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2019

Adolescents and Young Adults with Cancer

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- ✓ Based on treatment guidelines used by health care providers worldwide
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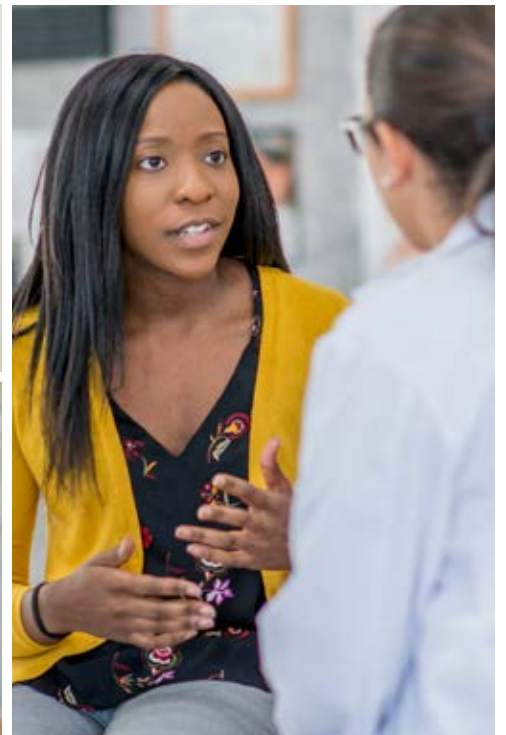
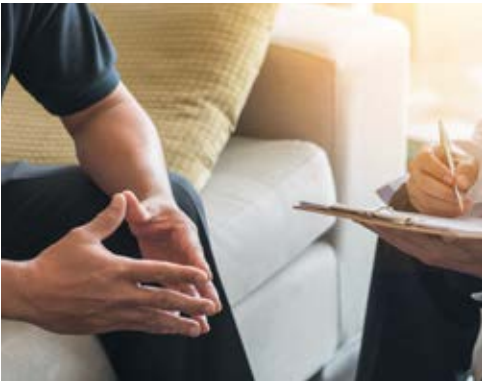
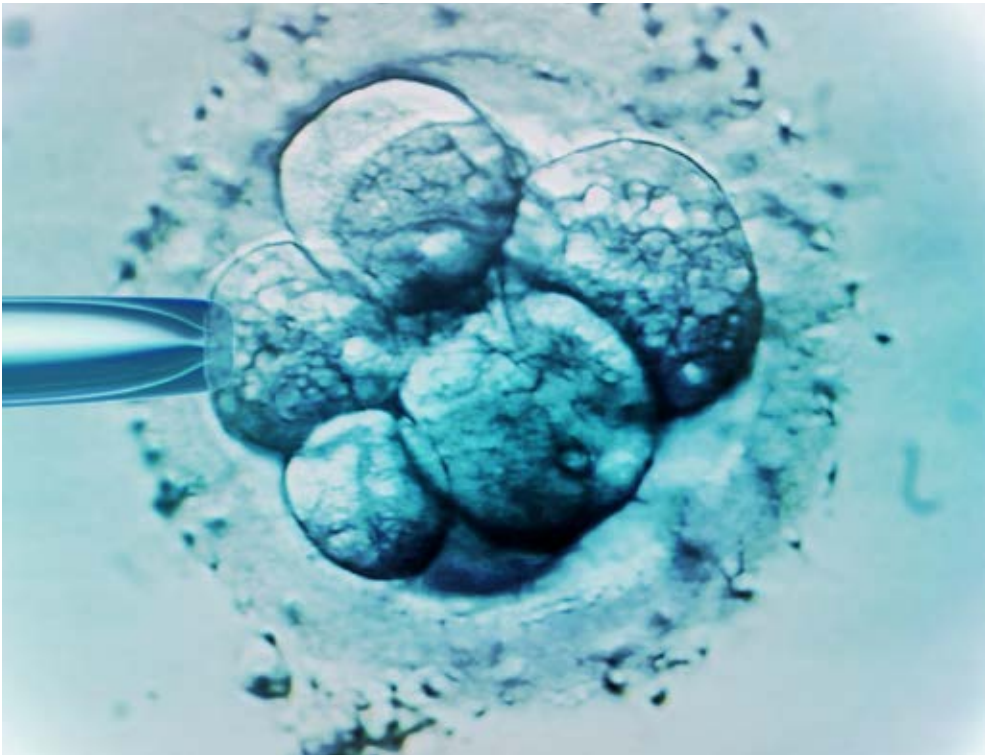


The Leukemia & Lymphoma Society

The Leukemia & 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. [LLS.org/information-specialists](https://lls.org/information-specialists)

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Adolescent & Young Adult Cancer

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Learn cancer basics and what it means to be an adolescent and young adult (AYA) with cancer.

Finding out you have cancer is hard. You are not alone! There are survivors out there just like you. This book is a supportive care guideline and not a treatment guideline. It will help you understand what makes an adolescent and young adult (AYA) with cancer unique and provide resources to support your care.

An AYA is a patient diagnosed with cancer between 15 and 39 years of age. As an AYA, you may have different needs and challenges than patients of other ages. Your body and mind are still growing and developing. This may be a confusing time. You will need support. Seek out support from friends, peers, and cancer survivors.

To get the best care, it helps to learn as much as you can about your cancer and treatment options. This guide will help you take an active role in your treatment.

Cancer basics

A disease of cells

Cancer is a disease that starts in the cells of your body. Each type of cancer is named after the cell from which it is formed.

Your body is made up of trillions of cells. Each cell in your body has a purpose or function. Your DNA (**deoxyribonucleic acid**) uses instructions to tell your cells what to do. These instructions are called genes. Genes tell cells what to become (for example, lung, heart, and skin) and what to do (make hormones, absorb nutrients, and kill germs).

Normal cells grow and divide and repeat the process over and over again. Normal cells die when they become old or damaged. When cells divide more than they should or do not die when they should, it forms an abnormal mass of tissue. Tissue is a group or layer of cells that work together. Abnormal tissue growth is called a tumor. Abnormal cells can grow out of control in places like the bone marrow and blood, but not form a tumor. Tumors may be benign (not cancer) or malignant (cancer). A solid tumor or mass can form anywhere in the body. Not all cancers are made up of tumors. **See Figure 1.**

Figure 1
Normal cells versus cancer cells

Normal cells grow and divide when needed and die when old or damaged. Genes tell the cells when to grow, work, divide, and die. Cancer cells divide more than they should and don't die when they should.

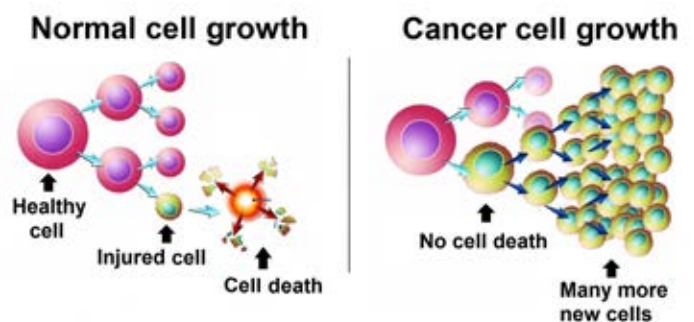


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Benign and malignant tumors

There are 2 types of tumors: benign and malignant.

Benign tumors are not cancer.

- The cells in benign tumors are similar to normal cells.
- The cells in benign tumors do not grow in nearby tissue.
- Benign tumors can grow large in size.
- Some benign tumors are pre-cancerous. This means if left untreated, the tumor could become cancer. Once removed, most benign tumors do not come back.

Common types of benign tumors

1. **cysts** – lumps filled with fluid
2. **lipomas** – lumps of fatty cells
3. **fibromas** – lumps of fibrous or connective tissue cells

Malignant tumors are cancer.

- Cancer cells do not act like normal cells.
- Malignant tumors can be any size.
- Malignant tumors can be found in more than one place in the body.
- Malignant tumors can invade nearby organs and grow (metastasize) in other parts of the body.

Cancer on the move

Normal cells stay where they are in the body. Cancer cells can break away from where they first formed (primary tumor) and travel to other parts of the body in a process called metastasis. In metastasis, cancer cells travel through your blood or lymph to different parts of the body.

Lymph is a clear fluid that carries cells that help fight infection and disease. Your blood carries oxygen and nutrients throughout the body and removes waste. 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.

- **Local metastasis** – Cancer that has spread to a nearby area close to the primary tumor
- **Distant metastasis** – Cancer that has spread to distant parts of the body far from the primary tumor

New tumors or metastatic tumors are the same type of cancer as the primary tumor. Your cancer will always be called by the name of the original place it started. For example, when breast cancer cells spread to the lung it is not called lung cancer; it is called metastatic breast cancer.

Causes of cancer

Cancer starts when something goes wrong in the DNA of a cell. This process is called mutation. Mutations may be caused by mistakes when cells divide or when DNA has been damaged.

There are 2 types of mutations: hereditary and acquired (somatic).

Hereditary mutations are mutations you are born with. Acquired mutations occur some time during your life and are found only in certain cells. If mutations occur in cells that make eggs or sperm,

they can be inherited. If mutations occur in other types of cells, they are not inherited.

Hereditary mutations are inherited from a parent and can be passed down to your offspring. You are born with these and have them throughout your life. Hereditary mutations are found in almost every cell in the body. People with inherited mutations have a higher risk for getting certain cancers. Only a very small number of AYA cancers have an inherited mutation. Hereditary mutations are also called germline mutations. If you are wondering about whether or not you have a hereditary mutation, ask your doctor.

Acquired (somatic) mutations occur at some point during your life. Acquired mutations are only found in certain cells, not every cell in the body.

Causes of acquired mutations

- **Environment** – Radiation from the sun or tanning bed that you cannot see, called ultraviolet (UV) rays, is a risk factor for cancer.
- **Lifestyle** – Smoking is a risk factor for cancer. If you smoke, it is never too late to quit.
- **Viruses** – Some viruses damage genes in your DNA. This can cause cancer.
 - For example, HPV (**human papillomavirus**) is a sexually transmitted virus that is the leading cause of cervical cancer. HPV has 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. When the copies are not perfect, they contain genetic mutations that damage DNA. The damaged DNA is passed down every time the cells divide. Over time, this may cause cancer.



