called alternative therapy or alternative treatment.

bone marrow
The soft, sponge-like tissue found in the center of most bones, where blood cells are formed.

bone marrow transplant
Procedure that gives blood or bone marrow stem cells intravenously to restore cells that have been destroyed by cancer or its treatment.

breast cancer
Cancer of the breast.

cataract
A health condition in which the lens of the eye becomes cloudy.

cell
The "building blocks" of tissues in the body.

central nervous system (CNS)
The brain and spinal cord.

cervical cancer
Cancer that started in cells within the neck of the womb, which is called the cervix.

chemotherapy
Drugs that kill cancer cells by damaging or disrupting the making of the genetic code.

clinical trial
Research study on a test or treatment to assess its safety or how well it works.

colorectal cancer
Cancer that starts in the colon, rectum, or both.

computed tomography (CT) scan
A test that combines many x-rays taken from different angles to make a picture of the insides of the body.

complementary medicine
Treatment given along with standard treatment. Also called complementary therapy or complementary treatment.

contrast material
A dye that is put into the body to make clearer pictures during imaging tests.

eligibility criteria
For a clinical trial, certain terms a person needs to meet to take part in the research study. These terms make sure the people on the clinical trial are alike so that research is focused on what is being tested. The terms may include things like age, type of cancer, and general health.

ejaculate
A mix of sperm and fluids. Also called semen.

embryo
A fertilized egg that has been growing for up to eight weeks.

endoscopic biopsy
Use of a thin tool that is guided down the esophagus to remove tissue samples.

enzyme
Proteins that speed up chemical reactions in the body.
**excisional biopsy**
Surgical removal of an entire tumor to test for disease.

**external beam radiation**
Treatment with radiation received from a machine outside the body.

**fertility**
The ability to become pregnant and have a baby.

**fertility preservation**
A way to preserve or protect the ability to become pregnant and have a baby.

**gastrointestinal (GI) tract**
The group of organs through which food passes after being eaten.

**gene**
A set of coded instructions in cells needed to make new cells and control how cells behave.

**genetic mutation**
An abnormal set of coded instructions within cells that are needed for making new cells and controlling how cells behave (genes).

**germ cells**
Cells that become sperm in men and eggs in women.

**growth factor**
A substance that helps new blood cells to be made.

**gynecologic oncologist**
A doctor who is an expert in cancer that starts in women’s organs that help to make babies.

**hair follicle**
Tube-like openings in the skin where hairs grow.

**hematologist**
A doctor who is an expert in diseases of the blood.

**hormone**
A chemical in the body that activates cells or organs.

**hypnotherapy**
Treatment that puts people into a trance-like state of deep relaxation.

**immunotherapy**
Treatment that uses the body's natural defense against disease.

**incisional biopsy**
A surgery that removes a tissue sample from a tumor to test for cancer cells.

**inherited mutation**
A mutation passed on from parent to a child that is present before birth.

**integrative medicine**
Use of standard treatment with complementary therapies that are safe and work together.

**internal radiation**
Treatment with radiation received from a radioactive object placed near or in the tumor.

**in vitro fertilization (IVF)**
Procedure that removes eggs from the ovaries and combines them with sperm for fertilization in a lab.

**leukemia**
Cancer of the bone marrow and blood.

**lymph**
A clear fluid that contains disease-fighting white blood cells.

**lymph node**
A small group of disease-fighting cells.

**lymphoma**
Cancer that starts in the cells of the immune system.

**magnetic resonance imaging (MRI)**
A test that uses radio waves and powerful magnets to make pictures of the inside of the body.

