# Caring for Adolescents and Young Adults

National
Comprehensive
Cancer
Network®

VERSION 2013

Also available at NCCN.com

# NCCN Guidelines for Patients®

Presented with support from the LIVE**STRONG** Foundation LIVE**STRONG**® and Critical Mass CRITICAL MASS THE YOUNG ADULT CANCER ALLIANCE

# About this booklet

## Its purpose

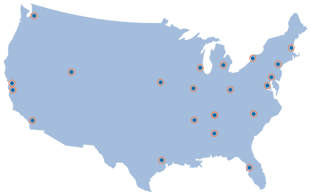
Learning that you have cancer is a shock. Learning that you have cancer when you're still in school, or just getting started in your career, or just starting a family makes the shock even greater.

This booklet is designed to help you understand what's happening and to get the support you need, including the best possible cancer treatment. It includes some basic information on the cancer tests and treatments you may go through, tips for coping with the physical, social, and emotional challenges of cancer treatment, and information on resources that can help make the process easier.

NATIONAL COMPREHENSIVE CANCER NETWORK
NCCN FOUNDATION®
Guiding Treatment, Changing Lives.

## Supported by the NCCN Foundation

The NCCN Foundation supports the mission of the National Comprehensive Cancer Network® (NCCN®) to improve the care of patients with cancer. One of its aims is to raise funds to create a library of booklets for patients. Learn more about the NCCN Foundation at www.nccn.com/nccn-foundation.



## The source of the information

NCCN is a not-for-profit network of 21 of the world's leading cancer centers. Experts from NCCN have written treatment guidelines for physicians and other medical professionals who care for adolescents and young adults (AYAs) with cancer. These treatment guidelines suggest what the best practice is for cancer care. The information in this booklet is based on these guidelines.

## For more information

This booklet focuses on the overall challenges faced by AYAs with cancer. Details on specific cancers are beyond the scope of this booklet. But, the full library of patient booklets and additional information on specific types of cancers can be found on **NCCN.com**.

# Table of contents

# How to use this booklet

## Who should read this booklet?

This booklet is designed for adolescent and young adult (AYA) patients dealing with cancer. It may also be useful for caregivers, family, and friends who want to assist them. Reading this booklet at home may help you absorb what your doctors have said and prepare for treatment. As you read, you may find it helpful to create a list of questions to ask your doctor.

## Where should I start reading?

That depends on what you need to know! Each topic is described at the start of Parts 1 through 9. Page numbers are listed so you can flip right to information you need. Your treatment team can also point out the sections that apply to you and provide you with more information.

## Does the whole booklet apply to me?

According to the National Cancer Institute, an adolescent or young adult is anyone between the ages of 15 and 39. That's a pretty big range, so not all of the information in this booklet will apply to every young person with cancer (for example, if you're still in school you might not need information on how to deal with cancer in the workplace). Feel free to skip over sections that don't apply to your particular situation.

And always, please keep in mind that this booklet does not replace the knowledge and suggestions of your doctors. The first and most important rule of dealing with cancer is to communicate openly and honestly with your treatment team. They are there to help.

## Help! I don't know these words!

This booklet includes many medical words that describe cancer, tests, and treatments. These are words that you will likely hear your treatment team use in the months and years ahead. Most of the information may be new to you, and it may be a lot to learn. Don't get discouraged. Keep reading and review the information.

Words that you may not know are defined in the text or in the sidebar. Words with sidebar definitions are underlined when first used on a page. All definitions are also listed in *A cancer dictionary* in Part 11. Acronyms—words made by using the first letter of other words, such as AYA for "adolescents and young adults"—are spelled out the first time they are used.

# Part 1: But I'm too young to have cancer!

> One day, I'm wondering why I keep getting all these bruises. The next, a doctor is telling me I have leukemia. All I could think was 'You've got to be kidding me! Somebody made a mistake. I'm too young to have cancer!'