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

– Berenise

Acute Myeloid Leukemia Survivor

Age at diagnosis: 22

Facts about AYAs

An adolescent and young adult (AYA) is a patient between 15 and 39 years of age at the time of initial cancer diagnosis. More than 70,000 patients in this age group are diagnosed with cancer each year in the United States. AYA cancers account for 5 out of 100 new cancer diagnoses and 2 out of 100 cancer deaths.

All AYA cancers are treatable and most are curable. Cancer diagnosis in AYAs is often delayed. One reason is that cancer in AYAs is uncommon. The range of cancer types that affect AYAs is unique and different from cancers that affect children or older adults. This makes AYA cancer diagnosis and treatment more challenging. Not all oncologists (doctors for patients with cancer) have experience treating AYA patients. It is important you seek out a health care provider who specializes in AYA cancer treatment.

AYA cancer treatment is complex. AYA bodies are still going through physical and hormonal changes. These changes affect how cancer develops and how your body responds to cancer treatment. Both the type of cancer you have and the age at which you were diagnosed play a role in how your cancer will be treated and your chance for survival. Treatment options will vary based on your unique needs.

Not many AYAs participate in clinical trials. Clinical trials are research studies that can help find new or better ways to treat cancer. If you are interested in clinical trials, ask your health care provider if a clinical trial is available for your type of cancer.

Breast and thyroid cancers are the most common cancer in AYA women.

Testicular cancer is the most common cancer in AYA men.

AYAs develop different types of cancer than other age groups. These cancers look and behave differently than the same cancers in children and older adults.

Some examples:

AYA women who develop breast cancer are more likely to have a family history of the disease. These same women are more likely to develop tumors that do not respond to hormone therapy. This means their breast cancer might be harder to treat.

Young adults with colorectal cancer are more likely to have an inherited mutation, or a mutation that has been passed down through family DNA. This type of colorectal cancer grows or spreads quickly.

Concerns unique to AYA cancer patients:

- fertility preservation
- parenting
- schooling
- employment attainment and retention

Review

- Cancer is a disease that starts in the cells of the body.
- Cancer cells can spread to other parts of the body through the blood or lymphatic system.
- Cancer starts when something goes wrong with the genes through a process called mutation.
- Both the type of cancer you have and the age at which you were diagnosed play a role in how your cancer will be treated and your chance for survival.
- Seek out a health care provider who specializes in AYA cancer treatment.



AYA cancers account for 5 out of 100 new cancer diagnoses each year.

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Cancer diagnosis

13 Testing for cancer

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Not all cancers are the same. This chapter is an overview of common tests and procedures used to diagnose cancer.

Testing for cancer

Being diagnosed with cancer is a process. It may have started with:

- a lump
- a mole
- a pain

To learn more about your cancer, your health care provider will ask you questions during office visits, order tests, and refer you to specialists. You will have tests and procedures to help the doctor learn what is happening in your body. Oncologists are cancer doctors who specialize in treating cancer. Look for an oncologist who specializes in your type of AYA cancer. This is important.

Medical history and physical exam

Not all cancers are the same. Your doctors will want to learn about the cancer you have. Your doctor will start with a medical history followed by a physical exam. Details about your medical history and an exam of your body are two of the most basic tools of diagnosis.

Medical history

A medical history is a record of your past and current medical problems and treatments. Your doctor will ask about all health issues and treatments you have had in your life. Be prepared to list any illness or injury and when it happened. Bring a list of old and new medicines. Tell your doctor about any symptoms

you have. Female patients will be asked about any pregnancies, abortions, or miscarriages and the end date of your last period.

Your health care provider will ask many questions. Some questions will be personal, about sex for example, and you may feel uncomfortable. This is normal. Your doctor needs as much information about you to diagnose and treat your cancer. Many drugs, medicines, and herbs can interfere with cancer treatment or make you sick. Be as honest as you can about any drug or alcohol use.

Tell your health care provider if you:

- drink alcohol
- use recreational drugs like marijuana or ecstasy or if you take pain pills that are not yours
- use CBD oil
- take prescription medicines
- have a substance abuse problem
- take over-the-counter (OTC) medicines, supplements, herbs, or vitamins
- are, were, or plan to be in a sexual relationship
- are, were, or plan to get pregnant
- use an inhaler or insulin
- have any allergies
- have depression and/or anxiety
- smoke cigars/cigarettes, or vape

Family History

Some cancers and other diseases can run in families. Your doctor will ask about the medical history of family members who are blood relatives. You can ask family members about their health issues like heart disease, cancer, and diabetes, and at what age they were diagnosed. Your health care

provider might refer you for genetic testing to learn more about your cancer. A genetic counselor will speak to you about the results.

Physical exam

A physical exam is a study of your body. A doctor will check your body for signs of disease.

A health care provider will:

- Check your temperature, blood pressure, pulse, and breathing rate
- Weigh you
- Listen to your lungs, heart, and gut
- Look in your eyes, ears, nose, and throat
- Feel and apply pressure to parts of your body to see if organs are of normal size, are soft or hard, or cause pain when touched. Tell your doctor if you feel pain.

Blood tests

Blood tests are an important part of cancer diagnosis and treatment. During the diagnosis phase, blood tests will be used to check your overall health and to look for signs of cancer. A blood sample is drawn by a nurse or a phlebotomist, a person who specializes in taking blood samples. A needle called a syringe is used to take blood. Some people feel a pinch when blood is drawn.

The complete blood count

One of the most common blood tests is a **complete blood count** or CBC. The CBC is a measure of the various types of cells found in your blood.

Your blood is made up of 3 types of cells:

- White blood cells fight infection
- Red blood cells carry oxygen
- Platelets help with blood clotting

A CBC measures the number of each cell type. Your CBC numbers are compared to the normal range for those cells in a healthy person who is about your age.

Blood chemistry tests

Blood chemistry tests measure the levels of minerals, enzymes, and waste products found in your blood. Blood chemistry tests tell your doctor how your heart, liver, kidneys, and other organs are working. Your blood will be drawn by a nurse or phlebotomist and sent to the lab for testing.

Pregnancy tests

Female patients who can have children will have a pregnancy test. It is important to have a pregnancy test before starting cancer treatment. Cancer treatment can hurt the baby if you are or get pregnant during treatment. Cancer and cancer treatment can affect your ability to have children in the future by causing infertility. Ask your oncologist about these risks and see a gynecologist during and after treatment. Your health care provider will discuss preventing pregnancy during cancer treatment and ways to preserve your fertility, or your ability to get pregnant.

Imaging tests

Imaging tests take pictures of the inside of your body. These tests are used in the diagnosis of cancer. Doctors can see the primary tumor, or where the cancer started, and look for cancer in other parts of your body.

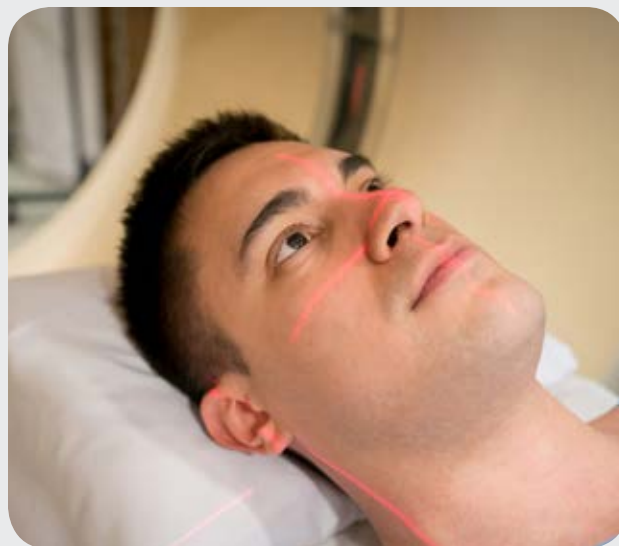
Common imaging tests:

- ▶ X-rays use low-dose radiation to take one picture at a time.
- ▶ Ultrasounds use high-energy sound waves to make pictures.
- ▶ CT (computed tomography) scans use x-rays to take pictures from many angles or cross-sections to create three-dimensional or real-looking images. A CT scan with contrast uses contrast materials to improve the pictures inside the body. Contrast materials are not dyes, but substances that help certain areas in the body stand out. **(Figure 2)**.
- ▶ MRI (magnetic resonance imaging) scans use radio waves and strong magnets to make detailed pictures.
- ▶ PET (positron emission tomography) scans use a radioactive drug called a tracer to find disease and take three-dimensional or real-looking pictures. A tracer is a substance put in your body to see how cancer is growing and where it is in the body. Cancer cells show up as bright spots on PET scans.

A radiologist, who is an expert that looks at test images, will review your pictures and write a report. The radiologist will send this report to your doctor. Your doctor will discuss this report with you. Feel free to ask as many questions as you like.

Figure 2 CT machine

Pictures of the inside of your body can be made with imaging. During the scan, you will lie on a table that will move into the tunnel of the imaging machine. The pictures will be viewed by a doctor who will look for signs of cancer.



Biopsy

The removal of tissue or group of cells by a surgeon is called a biopsy. A biopsy looks for signs of cancer in your cells. A pathologist is an expert who will test these cells for cancer and write a report. Your doctor will order a biopsy to learn more about your cancer and share the results with you. Ask questions about your biopsy results and what it means for your cancer treatment.

Since cancer cells can travel through the lymphatic system of the body, biopsies often include removal of tissue from nearby lymph nodes. Lymph nodes are groups of small round structures that help fight disease. By removing lymph nodes, your doctor can see if cancer has spread. Once the biopsy is complete, a pathologist will look at the tissue sample under a microscope.

The pathologist will look to see:

- if the tumor is benign or malignant
- the type of cancer
- if the cancer has spread

The pathologist may also perform other tests to see if the cancer cells have specific genes or proteins. This information will help you and your care team decide the best treatment plan for your type of cancer.