**medical oncologist**
A doctor who’s an expert in treating cancer with medication.

**melanoma**
A cancer that starts in the cells that give color to the skin (melanocytes).

**menopause**
The point in time when a woman will experience no more menstrual periods.

**needle biopsy**
Use of a needle to remove tissue from the body to test for disease.

**neutrophil**
A type of white blood cell.
normal range
A set of values that is based on test results of healthy people.

oncofertility
Cancer doctors and reproductive experts who work together to help patients keep their ability to have babies.

oncologist
A doctor who specializes in treating cancer.

osteoporosis
A disease that causes bones to thin and weaken.

ovarian cancer
Cancer of the ovary.

ovarian suppression
Methods used to lower the amount of hormones made by the ovaries.

ovary
One of a pair of organs in females that makes eggs (ova) and hormones.

pathologist
A doctor who is an expert in testing cells and tissue to find disease.

platelet
A type of blood cell that forms blood clots to control bleeding.

positron emission tomography (PET)
A test that uses of radioactive material to see the shape and function of body parts.

primary tumor
The first mass of cancer cells in the body.

radiation therapy
The use of radiation to treat cancer.

radiation oncologist
A doctor who is an expert in using radiation to treat cancer.

radiologist
A doctor who is an expert in reading imaging tests.

radiopharmaceutical
A drug that contains a radioactive substance.

red blood cell
A type of blood cell that carries oxygen from the lungs to the rest of the body.

reproductive system
The organs and tissues involved in the process of making babies—the vagina, cervix, uterus, fallopian tubes, and ovaries in women, and the penis, testicles, and prostate in men.

sarcoma
Cancer that starts in bones or soft tissue of the body.

secondary cancer
Cancer that start in cells that were damaged from the treatment of the first cancer.

side effect
An unhealthy or unpleasant physical or emotional response to treatment.

sperm
A sex cell from a man that enters a woman's egg to make a baby.

stem cell
An immature cell from which other types of cells develop.

stem cell transplant
A cancer treatment that destroys bone marrow with chemotherapy and then replaces it with healthy blood stem cells.

stroke
Blood flow to the brain is blocked and this causes damage to the brain tissue.

surgeon
A doctor who is an expert in operations to remove or repair a part of the body.

surgical oncologist
A doctor who is an expert in operations on cancer.

therapy
The use of radioactive drugs to treat cancer cells throughout the body with radiation.

targeted therapy
Treatment with drugs that target a specific or unique feature of cancer cells.

testicles
Two egg-shaped glands found inside a sac between the legs of a man.
**testicular cancer**  
Cancer of a testicle.

**thyroid**  
A gland located in the throat, just beneath the voice box.

**toxin**  
A poison made in nature.

**tumor grade**  
A rating of how much cancer cells look like normal cells.

**tumor marker**  
Substances in body fluid or tissue that may be a sign of cancer.

**ultrasound**  
A test that uses sound waves to take pictures of the inside of the body. Also called ultrasonography.

**uterus**  
The female organ where babies grow during pregnancy. Also called the womb.

**white blood cell**  
A type of blood cell that fights infection.

**x-ray**  
Use of small amounts of radiation to make pictures of the inside of the body.
Acronyms

AYA
adolescents and young adults

CAM
complementary and alternative medicine

CBC
complete blood count

CPR
cardiopulmonary resuscitation

CT
computed tomography

CTZ
chemoreceptor trigger zone

DNA
deoxyribonucleic acid

DNAR
do not attempt resuscitation

DNI
do not intubate

GI
gastrointestinal

IV
intravenous

IVF
in vitro fertilization

MAB
monoclonal antibodies

MRI
magnetic resonance imaging

PET
positron emission tomography

THC
tetrahydrocannabinol

TNM
tumor, node, and metastasis

NCCN Abbreviations and Acronyms

NCCN®
National Comprehensive Cancer Network®

NCCN Patient Guidelines
NCCN Guidelines for Patients®

NCCN Guidelines®
NCCN Clinical Practice Guidelines in Oncology®
NCCN GUIDELINES FOR PATIENTS®
Patient-friendly versions of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)

View and download your free copy ➡️ NCCN.org/patients
Order print copies ➡️ Amazon.com (Search ‘NCCN Guidelines for Patients’)