Nancy,
diagnosed with leukemia at age 28

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# Part 1: But I'm too young to have cancer!

## You're not alone

Finding out you have cancer is hard. Finding out you have cancer when you're still in high school, or college, or just starting a career or a family can be even harder.

Every year in the U.S. (**U**nited **S**tates), more than 70,000 AYAs (**a**dolescents and **y**oung **a**dults)—people between 15 and 39 years old—are diagnosed with cancer. So if you've just been diagnosed, you are anything but alone.

Dealing with cancer is different for AYAs. As a young person with cancer you face special challenges and bring special strengths to the fight to get well. You also need different kinds of support than older patients, whose bodies are no longer changing, and whose lives, careers, families, and financial situations may be more settled and stable.

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

## Cancer basics

The human body contains billions of cells that serve as the building blocks for everything from your brain to your toenails. Each of these cells is controlled by instructions contained in DNA—the genetic code that tells cells what to become (lung, heart, skin, etc.), what to do, (make hormones, absorb nutrients, kill germs, etc.), and when to die. Normal cells are programmed to die after a certain time—or when they become damaged—so that new cells can take their place (Figure 1).

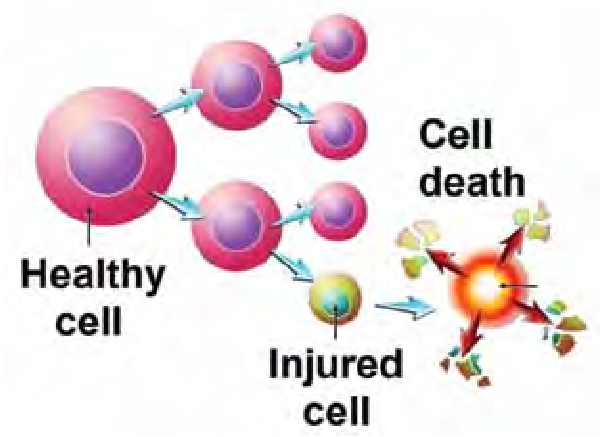

**Figure 1. Normal cell growth**
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# Part 1: But I'm too young to have cancer!

## Mutation: Where it all begins

Cancer gets its start when something goes wrong in the genetic code—a process called mutation. (Think the X-Men, minus the cool super powers.) Mutations can be inherited—passed on from parent to child and present before you are born—or acquired—caused by later genetic damage.

Inherited mutations are found in all of the body's cells. People with inherited genetic mutations have a higher risk for certain cancers, but that doesn't mean they will definitely develop cancer. That's because it usually takes more than one mutation to turn a normal cell into a cancer cell. People with inherited mutations are further along the road to getting cancer than people without mutations, but it takes additional damage—acquired mutations—to get cancer started.

Inherited mutations are quite rare, and are involved in only a few types of cancer. Acquired mutations, on the other hand, are found in every person with cancer. Unlike inherited mutations, which affect every cell in the body, acquired mutations happen in specific cells or types of cells. Acquired mutations can happen because of:

- **Exposure to carcinogens** (substances that damage DNA and cause cancer) – Common carcinogens include ultraviolet rays from the sun, various chemicals (including chemicals found in tobacco and alcohol), and radiation.
- **Viruses –** Some viruses damage the genetic code in a way that makes infected cells more likely to become cancerous. HPV (**h**uman **p**apilloma**v**irus), for example, is a sexually transmitted virus that is the leading cause of cervical cancer. It has also been linked to head and neck cancers in young adults. And some forms of hepatitis virus have been linked to liver cancer.
- **Time –** Every time a cell divides, it has to make a copy of its original DNA. Sometimes the copies aren't perfect, and contain genetic mutations. Usually, other genes repair the damage or the immune system gets rid of the abnormal cell before it can divide again. But sometimes abnormal cells survive and the damaged DNA is passed along every time the cells divide. Over time, the accumulated mutations may lead to cancer.