Biopsy types

The type of biopsy depends on the site or area of the body. The surgeon or other health care provider performing the biopsy will tell you if you will be asleep or awake during the procedure. No matter what, he or she will make sure the biopsy procedure is not painful.

- **Down-the-throat (endoscopic) biopsy** – uses a lighted scope inserted through the nose or mouth into your esophagus or windpipe to remove tissue or cells.
- **External needle biopsy** – uses a thin needle that goes through the skin into the tumor to remove fluid or tissue.
- **Incisional biopsy** – uses surgery to remove a sample or piece of tumor tissue for testing.
- **Excisional biopsy** – uses surgery to remove the entire tumor for testing.

Biopsies are the final step in a cancer diagnosis. You might need more than one biopsy. Ask your health care provider about the type of biopsy you will have and what you can do to get ready.

Cancer staging

Staging system

The **American Joint Committee on Cancer (AJCC)** created a way to determine how much cancer is in your body and where it is located. Staging describes how serious your cancer is and your chances of survival.

The staging system is based on 4 factors:

1. The location of the primary tumor
2. Tumor size and extent of other tumors
3. Whether or not the cancer has spread to other areas of the body
4. Whether or not the cancer has spread to the lymph nodes

The TNM staging system is the most common. In this staging system, the letters **T**, **N**, and **M** describe different areas of cancer growth. Your doctor will assign a score or number to each letter. Some cancers are rated using different staging systems. A TNM system example might look like this: T2N2M0. [See Guide 1.](#)

Once all of your tests are complete, your doctor will tell you the stage of your disease. The stage describes the likely course your cancer will take, called a prognosis. Together, you and your care team will decide the best treatment plan.

Guide 1. TNM staging system

Primary tumor (T)	Regional lymph nodes (N)	Distant metastasis (M)
TX: Main tumor cannot be measured	NX: Cancer in nearby lymph nodes cannot be measured	MX: Cancer in nearby lymph nodes cannot be measured
T0: Main tumor cannot be found	N0: There is no cancer in nearby lymph nodes	M0: Cancer has not spread to other parts of the body
T1, T2, T3, T4: Size of main tumor	N1, N2, N3: Number and location of lymph nodes with cancer	M1: Cancer has spread to other parts of body (metastasized)

Letter stages

The T score refers to the size of the main (primary) tumor. A number follows this letter. The higher the number after the T, the larger the tumor or the more it has grown into nearby tissue. The N refers to the number of nearby lymph nodes that have cancer. The M refers to whether the cancer has spread to other parts of the body or metastasized.

Number stages

Number stages range from stage 1 to stage 4, with 4 being the most serious. Doctors write these stages as stage 0, stage I, stage II, stage III, and stage IV.

Below are other terms you might hear to describe your cancer stage:

- **In situ** – Abnormal cells are present and limited to the layer of cells where it began.
- **Localized** – Cancer is limited to the place where it began, with no sign that it has spread.
- **Regional** – Cancer has spread to nearby lymph nodes, tissues, or organs.
- **Distant** - Cancer has spread to distant parts of the body.
- **Unknown** – There is not enough information to determine the cancer’s stage.

Letter stages

T	Tumor	How large or where the primary tumor is located
N	Node	How far the cancer has spread within nearby lymph nodes
M	Metastasis	Where the cancer has spread to other parts of your body

Number stages

Stage 0	This is a very early form of cancer. It has not spread to other areas of the body or nearby lymph nodes. Also called carcinoma in situ (CIS).
Stage I, Stage II, and Stage III	Cancer is present. The higher the number, the larger the cancer tumor. A stage III tumor is larger in size than a stage I tumor. Stage III means the cancer has spread to nearby organs or lymph nodes, but is close to the primary tumor.
Stage IV	This cancer has spread to distant parts of the body far from the primary tumor. Called metastatic cancer.

Since blood cancers like lymphoma and leukemia are not solid tumors, other staging systems are used. Brain and spinal cord tumors do not use the TNM system either. Each type of cancer has a slightly different staging system. The letters and numbers mean different things for different cancers.

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

The doctor also tests blood or other fluids for tumor markers. Certain tumor markers are used to check for certain types of cancer. For example, CA-125 is a tumor marker for possible ovarian cancer. A high level of CA-125 might mean that cancer is present, but this 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 treat the disease.



Snapshot: Cancer staging

- ✓ The cancer stage describes the extent of cancer in the body.
- ✓ Your doctor may try to diagnose and stage the cancer at the same time.
- ✓ The staging system uses the letters T, N, and M to describe different areas of cancer growth.
- ✓ The TNM scores will be combined to assign the cancer a stage.
- ✓ Stages I and II are early cancers.
- ✓ Stage III is locally advanced cancer.
- ✓ Stage IV is metastatic cancer.

Test results

The results from your blood tests, imaging studies, and biopsy will determine your treatment plan. It is important you understand what these tests mean. Ask questions and keep copies of your test results. You will need these for a second opinion.

Whether you are going for a second opinion, test, or office visit, keep these things in mind:

- Bring someone with you to doctor visits. Encourage this person to ask questions and take notes.
- Write down questions and take notes during appointments. Don't be afraid to ask your care team questions. Get to know your care team and let them get to know you.
- Get copies of blood tests, imaging results, and reports about the specific type of cancer you have. It will be helpful when getting a second opinion.
- Organize your papers. Create files for insurance forms, medical records, and test results.
- Keep a list of contact information for everyone on your care team.

Treatment planning

You may want to start cancer treatment as soon as you can after diagnosis. Start by seeking an AYA doctor and then get a second opinion right away from another AYA doctor. Ask each AYA doctor about any fertility concerns.

Find a care team that understands the unique needs of AYAs with cancer. Find a doctor or a cancer center that has experience treating AYA patients with your cancer type. This is important. Your cancer might be better treated at a pediatric (children's) clinic. Ask questions and gather as much information as you can from your care team.

Get to know your
care team and let
them get to
know you.

Getting a second opinion

After finding a doctor who specializes in treating AYA cancer patients, get a second opinion. Even if you like and trust your doctor, get a second opinion. Checking a biopsy sample requires skill and experience. Another doctor might see something the first pathologist missed. A cancer doctor (oncologist) may also bring a different view on the type of treatment that is best for you. For example, a surgical oncologist may suggest that surgery is your best option, while a medical oncologist may suggest chemotherapy. Explore your options.

Always seek a second opinion when:

- Your AYA oncologist has little knowledge or experience treating your type of cancer.
- 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 a clinical trial.

Finding your second opinion

Richard & Annette Bloch Family Foundation has a list of institutions across the country that offer second opinions.

<http://blochcancer.org/resources/multidisciplinary-second-opinion-centers/>

Cancer.net

<https://www.cancer.net/navigating-cancer-care/cancer-basics/cancer-care-team/seeking-second-opinion>

Many insurance companies will pay for a second opinion. Check with your insurance company first. You want to know about out-of-pocket costs for doctors who are not part of your insurance plan.

Plan ahead

Have copies of all your records and test results sent to the doctor you will see for a second opinion. This will take time and will need to be done before your appointment. Choose a doctor who listens to you and makes you feel like you have a say. Feel confident that you understand your cancer diagnosis and treatment plan. Your treatment should be a shared decision between you and your doctor. Choose a doctor you trust.

Review

- Oncologists are doctors who specialize in treating cancer. Look for an oncologist who specializes in your type of AYA cancer and has experience treating it.
- The results from your blood tests, imaging studies, and biopsy will determine your treatment plan.
- Staging tells the extent of cancer in your body. Each type of cancer has a slightly different staging system.
- Bring someone with you to appointments who can take notes and ask questions.
- After finding a doctor who specializes in AYA cancer patients, get a second opinion from another AYA doctor.

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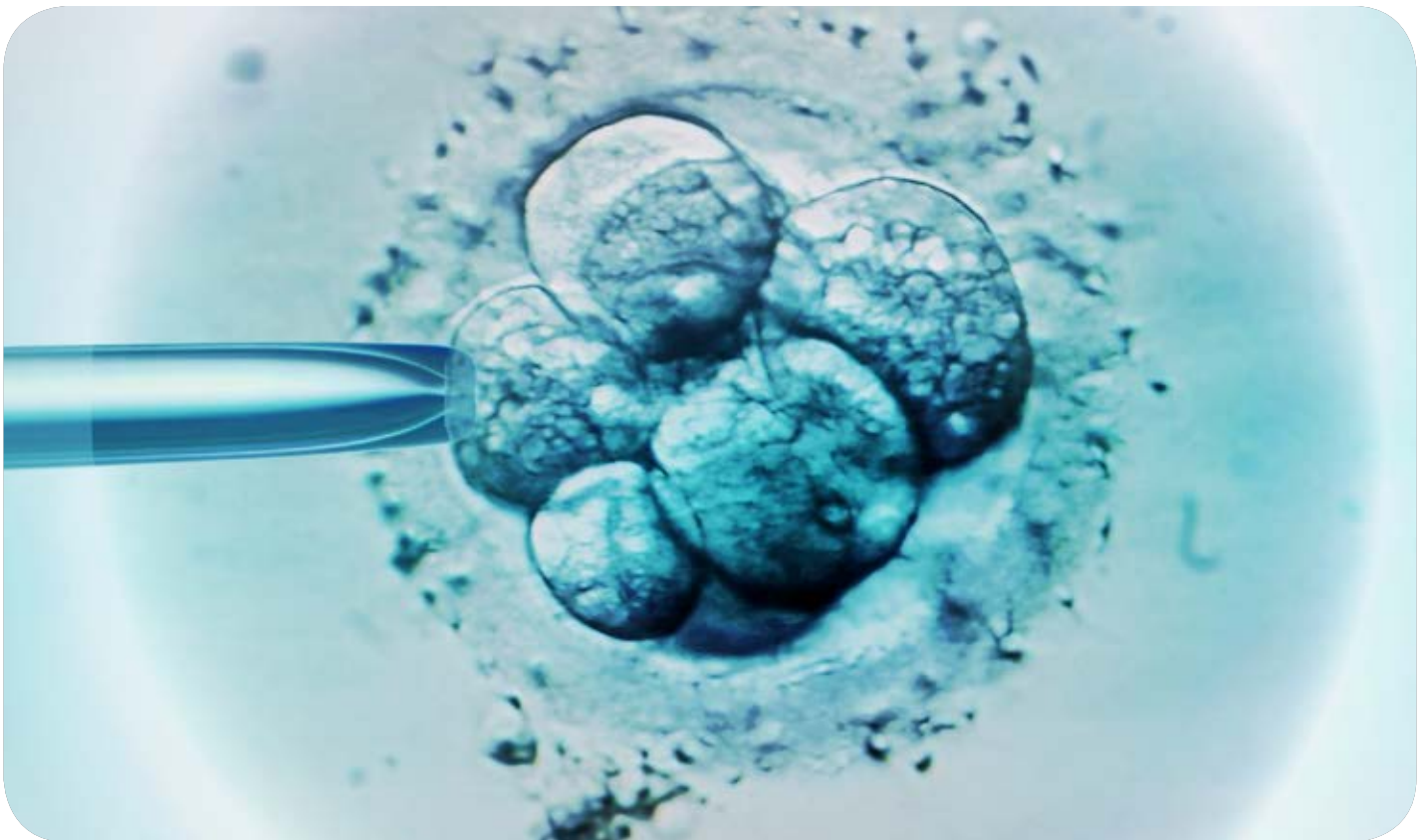
Fertility