Acute Lymphoblastic Leukemia
Adolescents and Young Adults (AYAs) with Cancer
Breast Cancer
  Carcinoma in Situ (Stage 0)
  Early-Stage (Stages I and II)
  Stage III Breast Cancer
  Stage IV Breast Cancer
Chronic Lymphocytic Leukemia
Chronic Myelogenous Leukemia
Colon Cancer
Esophageal Cancer
Hodgkin Lymphoma
Kidney Cancer
Lung Cancer Screening
Malignant Pleural Mesothelioma
Melanoma
Multiple Myeloma
Myelodysplastic Syndromes
Non-Hodgkin’s Lymphomas
Diffuse Large B-cell Lymphoma
Follicular Lymphoma
Mantle Cell Lymphoma
Mycosis Fungoides
Peripheral T-cell Lymphoma
Non-Small Cell Lung Cancer
Ovarian Cancer
Pancreatic Cancer
Prostate Cancer
Soft Tissue Sarcoma
Stomach Cancer

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As of September 12, 2016
State Fundraising Notices

**FLORIDA:** A COPY OF THE OFFICIAL REGISTRATION AND FINANCIAL INFORMATION OF NCCN FOUNDATION MAY BE OBTAINED FROM THE DIVISION OF CONSUMER SERVICES BY CALLING TOLL-FREE WITHIN THE STATE 1-800-HELP-FLA. REGISTRATION DOES NOT IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THE STATE. FLORIDA REGISTRATION #CH33263. **GEORGIA:** The following information will be sent upon request: (A) A full and fair description of the programs and activities of NCCN Foundation; and (B) A financial statement or summary which shall be consistent with the financial statement required to be filed with the Secretary of State pursuant to Code Section 43-17-5. **KANSAS:** The annual financial report for NCCN Foundation, 275 Commerce Drive, Suite 300, Fort Washington, PA 19034, 215-690-0300, State Registration # 445-497-1, is filed with the Secretary of State. **MARYLAND:** A copy of the NCCN Foundation financial report is available by calling NCCN Foundation at 215-690-0300 or writing to 275 Commerce Drive, Suite 300, Fort Washington, PA 19034. For the cost of copying and postage, documents and information filed under the Maryland charitable organizations law can be obtained from the Secretary of State, Charitable Division, State House, Annapolis, MD 21401, 1-410-974-5534. **MICHIGAN:** Registration Number MICS 45298. **MISSISSIPPI:** The official registration and financial information of NCCN Foundation may be obtained from the Mississippi Secretary of State’s office by calling 888-236-6167. Registration by the Secretary of State does not imply endorsement by the Secretary of State. **NEW JERSEY:** INFORMATION FILED WITH THE ATTORNEY GENERAL CONCERNING THIS CHARITABLE SOLICITATION AND THE PERCENTAGE OF CONTRIBUTIONS RECEIVED BY THE CHARITY DURING THE LAST REPORTING PERIOD THAT WERE DEDICATED TO THE CHARITABLE PURPOSE MAY BE OBTAINED FROM THE ATTORNEY GENERAL OF THE STATE OF NEW JERSEY BY CALLING (973) 504-6215 AND IS AVAILABLE ON THE INTERNET AT www.njconsumeraffairs.gov/ocp.htm#charity. REGISTRATION WITH THE ATTORNEY GENERAL DOES NOT IMPLY ENDORSEMENT. **NEW YORK:** A copy of the latest annual report may be obtained from NCCN Foundation, 275 Commerce Drive, Suite 300, Fort Washington, PA 19034, or the Charities Bureau, Department of Law, 120 Broadway, New York, NY 10271. **NORTH CAROLINA:** FINANCIAL INFORMATION ABOUT THIS ORGANIZATION AND A COPY OF ITS LICENSE ARE AVAILABLE FROM THE STATE SOLICITATION LICENSING BRANCH AT 888-830-4989 (within North Carolina) or (919) 807-2214 (outside of North Carolina). THE LICENSE IS NOT AN ENDORSEMENT BY THE STATE. **PENNSYLVANIA:** The official registration and financial information of NCCN Foundation may be obtained from the Pennsylvania Department of State by calling toll-free within Pennsylvania, 800-732-0999. Registration does not imply endorsement. **VIRGINIA:** A financial statement for the most recent fiscal year is available upon request from the State Division of Consumer Affairs, P.O. Box 1163, Richmond, VA 23218; 1-804-786-1343. **WASHINGTON:** Our charity is registered with the Secretary of State and information relating to our financial affairs is available from the Secretary of State, toll free for Washington residents 800-332-4483. **WEST VIRGINIA:** West Virginia residents may obtain a summary of the registration and financial documents from the Secretary of State, State Capitol, Charleston, WV 25305. Registration does not imply endorsement.