> “Here’s the thing—when you’re relatively young and have never had any major illnesses, cancer is the last thing on your mind. Even when you’re regularly drenching the bed from profuse night sweats. Even when you begin to have trouble taking deep breaths, because something is growing inside your chest cavity. Even when a lymph node ‘pops’ in your neck, out of the blue one morning.”

Allyson
Non-Hodgkin’s lymphoma survivor, diagnosed at age 37

# Part 1: But I'm too young to have cancer!

## Carcinogenesis: The road from normal to cancer

The process of changing from a normal cell to a cancer cell is called carcinogenesis. Carcinogenesis happens when genes that control cell growth and death are damaged and instead of dying the cells continue to grow and divide (Figure 2).

Over time, these abnormal cancer cells grow and divide enough to form a clump of cells called a primary tumor. As the tumor grows, it can start to invade nearby healthy tissues, causing damage and making it hard for organs to function properly.

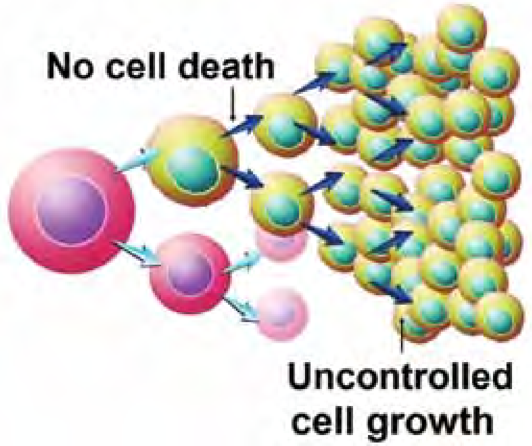

**Figure 2. Carcinogenesis**

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## Metastasis: Cancer on the move

Normal cells typically stay where they are—liver cells stay in the liver, lung cells stay in the lungs, etc. But cancer cells can escape from the primary tumor and move to other parts of the body—a process called metastasis.

The ability to spread is what makes cancer so dangerous. Once cancer cells get loose, they can travel to distant parts of the body through the lymphatic system or blood vessels.

When cancer cells settle into new places in the body, they can replace or damage healthy cells, and eventually may damage other tissues or organs. Cancer that has spread to a nearby body part is called a local metastasis. Cancer that has spread to a body part far from the primary tumor is called a distant metastasis.

## Benign versus malignant tumors

You may have heard some people use the phrase "benign tumors." The word benign comes from two Latin words that mean "well born," and is used to describe tumors that:

- Are confined to one place,
- Are very similar to normal cells,
- Do not invade nearby tissues, and
- Cannot break away and metastasize.

Common forms of benign tumors include cysts (lumps filled with fluid), lipomas (lumps of fatty cells), and fibromas (lumps of fibrous or connective tissue cells).

# Part 1: But I'm too young to have cancer!

Strictly speaking, benign tumors aren't really cancer. But they can cause problems if they grow so large they press on nearby organs or damage healthy tissues. In addition, some benign tumors are considered pre-cancerous, meaning that they may progress to cancer. Fortunately, once removed, most benign tumors do not come back.

Malignant—from Latin words meaning "badly born"—refers to true cancers. The cells of a malignant tumor tend to be very different from those of normal tissue, and are likely to invade nearby organs and metastasize to other parts of the body.

## This is not your grandmother's cancer

It's estimated that only 5% of cancer cases in the U.S. are diagnosed in people between 15 and 39 years of age. Yet cancer is the leading cause of death among AYAs. While many of the cancers diagnosed in AYAs are treatable and even curable, survival rates for AYAs have not improved to the same extent that they have for young children and older adults.

# Part 1: But I'm too young to have cancer!

Why?

One reason is that younger people go to the doctor less often than people older than age 40, so early signs of cancer are more likely to be missed. Teens and young adults who have no or minimum health insurance are unlikely get regular health tests that might detect cancer before it has spread.