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Treatment can affect your fertility or your ability to have children. This chapter presents fertility risks and steps you can take to preserve your fertility.

Having children

Your fertility or ability to have children may be important to you now or later. Ask your doctor how cancer and cancer treatment will change your fertility and sexual health now and in the future. It is recommended that you seek a referral for a fertility preservation clinic within 24 hours of diagnosis. Also, seek a referral for a mental health professional or counselor to help you decide on what is best for you.

Females

Female patients who can have children will have a pregnancy test before starting treatment. Cancer treatment can hurt the baby if you are or get pregnant during treatment. As a result, your doctor will talk to you about the use of contraception (birth control) to prevent pregnancy during and after treatment. If you think you want children in the future, talk to your doctor. Together, you may be able to take steps to preserve your fertility.

In order to preserve your fertility, you may need to take action before starting cancer treatment. You and your doctor should talk about your options. Whenever possible, your doctor should refer you to a fertility specialist before you start cancer treatment. For women, it is important to see a gynecologist or fertility specialist during and after treatment (not just before starting treatment).

Males

Cancer and cancer treatment can damage sperm in male patients. Talk with your doctor about the use of contraception (birth control) to prevent pregnancy during and after cancer treatment. If you think you want children in the future, talk to your doctor now. Men are also at risk for infertility. Sperm banking is an option. Your doctor might refer you to a fertility specialist.

Understanding the risks

Cancer treatment can harm the reproductive system. This depends on the treatment area, the type of treatment, and the intensity or combination of drugs.

Treatments that affect the reproductive area include:

- High-dose or targeted radiation to places like the pelvic area
- A type of chemotherapy that includes alkylating agents
- Surgery to remove tissue or organs from the reproductive area

If your treatment plan includes medicine or procedures that can have an effect on your fertility, work with your doctor and a fertility 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.

Your doctor will discuss with you the risks of delaying treatment. Together, you and your doctor will decide the timing of fertility preservation.

Infertility

Infertility is the complete loss of the ability to have children. The actual risk of infertility is related to your age at time of diagnosis, treatment type(s), treatment dose, and treatment length. Chemotherapy with alkylating agents has a higher risk of infertility in both men and women.

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 release 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; as a result:
 - the eggs can't get fertilized
 - fertilized eggs can't implant and grow inside the uterus

Sometimes, there isn't time for fertility preservation before you start treatment. Talk to your doctor about your concerns.

Fertility plan

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** should start the conversation about cancer-related infertility and help you understand the risks.
- **A nurse navigator** or case manager will help you navigate the referral process, coordinate the various specialists involved in your care, and deal with the insurance company.
- **An endocrinologist/reproductive specialist** specializes in fertility and cancer. This doctor will explain your fertility preservation options, including how they are done, success rates, timing, and costs. This specialist will carry out the fertility-sparing procedure that is right for you.
- **A genetics counselor** can assess your risk of passing on genetic abnormalities to your children. This is usually done within the first 2 months of starting treatment.
- **A gynecologist (for women) or urologist (for men)** can assess your risk of infertility and guide you in addressing your fertility needs.
- **A gynecologic oncologist** specializes in female cancers. This is usually a surgeon and may be the one to perform fertility-sparing surgery.

- **A family-planning specialist** can offer information about many different options for becoming a parent.
- **An adoption professional** 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** 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, think about your answer to the following questions:

- Have you always wanted children?
- How many children do you want to have? When?
- How do you feel about adoption?
- How would you feel about using donor sperm or donor embryos?
- How would you feel about having another woman, a surrogate, or a volunteer carry and give birth to your child?
- Do you have any religious or moral concerns about technologies such as IVF (in vitro fertilization) or embryo transplantation?

Consider the cost and your finances. All fertility preservation methods have an out-of-pocket cost. Check with your insurance company about which fertility preservation methods are covered.



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

Fertility 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 in the future must be done before you start cancer treatment. [See Guides 2 and 3.](#)

Before treatment

When possible, fertility preservation occurs before cancer treatment starts. Two methods of fertility preservation involve techniques that prevent damage and move healthy cells (sperm, eggs, or embryos) and store them for later use.

Damage prevention

The reproductive organs can be protected through fertility-sparing surgery. The surgeon removes only the cancerous tissue leaving 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. In radiation therapy, a special shield made of lead is used to prevent radiation from damaging the ovaries or testicles.

Ovarian transposition (oophoropexy) is another method to prevent damage to the ovaries during radiation therapy. A surgeon will move the healthy ovary (or ovaries) out of the radiation field and attach it to the wall of your abdomen. An oophoropexy is a proven option to preserve fertility.

An experimental technique called ovarian suppression 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 is no research on how well it works for protecting fertility. Also, there is limited evidence on how well male hormone suppression works to reduce the risk of male infertility during chemotherapy.

Banking healthy cells

Below is a list of proven and reliable methods for fertility preservation in AYAs.

- **Sperm banking (semen cryopreservation)** is a procedure that collects and freezes one or more samples of ejaculate. Men can find a local sperm bank or go online to order a sperm banking kit.
- **Embryo freezing (embryo cryopreservation) after in vitro fertilization (IVF)** is a process in which eggs are removed from the ovaries and fertilized with sperm in a lab. The embryo is then frozen. IVF can be done using a sperm donor.
 - IVF involves a series of hormone shots to prompt the ovaries to produce more than one egg. This may delay cancer treatment.
- **Egg freezing (oocyte cryopreservation)** is the use of hormones to make the ovaries produce multiple eggs. These eggs are removed and frozen. This procedure is no longer considered experimental. It does require hormone shots, which may delay treatment.

Experimental options

- **Ovarian tissue cryopreservation** is the surgical removal and freezing of a healthy ovary (or part of an ovary). After cancer treatment, the tissue is put back into the body. This is an option, if available.
- **Testicular sperm extraction** is the removal of 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). Sperm cells are taken from this tissue and frozen.

Guide 2. Fertility preservation for women

What are the options?	What is it?
Embryo freezing (embryo cryopreservation) after in vitro fertilization (IVF)	A process in which eggs are removed from the ovaries and fertilized by sperm in a lab. Then the embryo is frozen.
Egg freezing (oocyte cryopreservation)	A process in which eggs are removed from the ovaries and frozen.
Ovarian transposition (oophoropexy)	A surgeon will move the healthy ovary (or ovaries) out of the radiation field and attach it to the wall of your abdomen inside your body.
Ovarian tissue cyropreservation	A surgeon removes the ovary or part of it and freezes it. After cancer treatment, the ovary or tissue is put back. This option is not always available.

Guide 3. Fertility preservation for men

What are the options?	What is it?
Sperm banking (semen cryopreservation)	A procedure that collects semen and freezes one or more samples of ejaculate. Sperm banking kits can be ordered online.
Testicular sperm extraction	A surgeon removes a small portion of tissue from the testicle. Sperm cells are taken from the tissue and frozen. This option is not always available.

After treatment

Maybe you already started cancer treatment or you found out you are infertile from cancer treatment. You still have options.

- **Donor eggs or donor embryos** – Donor eggs are removed from women who have volunteered to go through hormone treatment to produce multiple eggs. Donor eggs are fertilized through IVF using sperm. Some couples donate their frozen embryos.
- **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 or frozen eggs (oocytes) 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.

A follow-up with a fertility specialist after treatment may be helpful for some patients.

Review

- Ask your doctor how cancer and cancer treatment will change your fertility and sexual health now and in the future. Know the risks.
- It is recommended that you seek a referral for a fertility preservation clinic within 24 hours of diagnosis. Also, seek a referral for a mental health professional or counselor to help you decide on what is best for you.
- Your fertility preservation options will vary depending on your age, gender, and type of cancer you have. If you think you might want children in the future, talk to your doctor now.
- For men: sperm banking is a reliable and proven method of fertility preservation.
- For women: embryo freezing, egg freezing, and ovarian transposition are reliable and proven methods of fertility preservation.

4

Treatment process

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This chapter focuses on the treatment process. Together, you and your doctor will choose a treatment plan.

Treatment team

To get the best care, you will need an AYA medical team that looks at the whole picture. Find a doctor who will not only care for your body or your physical health, but also your emotional well-being. Ask for a referral to a cancer center that has experts in treating AYAs 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. Seek out supportive care services by asking your care team.

Some members of your care team will be with you throughout cancer treatment, while others will only be there for parts of it. Get to know your care team and let them get to know you.