Consult with the IRS or your tax professional regarding tax deductibility. REGISTRATION OR LICENSING WITH A STATE AGENCY DOES NOT CONSTITUTE OR IMPLY ENDORSEMENT, APPROVAL, OR RECOMMENDATION BY THAT STATE. We care about your privacy and how we communicate with you, and how we use and share your information. For a copy of NCCN Foundation’s Privacy Policy, please call 215.690.0300 or visit our website at www.nccn.org.
NCCN Panel Members for Adolescent and Young Adult Oncology

Peter F. Coccia, MD/Chair  
Fred & Pamela Buffet Cancer Center

Alberto S. Pappo, MD/Vice-Chair  
St. Jude Children’s Research Hospital/ 
The University of Tennessee  
Health Science Center

Lynda Beaupin, MD  
Roswell Park Cancer Institute

Virginia F. Borges, MD, MMSc  
University of Colorado Cancer Center

Scott C. Borinstein, MD, PhD  
Vanderbilt-Ingram Cancer Center

Rashmi Chugh, MD  
University of Michigan  
Comprehensive Cancer Center

Shira Dinner, MD  
Robert H. Lurie Comprehensive Cancer Center of Northwestern University

Jeanelle Folbrecht, PhD  
City of Hope Comprehensive Cancer Center

Lindsay Frazier, MD, ScM  
Dana-Farber/Brigham and Women’s Cancer Center | Massachusetts General Hospital Cancer Center

Robert Goldsby, MD  
UCSF Helen Diller Family Comprehensive Cancer Center

Alexandra Gubin, MSW  
The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

Robert Hayashi, MD  
Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine

Mary S. Huang, MD  
Dana-Farber/Brigham and Women’s Hospital Cancer Center

Michael P. Link, MD  
Stanford Cancer Institute

Yousif Matloub, MD  
Case Comprehensive Cancer Center/ 
University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute

Frederick Millard, MD  
UC San Diego Moores Cancer Center

Kevin C. Oeffinger, MD  
Memorial Sloan Kettering Cancer Center

Damon R. Reed, MD  
Moffitt Cancer Center

Steven Robinson, MBBS  
Mayo Clinic Cancer Center

Abby R. Rosenberg, MD, MS  
Fred Hutchinson Cancer Research Center/ 
Seattle Cancer Care Alliance

Tara Sanft, MD  
Yale Cancer Center/Smilow Cancer Hospital

Cindy L. Schwartz, MD, MPH  
The University of Texas MD Anderson Cancer Center

Holly L. Spraker-Perlman, MD, MS  
Huntsman Cancer Institute at the University of Utah

Margaret Von Mehren, MD  
Fox Chase Cancer Center

Daniel S. Wechsler, MD, PhD  
Duke Cancer Institute

Kimberly F. Whelan, MD  
University of Alabama at Birmingham Comprehensive Cancer Center

Nicholas Yeager, MD  
The Ohio State University Comprehensive Cancer Center - James Cancer Hospital and Solove Research Institute

NCCN Staff

Susan Darlow, PhD  
Oncology Scientist/Senior Medical Writer

Dorothy A. Shead, MS  
Director, Patient and Clinical Information Operations

For disclosures, visit www.nccn.org/about/disclosure.aspx.
NCCN Member Institutions

Fred & Pamela Buffett Cancer Center  
Omaha, Nebraska  
800.999.5465  
nbaskamed.com/cancer