Young adults also develop different types of cancer than older adults (Table 1). Lymphomas, for example, are the most common cancers in people who are 15 to 24 years old, but are less common as people get older. In addition, the cancers young people do develop often have different mutations and behave very differently than the same cancers in children and older patients. For example:

## Table 1. Top cancers by age group

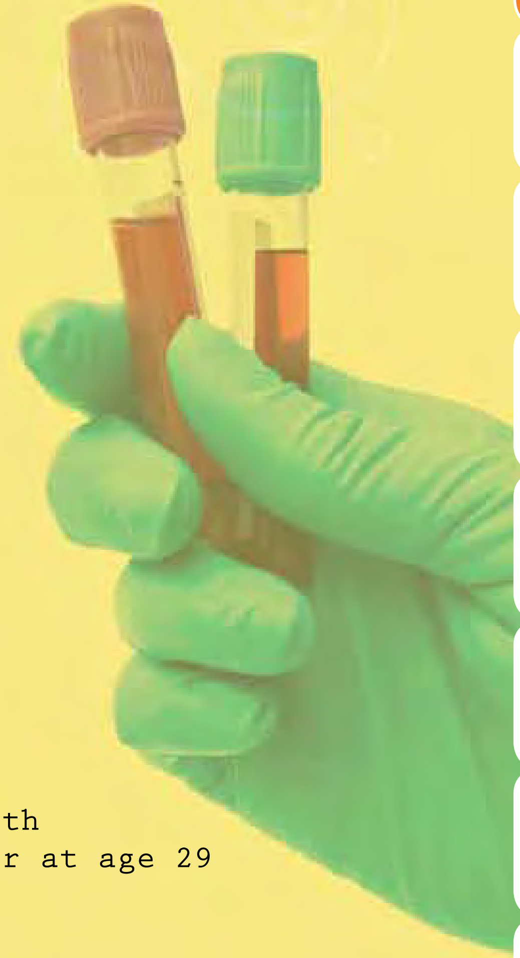
| 15 to 19 | 20 to 24 | 25 to 29 | 30 to 34 | 35 to 39 | 40 + |
|---|---|---|---|---|---|
| Lymphomas | Lymphomas | Thyroid cancer | Breast cancer | Breast cancer | Prostate cancer |
| Leukemias | Germ cell | Lymphomas | Thyroid cancer | Thyroid cancer | Breast cancer |
| Germ cell | Thyroid cancer | Germ cell | Melanoma | Melanoma | Colorectal cancer |
| Central nervous system (CNS) | Melanoma | Melanoma | Lymphomas | Cervical & uterine cancer | Lung cancer |
| Thyroid cancer | Leukemias | Breast cancer | Germ cell | Lymphomas | Bladder cancer |
| Bone sarcomas | CNS | Cervical & uterine cancer | Cervical & uterine cancer | Colorectal cancer | Lymphomas |
| Melanoma | Soft tissue sarcomas | CNS | Colorectal cancer | Germ cell | Melanoma |
| Soft tissue sarcomas | Bone sarcomas | Leukemias | Soft tissue sarcomas | Soft tissue sarcomas | Ovarian cancer |
| Colorectal cancer | Colorectal cancer | Soft tissue sarcomas | Leukemias | Leukemias | Kidney cancer |

- Women younger than age 40 who develop breast cancer are more likely to have a family history of the disease and are more likely than older patients to develop tumors that do not respond to hormone therapies.
- Melanoma in young adults is less likely to be caused by sun exposure and also tends to be less severe than melanoma in older people.
- Young adults with colorectal cancer are more likely to have inherited mutations and more aggressive disease.

Cancer treatment in AYAs is also complicated by the fact that their bodies are still changing. The years between 15 and 40 are filled with physical and hormonal changes that affect not only how cancer develops, but also how the body responds to various cancer treatments. As a result, a treatment plan that works well in children or older adults with a particular cancer may be less effective for patients in their 20s or 30s.