- **A primary care practitioner** (family doctor, internist, or general practitioner) handles medical care not related to your cancer. Keep this person up-to-date on your cancer care. This person should receive notes on your progress.
- **A medical oncologist or hematologist** specializes in the systemic treatment of cancer. This person prescribes chemotherapy. Often, this person will lead the overall treatment team and keep track of tests and exams done by other specialists.
- **Oncology nurses** provide 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 perform health checks and physical exams. They can also order and review tests, prescribe medicine, and order chemotherapy.
- **Social workers** provide counseling and help with discharge plans and home care. They can find local resources that offer support.
- **A patient navigator** helps with arranging financial support, transportation, and childcare during treatment. This person can also coordinate care among several doctors.
- **A dietitian or nutritionist** gives nutritional advice and help you plan menus to meet your nutritional needs during cancer treatment.

Depending on your diagnosis, your team might include:

- **A surgical oncologist** who performs cancer surgery
- **An anesthesiologist** who gives anesthesia, a medicine, so you do not feel pain during surgery or procedures
- **A radiation oncologist** who prescribes and plans radiation therapy to treat cancer
- **A pathologist** who reads tests and studies the cells, tissues, and organs removed during a biopsy or surgery
- **A diagnostic radiologist** who reads the results of x-rays and other imaging tests
- **A psychiatrist or clinical psychologist** who helps you cope with the thoughts and feelings you might have about cancer
- **A physical, occupational, speech, or respiratory therapist** who works with you on problems like breathing, moving, or speaking

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.

You know your body better than anyone. Help other team members understand:

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

Ask questions and seek support. Speak up! Let your treatment team know when it is too much or you need to take a break.

Your care team will grow during your cancer journey. Keep a list of names and contact information for each member of your team. This will make it easier for you and anyone involved in your care to know who to contact with questions or concerns.



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

Treatment therapies

Cancer treatment is rarely a one-shot deal. Most patients go through several rounds of therapy. Although the specific therapies used during each stage will depend on your diagnosis, your treatment plan is likely to take you through several stages. For example, you might have chemotherapy first, then surgery, followed by more chemotherapy. Your treatment plan is more than just therapy. It should include a plan for financial support. It should include mental, emotional, and spiritual support. Ask your care team for more information.

Neoadjuvant therapy

Neoadjuvant therapy is the first step used to shrink a tumor before the main treatment, usually surgery. This also happens before your first-line or primary therapy. Shrinking a tumor will make it easier to remove during surgery. Chemotherapy, radiation therapy, and hormone therapy are neoadjuvant therapies. If the cancer does not change or continues to grow during neoadjuvant treatment, your doctor may try a different therapy or stop neoadjuvant therapy and move forward with surgery or a first-line therapy.

Induction therapy

Induction therapy is given to reduce the amount of cancer in the body. Your next treatment will be based on how your body responds. Induction therapy is often part of other treatments and may be used to prepare the body for a **stem cell transplant (SCT)** or bone marrow transplant in patients with leukemia or lymphoma. The transplant takes healthy blood or bone marrow stem cells to restore cells and replaces ones that have been damaged by disease or cancer treatment.

First-line or primary therapy

First-line or primary therapy is the first attempt to get rid of (or control) the cancer in your body. Treatment can be delivered locally, systemically, or a combination of both. Local therapies target specific areas of the body that contain cancer cells. Systemic therapies attack cancer cells throughout the body.

There are 2 types of first-line therapy:

- **Local therapy** focuses on a certain area. It includes surgery and radiation therapy.
- **Systemic therapy** works throughout the body. It includes chemotherapy, targeted therapy, and immunotherapy. For some patients, the best option for primary therapy may be a clinical trial of a new treatment.

After primary therapy is complete, your doctor will perform 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 might be in **complete remission**.
- If some, but not all, signs and symptoms of cancer have disappeared, you may be in **partial remission**.
- If the cancer has grown or spread to other places in your body, it means the cancer is in **progression**.

Since every cancer cell is hard to find and destroy, you might need more rounds of treatment.

Adjuvant therapy

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

Second-line therapy (and beyond)

When cancer does not respond to first-line or primary therapy, or reappears after a period of remission, second-line therapy is tried. You may have more than one remission and recurrence, and you may need more lines of therapy. Treatment options may include another round of the first-line therapy or surgery, radiation therapy, immunotherapy, targeted therapy, chemotherapy, or a combination of all the above.

Clinical Trials

Clinical trials are an option during any stage of treatment and are encouraged in AYAs with cancer. As always, it is your choice whether or not to participate in any clinical trial.

Supportive care

Supportive care (also known as palliative care) is health care that relieves your symptoms caused by cancer and improves your quality of life. It is not cancer treatment. It might include pain relief, emotional or spiritual support, financial aid, or family counseling. In AYAs with cancer, supportive care should be included in every stage of cancer treatment, from the time of diagnosis until the time of death or cure. Don't be afraid to ask for it.

Survivorship care

A survivor is someone with a history of cancer. A person is a cancer survivor from the time of diagnosis until end of life. When treatment leads to remission (or no evidence of disease), you will need follow-up or survivorship care. During survivorship care you will still have a care team, but it will look different. You will need support. Seek out peer support groups, whether online or in-person, to help you adjust.

Recurrence (or relapse) vs. progression

You might hear words like recurrence, relapse, or progression during cancer treatment. These words 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. In remission, the signs and symptoms of cancer decrease or disappear. Remission can be partial or complete. Progression happens when cancer spreads or gets worse with no period of remission in between.

End-of-life care

Your treatment options will vary depending on your diagnosis. Your needs will change during and after treatment. The goal is to make you as comfortable as possible. Not all cancer can be cured. It helps to prepare yourself.

No one wants to think about death. Completing an advance directive to plan for end-of-life care is important. It will help you feel in control. An advance directive is a legal document that states your wishes in writing. Discuss your options for end-of life care with your doctor. Ask what life might be like as your cancer progresses. Talk things over with your friends and family. You are never too young for an advance directive.

Many AYAs want to die at home. This is not always possible. Discuss your wishes early on and throughout your treatment.

Side effects

Side effects happen. Most side effects happen when healthy cells are damaged during cancer treatment. 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. There are ways to manage side effects. Ask your doctor about the side effects of certain treatment options and how these side effects can be treated.

You might have long-term side effects from your cancer treatment such as early menopause and infertility. There is a risk of later health problems, even some forms of leukemia and cancer. Most side effects tend to be worst in the days after treatment and go away in time. Remember, you and your doctor are partners in care. Together, you should decide about the best course of treatment for your type of cancer. Know the side effects cancer treatment will cause now and in the future.

Follow your plan

Sticking with your treatment plan is very important. 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. Sometimes, you might want to forget about and take a break from cancer. When hanging with friends and having fun, you might forget to take your medicine or do drugs that interfere with treatment.

Cancer treatment can be tough. It is important to pick a treatment plan you know you can stick with. Talk to your care team about problems you might be having. There are things you can do to make it easier.

Take all of your medicine as prescribed. Take 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 can't afford cancer treatment. There is also more information under *Resources* in this guide.

Financial challenges

Lack of money to pay for medical tests, doctor appointments, or treatment is a real concern. AYAs do not always have a job or health insurance to pay for cancer treatment. Even if you have a job or health insurance, not everything is covered and you may struggle to pay for food, housing, and treatment. This is stressful. The good news is you are not alone and there are many options. Tell your care team about any money problems you have or if you have trouble getting to your appointments. They can help! Talk with your team's social worker, patient navigators, and hospital financial services about getting financial support.



Tips for side effects

- ✓ **Talk to your treatment team.** If you're having trouble coping with the treatment plan, let your care team know. They can find emotional, spiritual, 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.
- ✓ **Be honest.** Talk with your care team. They are there to help you. Find someone you can trust and feel comfortable talking to on your team.

Review

- A treatment plan is a written course of action that covers every stage of the treatment process. Most patients go through several rounds of treatment. Pick a treatment plan you can follow.
- Supportive care should be included in every stage of cancer treatment and be part of your treatment plan.
- Clinical trials are an option during any stage of treatment.
- When treatment leads to remission (or no evidence of disease) you move into follow-up care.
- Most side effects happen because healthy cells get damaged in the battle to rid your body of cancer. 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.

5

Treatment options

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Find out if a clinical trial for is an option for your AYA cancer. This chapter will discuss commonly used cancer treatments.

Clinical trials

Clinical trials study how safe and helpful tests and treatments are for people. Clinical trials find out 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.

Clinical trials have 4 phases.

- **Phase I trials** aim to find the safest and best dose of a new drug. Another aim is to find the best way to give the drug with the fewest side effects. These trials often involve about 20 people.
- **Phase II trials** assess if a drug works for a specific type of cancer. These trials often involve 20 to 100 people.
- **Phase III trials** compare a new drug to a standard treatment. These trials often involve hundreds or thousands of people.
- **Phase IV trials** test drugs approved by the U.S. FDA (**F**ood and **D**rug **A**dministration) to learn more about side effects with long-term use.

AYA patients should consider enrolling in open clinical trials for their specific disease if available. All clinical trials have a plan and are led by your treatment 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 a consent form, you can stop taking part in a clinical trial at any time.

Some benefits:

- 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.

Finding a clinical trial

Search the National Institutes of Health (NIH) database for clinical trials. It includes publicly and privately funded clinical trials, who to contact, and how to enroll. Look for an open clinical trial for your specific type of cancer. Go to ClinicalTrials.gov.

The National Cancer Institute's Cancer Information Service (CIS) provides up-to-date information on clinical trials. You can call, e-mail, or chat live. Call 1.800.4.CANCER (800.422.6237 or go to <https://www.cancer.gov>)

More information can be found under *Resources*.

Local treatments

Local treatments remove or destroy individual tumors or cancerous tissues. This type of treatment can be surgery or radiation. It treats a specific area of the body.



Surgery

Surgery is a local form of treatment. It is an operation or procedure done by a surgeon to remove cancer from the body. Surgery is usually one part of a treatment plan.

Surgery can be used to:

- ✓ cure the cancer by removing it all
- ✓ remove a section or debulk the tumor
- ✓ provide supportive care (relieve pain or discomfort)

There are 2 types of surgery:

Open – In open surgery, the surgeon makes a large cut or incision. The surgeon will remove the tumor and some surrounding tissues or lymph nodes.