Case Comprehensive Cancer Center/  
University Hospitals Seidman  
Cancer Center and Cleveland Clinic  
Taussig Cancer Institute  
Cleveland, Ohio  
800.641.2422 • UH Seidman Cancer Center  
uhospitals.org/seidman  
866.223.8100 • CC Taussig Cancer Institute  
my.clevelandclinic.org/services/cancer  
216.844.8797 • Case CCC  
case.edu/cancer

City of Hope Comprehensive  
Cancer Center  
Los Angeles, California  
800.826.4673  
cityofhope.org

Dana-Farber/Brigham and  
Women’s Cancer Center  
Massachusetts General Hospital  
Cancer Center  
Boston, Massachusetts  
877.332.4294  
dfbwcc.org  
mgmgeneral.org/cancer

Duke Cancer Institute  
Durham, North Carolina  
888.275.3853  
dukecancerinstitute.org

Fox Chase Cancer Center  
Philadelphia, Pennsylvania  
888.369.2427  
foxchase.org

Huntsman Cancer Institute  
at the University of Utah  
Salt Lake City, Utah  
877.585.0303  
huntsmancancer.org

Fred Hutchinson Cancer  
Research Center/  
Seattle Cancer Care Alliance  
Seattle, Washington  
206.288.7222 • seattlecca.org  
206.667.5000 • fredhutch.org

The Sidney Kimmel Comprehensive  
Cancer Center at Johns Hopkins  
Baltimore, Maryland  
410.955.8964  
hopkinskimmelcancercenter.org

Robert H. Lurie Comprehensive Cancer  
Center of Northwestern University  
Chicago, Illinois  
866.587.4322  
cancer.northwestern.edu

Mayo Clinic Cancer Center  
Phoenix/Scottsdale, Arizona  
Jacksonville, Florida  
Rochester, Minnesota  
800.446.2279 • Arizona  
904.953.0853 • Florida  
507.538.3270 • Minnesota  
mayoclinic.org/departments-centers/mayo- 
clinic-cancer-center

Memorial Sloan Kettering  
Cancer Center  
New York, New York  
800.525.2225  
mskcc.org

Moffitt Cancer Center  
Tampa, Florida  
800.456.3434  
moffitt.org

The Ohio State University  
Comprehensive Cancer Center -  
James Cancer Hospital and  
Solove Research Institute  
Columbus, Ohio  
800.293.5066  
cancer.osu.edu

Roswell Park Cancer Institute  
Buffalo, New York  
877.275.7724  
roswellpark.org

Siteman Cancer Center at Barnes-  
Jewish Hospital and Washington  
University School of Medicine  
St. Louis, Missouri  
800.600.3606  
siteman.wustl.edu

St. Jude Children’s Research Hospital/  
The University of Tennessee  
Health Science Center  
Memphis, Tennessee  
888.226.4343 • stjude.org  
901.683.0055 • westclinic.com

Stanford Cancer Institute  
Stanford, California  
877.668.7535  
cancer.stanford.edu

University of Alabama at Birmingham  
Comprehensive Cancer Center  
Birmingham, Alabama  
800.822.0933  
www3.ccc.uab.edu

UC San Diego Moores Cancer Center  
La Jolla, California  
858.657.7000  
cancer.ucsd.edu

UCSF Helen Diller Family  
Comprehensive Cancer Center  
San Francisco, California  
800.689.8273  
cancer.ucsf.edu

University of Colorado Cancer Center  
Aurora, Colorado  
720.848.0300  
coloradocancercenter.org

University of Michigan  
Comprehensive Cancer Center  
Ann Arbor, Michigan  
800.865.1125  
cancer.org

The University of Texas  
MD Anderson Cancer Center  
Houston, Texas  
800.392.1611  
mdanderson.org

Vanderbilt-Ingram Cancer Center  
Nashville, Tennessee  
800.811.8480  
vicc.org

University of Wisconsin  
Carbone Cancer Center  
Madison, Wisconsin  
608.265.1700  
uwhealth.org/cancer

Yale Cancer Center/  
Smilow Cancer Hospital  
New Haven, Connecticut  
855.4.SMILOW  
yalecancercenter.org
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