Minimally invasive – In minimally invasive surgery, small cuts are made and a thin, lighted scope (laparoscope) is inserted. Special tools or a robot controlled by the surgeon is used.

Other surgery done before or after treatment:

- **Restorative (or reconstructive) surgery** repairs damage caused by other cancer treatments. In breast reconstruction, a surgeon rebuilds the shape of the breast after the removal of breast cancer.
- **Preventive (or prophylactic) surgery** removes tissue that carries a high risk of becoming cancer, such as precancerous polyps

in the colon. Preventive surgery can 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. 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 will plan ahead and give support after surgery. Follow-up care is needed for you to heal.



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. 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 2 main types of radiation treatment:

External beam radiation therapy (EBRT) uses a machine outside of the body to aim radiation at the tumor(s).

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

- The **solid form, called brachytherapy**, is placed in or around the tumor. This is a local form of treatment.

- **Liquid radiation** is given intravenously to attack cancer cells. This is a systemic form of treatment.

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

Radiation is given at different doses and schedules. You might have to plan time off from work or school. Discuss your concerns about the schedule or side effects before you start.



When you're fairly young and told 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

Systemic treatments

A systemic treatment works throughout the body.

There are 4 types of systemic treatment drugs used for cancer.

1. **chemotherapy** – attacks rapidly dividing cells in the body
2. **immunotherapy** – uses your body’s natural defenses to find and destroy cancer cells
3. **targeted therapy** – focuses on certain cell characteristics to find and destroy cancer
4. **corticosteroids** - uses synthetic (man-made) versions of hormones made by the adrenal glands

Oncologists often use more than one drug to treat cancer. This gives you a better chance of getting rid of the cancer, but it also puts healthy cells at risk for damage. Cell damage can lead to harmful side effects. In some cases, you might have to stop or delay treatment. Your doctor might have to change the systemic treatment approach. If you are concerned about the side effects, talk to your oncologist.



Chemotherapy

Chemotherapy is a main systemic treatment. All chemotherapy drugs affect the instructions (genes) that tell cancer cells how and when to grow and divide. Some chemotherapies damage DNA directly. Others get in the way of how cancer cells build DNA.

Chemotherapy can be given in a few ways. This depends on what your oncologist prescribes. You can get it in a cream (topical), a pill, or through a needle (injection).

Chemotherapy drugs are usually given as liquids through the following ways:

- **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 complete. Medical staff can also take blood from a catheter. This is also called a central line, Hickman catheter, or PICC (**peripherally inserted central catheter**).
- **Port** – small, round disc that is usually placed in the chest. It is where a catheter delivers chemotherapy. A minor procedure places the port where it stays in the body for days or weeks until treatment is complete. This is also called a port-a-cath.
- **Pump** – attached to a port or catheter. It allows chemotherapy to be given outside of the hospital. The pump controls the amount of the drug going into your body.

A chemotherapy cycle will have days of treatment followed by days of rest. These cycles vary in length depending on which drugs are used.



Immunotherapy

The immune system usually does a good job of defending your body against germs, viruses, and parasites. 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. Immunotherapy boosts immune activity. It helps the immune system find and attack cancer cells.



Targeted therapy

Targeted therapies seek out how cancer cells grow, divide, and move in the body. Targeted therapies are usually grouped by what they do or the part of the cell they target. These therapies target

molecules inside cancer cells. As a result, targeted therapies are less likely to damage healthy cells or cause side effects. Targeted therapies might be in pill form or given through a vein or IV.

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



Corticosteroids

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 near the kidneys, which help regulate blood pressure and reduce inflammation. Corticosteroids are not the same thing as the steroids used by some athletes.

Used alone or with chemotherapy, corticosteroids can be given as a pill or through an IV, cream, or injection. If your doctor gives you corticosteroids, be sure to take them exactly as prescribed.

Make use of your team

Your treatment team has a wealth of experience and information. An AYA cancer program will have 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 similar therapies. Complementary therapy is used with standard therapies and can help prevent or manage side effects.

Talk with your treatment team about any complementary therapies you are using or thinking about using. This is important. Nutritional supplements, vitamins, and herbs can prevent some cancer drugs from working. Your team can help you decide which complementary medicines are best for your age and type of cancer.

Your team will watch for and ask you about side effects. Tell your care team about how you are feeling. Keeping a journal might help keep track of your side effects and how bad they are at different times of the day.

Review

- Clinical trials study how safe and helpful tests and treatments are for people.
- Radiation therapy uses high-energy particles or rays to kill cancer cells.
- Chemotherapy is a systemic cancer treatment.
- Immunotherapy boosts immune activity.
- Targeted therapies seek out how cancer cells grow, divide, and move in the body.

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After treatment

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This chapter 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.

Follow-up care

Follow-up care is important to a cancer survivor. Even though treatment is over, you will still need tests and have to see your health care providers.

Some survivors have few or no health problems. Many have ongoing health challenges caused by cancer treatment and surgery. Some symptoms take time to show up, called late effects. Your risk for late effects will depend on the type(s) of cancer treatment you had, and the dose and the length of time you were treated. AYA cancer survivors have a high risk of developing a wide range of late effects. It is important to go to your follow-up appointments. The sooner late effects are treated the better. Ask your care team about what late effects could occur. This will help you know what to look for.

Possible late effects from cancer treatment

- Secondary cancers
- Heart, lung, and kidney problems
- Hearing and vision problems
- Infertility

Survivorship care

There are 3 goals of a cancer treatment plan:

- To cure the cancer: to get rid of all the cancer cells in your body
- To control the cancer: to keep cancer from spreading, slow its growth, or destroy cancer cells that have spread to other parts of your body
- To ease cancer symptoms (sometimes called palliation): to shrink cancer tumors that are causing pain or pressure

The goals of a survivorship care plan are different. A survivor is someone with a history of cancer. A person is a cancer survivor from time of diagnosis until end of life.

A survivorship 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.

There are 3 areas in a survivorship 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

Your survivorship plan should include:

- A good relationship with your primary care provider for routine health issues
- A summary of your cancer treatment history so your new doctors have a complete understanding of your case
- Recommendations for follow-up care:
 - Names and contact information for follow-up doctors
 - A schedule for follow-up visits with an oncology specialist
 - Tests to check for recurrence like blood tests, imaging tests, and other screenings
 - Routine check-ups with your primary care provider
 - Dental exam and cleaning every 6 months for patients who received chemotherapy or radiation
 - Signs and symptoms of long-term and late effects
- Recommended vaccinations:
 - Annual flu (influenza) vaccination
 - HPV vaccination for males and females ages 9 to 26
- Resources on survivorship challenges like:
 - Physical problems
 - Anxiety, depression, and emotional distress
 - Financial concerns
 - Health care coverage/insurance
 - Disability benefits
 - Lifestyle changes (smoking cessation, nutrition, exercise)

AYA survivors

Distress, depression, and anxiety are common among AYA cancer survivors. Counseling and practical support will help you during and after cancer treatment. Seek out peer support groups. Talk to your care team. Ask for a referral to a specialist or other professional who can help.

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. It can take time to recover from the effects of cancer treatment. Survivors may take on too much. Friends and family may not realize you still need their support.

Surviving cancer can also give you a 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. Try cutting back on your course load. Plan 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 these limits. 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 available to students who are cancer survivors.

At work

Cancer survivors can still be productive in the work place. You may worry about what others think of you returning to work. You may be concerned about how you will cope when going back to full-time work.

If you were able to keep working during your treatment, the transition may come easier. If you are moving into a new job or will be working with people who don't know about your illness, 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.

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 refers to changes that will allow you to continue to do your job without causing a significant hardship for the employer.

When cancer returns

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. 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. Use your valuable time and energy to move forward not backward. This time around you know what to expect.

- You know more. The first time out, everything was a surprise. Now, you have experience.
- You have built relationships. If the same treatment team is seeing you, you are 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.

Review

- Regular follow-up care is critical to protecting your long-term health.
- Instead of a cancer treatment team, you will now need a cancer survivorship team.
- Your risk for late effects will depend on the type(s) of cancer treatment you had.
- AYA cancer survivors have a high risk of developing a wide range of late effects.
- A survivorship 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.



People assume that when treatment is finished, cancer is finished. It is not that simple. The people around you return to their normal routines, but your life is forever changed. Treatment might be over, but the doctors' 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

7

Care planning

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Find out what is advance care planning. Prepare 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.

Advance care planning

Advance care planning (ACP) is making decisions now about the care you would want to receive if you become unable to speak for yourself. Advance care planning is for everyone, not just for those who are very sick. It is a way to ensure your wishes are understood and respected.

Advance care planning starts with an open and honest discussion with your doctor and/or your family and loved ones. Ask your doctor about your cancer prognosis and what to expect if your cancer progresses. Discuss the medicines or therapies that will give you the best quality of life. Include family and friends in your advance care planning. Make your wishes clear. It is important that everyone understands what you want.

Once you have decided, you will fill out a legal document called an advance directive that states what you want done if you are too sick or unable to tell the doctors yourself.

Doctors are required by law to follow the care instructions in an advance directive. Health care professionals will not do anything that is illegal even if it is in your advance directive. This is why it is important to speak with your care team.

If your family disagrees with your plan, speak to your care team. Sometimes they or other specialists, called palliative care providers, can help you and

your family navigate these difficult conversations. Research studies show that talking helps. When AYA patients share their wishes, families usually follow their requests, even when they would not have made the same choices themselves.

- 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.
- An advance directive may ask what you would want if you had a severe disability, or were no longer able to think or act for yourself.
- Many advance directives include plans to limit what can be done if you want a natural death. DNAR or DNR (**Do Not Attempt Resuscitation** or **Do Not Resuscitate**) and DNI (**Do Not Intubate**) orders tell medical providers not to revive you with CPR (**cardiopulmonary resuscitation**) or hook you up to a breathing machine.

Name the person who will make health care decisions for you (health care proxy) in the advance directive. This person may have to make some very tough decisions. Choose carefully when selecting your proxy and make sure the proxy feels comfortable representing you.

Tell your care team and family about your advance directive and its contents. Give a copy of your advance directive to all of your doctors. Make sure the person you have chosen to speak on your behalf has a copy. Make your wishes clear. If you and your family disagree about treatment, the advance directive should reflect **YOUR** wishes—not what you think your parents or partner would want. An advance directive can be changed. If your thoughts on feeding tubes or respirators change, you can change your advance directive. When you make changes, give everyone a copy of the new advance directive.

Hospice care

Hospice is a type of care designed to provide medical, psychological, and spiritual support to patients with incurable disease and the people who love them. The goal is comfort. Many insurance plans will only cover hospice services when you have less than 6 months to live and/or cancer treatment aimed at a cure has stopped.

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.

The goal of hospice care is:

- To control symptoms
- To ease physical and emotional suffering
- To improve quality of life

Services can be provided in your home, a hospice facility, or even in the hospital. Hospice doctors, nurses, social workers, and chaplains are experts in helping patients work through the spiritual and emotional challenges of coping with death. 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 grief support after the patient has died.

In addition to making plans about your end-of-life 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*, (<https://www.cancer.gov/publications/patient-education/advanced-cancer>) has a detailed worksheet you can use.
- Think about making the arrangements for a funeral or memorial service in advance.

Review

- Advance care planning (ACP) is making decisions now about the care you would want to receive if you become unable to speak for yourself. Advance care planning is for everyone.
- An advance directive is a legal document of your wishes for treatment should you become unable to speak for yourself.
- When AYA patients share their wishes, families usually follow their requests, even when they would not have made the same choices themselves.
- Hospice is a type of care designed to provide medical, psychological, and spiritual support to patients with incurable disease and the people who love them.
- Providing support for family members is a major part of the hospice approach to end-of-life care.

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Resources

52 Questions to ask your doctors

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Learn all you can about cancer. Resources are available for people with cancer and their loved ones.

Questions to ask your doctors

You may meet with experts from many fields of medicine during this time. Strive to have helpful talks with each person. Prepare questions before your visit. Take notes and get copies of your medical records. Bring a family member or friend with you to these visits. They can take notes and also ask questions.

Suggested questions are listed on the following pages.



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 of diagnosis: 27

Websites

General information on AYA cancer

LIVESTRONG

Not-for-profit organization providing resources and services for patients with cancer, including AYAs.
<https://www.livestrong.org/we-can-help/young-adults>

Teen Cancer America

Not-for-profit organization aiming to educate and support medical institutions and health care professionals in the development of specialized AYA cancer care units.
<https://teencanceramerica.org/>

Stupid Cancer (The I'm Too Young for This! Cancer Foundation, i[2]y)

The nation's largest online support community for AYAs affected by cancer. In addition to providing resources for AYAs with cancer, this organization holds conferences and podcasts and hosts a peer-to-peer matching app.
<https://stupidcancer.org>

13Thirty Cancer Connect

National non-profit organization dedicated to helping teens and young adults 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.
13thirty.org

Ulman Cancer Fund for Young Adults

Grassroots organization dedicated to supporting, educating, connecting, and empowering AYA cancer patients and survivors.
<https://ulmanfoundation.org/>

Cancer diagnosis and treatment

American Cancer Society

Understanding your diagnosis
<https://www.cancer.org/treatment/understanding-your-diagnosis.html>

The Leukemia & Lymphoma Society

Personalized clinical trial navigation by registered nurses.
<https://www.lls.org/CTSC>

The Leukemia & Lymphoma Society

Blood cancer disease information
<https://www.lls.org/disease-information>

The Leukemia & Lymphoma Society

Types of treatment
<https://www.lls.org/treatment>

National Cancer Institute

How to find a doctor or treatment facility if you have cancer.
<https://www.cancer.gov/about-cancer/managing-care/services>

National Center for Complementary and Integrative Health

<https://nccih.nih.gov/>

National Comprehensive Cancer Network

Cancer staging guide
<https://www.nccn.org/patients/resources/diagnosis/staging.aspx>

US National Institutes of Health

Registry and results database of publicly and privately supported clinical studies.
<https://www.clinicaltrials.gov/>

Fertility

American Society of Clinical Oncology (ASCO)

What to Know: ASCO's Guideline on Fertility Preservation

<https://www.cancer.net/navigating-cancer-care/dating-sex-and-reproduction>

LIVESTRONG Fertility Program

LIVESTRONG Fertility is a LIVESTRONG initiative dedicated to providing reproductive information, support, and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

<https://www.livestrong.org/what-we-do/program/fertility>

Hope for Two...The Pregnant with Cancer Network

Free support for women diagnosed with cancer while pregnant.

www.hopefortwo.org

The Oncofertility Consortium

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 United States.

<http://oncofertility.northwestern.edu/>

Verna's Purse

Financial assistance program for those in need of fertility services.

<https://www.reprotech.com/verna-s-purse.html>

Financial

FinAid! The Smart Student Guide to Financial Aid

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.

www.finaid.org/scholarships/cancer.phtml

The Leukemia & Lymphoma Society

Copay and other financial resources

<https://www.lls.org/support/financial-support>

National Comprehensive Cancer Network (NCCN) Virtual Reimbursement Resource

https://www.nccn.org/reimbursement_resource_room/

The Patient Access Network (PAN) Foundation

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.

<https://www.panfoundation.org>

Patient Advocate Foundation Co-Pay Relief Program

Provides direct financial support for pharmaceutical co-payments to insured patients who financially and medically qualify.

<https://www.copays.org/>

RxAssist

Searchable online database of pharmaceutical companies' patient assistance.

<https://www.rxassist.org/patients>

Surviving and Moving Forward: The Samfund for Young Adult Survivors of Cancer

Helps young adult survivors of cancer successfully transition into their post-treatment life, by providing financial support through grants and scholarships.

<https://www.thesamfund.org>

Legal

CaringInfo

Provides free resources and information to help people make decisions about end-of-life care and services.

<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

Five Wishes

<https://fivewishes.org/>

Advance care planning for patients. Easy to understand advance directive form in many languages and legal in 42 states.

Disability Rights Legal Center (DRLC)

Education and support for cancer patients, their families, health care professionals, and advocates on matters like maintaining employment through treatment, accessing health care and government benefits, taking medical leave, and estate planning.

<https://thedrlc.org/cancer/>

Cancer and Careers

Resources for those with cancer on how to thrive in the workplace.

<https://www.cancerandcareers.org/en/at-work/back-to-work-after-cancer/back-to-work>

GYST

Online resource to help you take care of important documents such as your will and power of attorney.

<https://gyst.com/>

LGBTQ

CancerCare

Coping with cancer as an LGBT person

<https://www.cancercare.org/publications/209-coping-with-cancer-as-an-lgbt-person>

National LGBT Cancer Network

The National LGBT Cancer Network works to improve the lives of LGBT cancer survivors and those at risk.

<https://cancer-network.org/>

National LGBT Cancer Project

Lesbian, gay, bisexual, and transgender cancer survivor support and advocacy nonprofit organization.

<https://lgbtcancer.org/>

Managing side effects

American Cancer Society

Information about cancer, sex, and sexuality.

<https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html>

<https://www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer/cancer-sex-sexuality.html>

The American Cancer Society's

“tlc”™ Tender Loving Care

Affordable wigs and hair loss products, as well as mastectomy products.

www.tlcdirect.org

American Institute for Cancer Research

Nutrition information

www.aicr.org/reduce-your-cancer-risk/diet/

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

Body changes

<https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/body-changes>

Diet and exercise

<https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/diet-and-exercise>

Managing pain

<https://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer/managing-pain>

Cancer and Careers

Information about what to look for in and how to care for wigs.

<https://www.cancerandcareers.org/en/at-work/where-to-start/managing-treatment-side-effects/wigs-for-cancer-patients>

Look Good, Feel Better

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.

lookgoodfeelbetter.org (for women)

www.lookgoodfeelbetterformen.org/ (for men)

National Cancer Institute

Side Effects of Cancer Treatment

<https://www.cancer.gov/about-cancer/treatment/side-effects>

Nutrition in Cancer Care

<https://www.cancer.gov/about-cancer/treatment/side-effects/appetite-loss/nutrition-pdq>

National Institutes of Health (NIH)
In Brief: Your Guide to Healthy Sleep

<https://www.nhlbi.nih.gov/files/docs/public/sleep/healthysleepfs.pdf>

Navigating life

American Society of Clinical Oncology (ASCO)

Coping With Cancer

<https://www.cancer.net/coping-with-cancer>

Patient information on survivorship, including late effects

<https://www.cancer.net/survivorship/late-effects>

American Cancer Society Road to Recovery Program

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

<https://www.cancer.org/treatment/supportprogramsservices/road-to-recovery>

Cancer101

CANCER101 helps cancer patients and their families function as active partners in their care. The site offers tools such as the Cancer101 Planner that can help patients navigate their cancer journey.

www.cancer101.org/

Cancer and Careers

Empowers and educates people with cancer to thrive in the workplace, by providing expert advice, interactive tools, and educational events.

<https://www.cancerandcareers.org/en>

Cancer Care

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.

<https://www.cancercares.org/>

CaringBridge

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.

<https://www.caringbridge.org/>

Caregiver Action Network

Provides resources for family and caregivers, such as education and peer support.

<https://caregiveraction.org/>

Children's Oncology Group

Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers.

<http://survivorshipguidelines.org/>

Family Patient Online Patient Update Reports

Website that allows family members to post up-to-date information about the condition of their loved ones.

www.familypatient.com

First Descents

Provides free outdoor experiences for young adults with cancer. Helps participants find support, face fears, and heal.

<https://firstdescents.org/>

Imerman Angels

Pairs individuals touched by cancer with other people who have fought and survived the same type of cancer (a Mentor Angel). These 1-on-1 relationships inspire hope and offer support from someone who is uniquely familiar with the experience of cancer.

<https://www.imermanangels.org/>

Job Accommodation Network

Offers tools to help patients understand the types of workplace adjustments that may help them continue working during and after cancer treatment.

<https://askjan.org/>

The Leukemia & Lymphoma Society

Listen in as patients, caregivers and other health care professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics.

<https://www.lls.org/TheBloodline>

The Leukemia & Lymphoma Society

Virtual meeting place for talking with other patients and keeping up to date with the latest blood cancer resources and information.

<https://www.lls.org/community>

The Leukemia & Lymphoma Society

Moderated weekly online chat that provides support for young adults and allows them to share information.

<https://www.lls.org/chat>

LIVESTRONG**Late Effects of Cancer Treatment**

<https://www.livestrong.org/we-can-help/healthy-living-after-treatment/late-effects-of-cancer-treatment>

Your Survivorship Care Plan

<https://www.livestrong.org/we-can-help/healthy-living-after-treatment/your-survivorship-care-plan>

Lotsa Helping Hands

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.

<https://www.lotsahelpinghands.com/>

MyLifeLine

Nonprofit organization that encourages cancer patients and caregivers to create free, customized websites to build an online support community of family and friends.

<https://www.mylifeline.org>

National Cancer Institute**Adolescents and Young Adults with Cancer: Survivorship**

<https://www.cancer.gov/types/aya#5>

Facing Forward: Life After Cancer Treatment

<https://www.cancer.gov/cancertopics/coping/life-after-treatment/>

National Coalition for Cancer Survivorship

The oldest survivor-led cancer advocacy organization in the country, advocating for quality cancer care for all Americans and empowering cancer survivors.

<https://www.canceradvocacy.org>

Patient Advocate Foundation

Provides professional case managers who serve as advocates for patients in dealing with insurance companies, employers, and/or creditors.

<https://www.patientadvocate.org>

Young Survival Coalition (YSC)

Network of breast cancer survivors and supporters dedicated to the concerns and issues that are unique to young women and breast cancer.

<https://www.youngsurvival.org/>

Words to know

ACP

advance care planning

acquired mutation

A mutation that happens after conception.

adolescents and young adults (AYA)

People who are 15 to 39 years of age.

AJCC

American Joint Committee on Cancer

alkylating agent

A drug that damages a cell's DNA by adding a chemical to it.

apoptosis

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

bone marrow

The sponge-like tissue in the center of most bones.

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.

cell

The building blocks of tissues in the body.

cervical cancer

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

chemotherapy

Cancer drugs that stop the cell life cycle so cells don't increase in number.

clinical trial

A type of research that assesses how well health tests or treatments work in people.

colorectal cancer

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

complementary medicine

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

complete blood count (CBC)

A lab test that measures the number of red blood cells, white blood cells, and platelets.

computed tomography (CT) scan

A test that uses x-rays from many angles to make a picture of the insides of the body.

contrast material

A dye put into your body to make clearer pictures during imaging tests.

CPR

cardiopulmonary resuscitation

deoxyribonucleic acid (DNA)

A chain of chemicals in cells that contains coded instructions for making and controlling cells. Also called the "blueprint of life."

DNAR

do not attempt resuscitation

DNI

do not intubate

DNR

do not resuscitate

ejaculate

A mix of sperm and fluids. Also called semen.

eligibility criteria

For a clinical trial, certain terms a person needs to meet to take part in the research study. The terms may include things like age, type of cancer, and general health.

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

A protein that helps to digest food.

excisional biopsy

A procedure that removes an entire tumor to test for cancer cells.

external beam radiation therapy (EBRT)

A cancer treatment with radiation delivered 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.

FDA

Food and Drug Administration

gene

Coded instructions in cells for making new cells and controlling how cells behave.

genetic mutation

An abnormal change in the coded instructions within cells.

germ cell

A type of cell that becomes an egg within a woman's ovary and a sperm within a man's testis.

gynecologic oncologist

A doctor who's an expert in female reproductive cancers.

hematologist

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

hormone

A chemical in the body that triggers a response from cells or organs.

hypnotherapy

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

immunotherapy

A treatment with drugs that help the body find and destroy cancer cells.

incisional biopsy

A procedure that removes a tissue sample from a tumor.

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 an object placed near or in the tumor. Also called brachytherapy.

in vitro fertilization (IVF)

Procedure that removes eggs from the ovaries and combines them with sperm for fertilization in a lab.

IV

Intravenous

leukemia

Cancer of the bone marrow and blood.

lymph

A clear fluid containing white blood cells.

lymph node

A small, bean-shaped disease-fighting structure.

lymphoma

A cancer of white blood cells called lymphocytes that are within the lymph system.

magnetic resonance imaging (MRI)

A test that uses radio waves and powerful magnets to make pictures of the insides of the body.

medical oncologist

A doctor who's an expert in cancer drugs.

melanoma

A skin cancer of pigment-making cells.

menopause

The point in time when menstrual periods end.

needle biopsy

A procedure that removes tissue or fluid samples with a needle.

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's an expert in the treatment of cancer.

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 women that produce eggs and hormones.

pathologist

A doctor who's an expert in testing cells and tissue to find disease.

platelet

A type of blood cell that forms clots to control bleeding. Also called thrombocyte.

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 a certain type of cancer cells.

radiation oncologist

A doctor who's an expert in treating cancer with radiation.

radiation therapy

A treatment that uses intense energy to kill cancer cells.

radiologist

A doctor who is an expert in reading imaging tests.

red blood cell

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

reproductive system

The group of organs that work together to make a baby. The vagina, cervix, uterus, fallopian tubes, and ovaries in women, and the penis, testicles, and prostate in men.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

sperm

A sex cell from a man that can enter a woman's egg to make a baby.

stem cell

An immature cell from which other types of cells develop.

stem cell transplant (SCT)

A cancer treatment that replaces abnormal blood stem cells with healthy cells. Also called hematopoietic cell transplant (HCT).

surgeon

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

surgical oncologist

A doctor who's an expert in operations that remove cancer.

systemic therapy

A type of treatment that works throughout the body.

targeted therapy

A drug treatment that impedes the growth process specific to cancer cells.

testicle

One of a pair of egg-shaped glands found inside the sac between the legs of a man.

thyroid

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

TNM

tumor, node, and metastasis

tumor grade

A rating of how much cancer cells look like normal cells.

tumor marker

A substance found in body tissue or fluid 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 in which babies grow until birth. Also called womb.

white blood cell

A type of blood cell that fights disease and infection.

x-ray

A test that uses small amounts of radiation to make pictures of the insides of the body. Also called a plain radiograph.

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Adolescent and Young Adult (AYA) Oncology. It was adapted, reviewed, and published with help from the following people:

Dorothy A. Shead, MS
Director, Patient Information
Operations

Erin Vidic, MA
Medical Writer

Tanya Fischer, MEd, MSLIS
Medical Writer

Susan Kidney
Graphic Design Specialist

Laura J. Hanisch, PsyD
Medical Writer/Patient
Information Specialist

Rachael Clarke
Senior Medical Copyeditor

Kim Williams
Creative Services Manager

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Adolescent and Young Adult (AYA) Oncology, Version 2.2019 were developed by the following NCCN Panel Members:

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

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

Frederick Millard, MD
UC San Diego Moores Cancer Center

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

Shipra Gandhi, MD
Roswell Park Comprehensive Cancer Center

Kevin C. Oeffinger, MD
Duke Cancer Institute

Lynda Beaupini, MD
Roswell Park Cancer Institute

Robert Goldsby, MD
UCSF Helen Diller Family
Comprehensive Cancer Center

Diane Puccetti, MD
University of Wisconsin
Carbone Cancer Center

Smita Bhatia, MD
University of Alabama at Birmingham
Comprehensive Cancer Center

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

Damon Reed, MD
Moffitt Cancer Center

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

Alex Huang, MD
Case Comprehensive Cancer Center/
University Hospitals Seidman Cancer
Center and Cleveland Clinic Taussig
Cancer Center

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

Rashmi Chugh, MD
University of Michigan
Rogel Cancer Center

Tara Sanft, MD
Yale Cancer Center/Smilow Cancer Hospital

Carrye R. Cost, MD
University of Colorado Cancer Center

Mary S. Huang, MD
Dana-Farber/Brigham and Women's
Cancer Center | Massachusetts General
Hospital Cancer Center

Margaret von Mehren, MD
Fox Chase Cancer Center

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

Linda A. Jacobs, PhD CRNP
Abramson Cancer Center at the
University of Pennsylvania

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

Douglas Fair, MD, MSCI
Huntsman Cancer Institute at the
University of Utah

Michael P. Link, MD
Stanford Cancer Institute

NCCN Staff

Jeanelle Folbrecht, PhD
City of Hope Comprehensive Cancer Center

John A. Livingston, MD
The University of Texas
MD Anderson Cancer Center

Lisa Gurski, PhD
Oncology Scientist/Medical Writer

Dorothy A. Shead, MS
Director, Patient Information Operations

* Reviewed this patient guide.
For disclosures, visit www.nccn.org/about/disclosure.aspx.

NCCN Cancer Centers

Abramson Cancer Center
at the University of Pennsylvania
Philadelphia, Pennsylvania
800.789.7366
penmedicine.org/cancer

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska
800.999.5465
nebraskamed.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
uhhospitals.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 National Medical 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
massgeneral.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
hopkinskimmelfcancercenter.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
www.mayoclinic.org/cancercenter

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 Comprehensive
Cancer Center
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
Rogel Cancer Center
Ann Arbor, Michigan
800.865.1125
mcancer.org

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

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

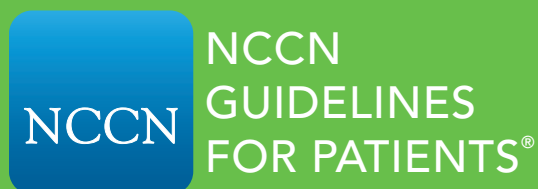
Vanderbilt-Ingram Cancer Center
Nashville, Tennessee
800.811.8480
vicc.org

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

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National Comprehensive
Cancer Network®

3025 Chemical Road, Suite 100
Plymouth Meeting, PA 19462
215.690.0300

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