On the plus side, younger patients are often in better overall physical shape than older patients, which means they can tolerate more aggressive treatment than someone who is middle-aged or elderly. In fact, young adults with cancer are ideal candidates for clinical trials of new cancer treatments. (More on that topic in Part 5.)

# Part 2: Dealing with the diagnosis



> "I received [the call] while at work . . . 'I got the results back from the biopsy. You have cancer.' I sank into a nearby chair in shock, and when I could finally speak, I said 'ok.' I barely comprehended what the doctor said next. She went on to give me a list of names of doctors and instructions on what to do next . . . I wrote everything down as fast as I could, while my knees and legs wobbled in shock."

Gloria,
diagnosed with
breast cancer at age 29

# Part 2: Dealing with the diagnosis

## Getting diagnosed

Getting diagnosed with cancer is a process. It starts when you or your doctor notices something abnormal: like a lump that wasn't there before, or a mole that changes shape or color, or a pain that can't be explained. Your doctor will usually begin with relatively simple tests, then move on to more complex and invasive procedures in order to get the best possible information about what is happening in your body. Very often he or she may send you to a specialist who is more experienced in diagnosing and treating the specific type of cancer you have.

### Medical history and physical exam

A medical history and physical exam are two of the most basic tools of diagnosis. A medical history is just what it sounds like—a history of everything that has ever happened to you health-wise, including any symptoms you recently have had or currently have.

When taking your medical history, your doctor will gather information about any health events that have happened in your life—including surgeries, accidents, and past illnesses—as well as information on current problems and any medications you are taking. (It may help to make a list before you go to your appointment to make sure you don't forget anything.) Because some cancers and other health problems can run in families, your doctor will also ask about the medical histories of close relatives such as your parents, grandparents, and brothers or sisters.

Doctors often perform a physical exam along with taking a medical history. A physical exam is an examination of your body for signs of disease. During this exam, your doctor will listen to your lungs, heart, and belly. He or she will also likely feel and apply pressure to various parts of your body to see if organs are of normal size, are soft or hard, or cause pain when touched.

### Giving your medical history: Honesty is the best policy

Because the information in your medical history will help determine what treatment is best for you, it's important to be as complete and as accurate as possible.

Be honest and tell your doctor if you drink alcohol, use recreational drugs such as marijuana, or are taking over-the-counter medications, supplements, or naturopathic treatments. Be honest about your sexual history and habits. Remember, doctors aren't there to judge you. They just need to understand everything that can have an impact on your health so they can make the best possible decisions about your care.

# Part 2: Dealing with the diagnosis

## 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 tumor markers that can sometimes be found in the blood when cancer is present. Once treatment starts, blood tests will be used to check your response to treatment and to monitor potential side effects.

Before blood tests can be run your doctor will need to get blood samples. This can be done at a doctor's office, a laboratory, or in the hospital, and is usually done by a nurse or a phlebotomist, a technician who specializes in taking blood samples. Most nurses and phlebotomists are really, really good at taking blood as smoothly and painlessly as possible. If you don't like needles or get a little freaked out by the sight of blood, be sure to let the nurse or technician know right up front so he or she can help ease you through the process.

### *The complete blood count*

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

### *Blood chemistry tests*

In addition to the CBC, your doctors will probably order frequent blood chemistry tests to keep track of what's happening in other parts of your body. Blood chemistry tests measure the levels of minerals, enzymes, and waste products that are normally found in the blood. A blood chemistry panel may include more than a dozen different tests, including several measures that will allow your doctor to track how your heart, liver, kidneys, and other organs are working.

## Definitions

**Enzymes:** Proteins that speed up chemical reactions in the body

**Normal range:** A set of values based on results seen in 95% of healthy individuals

**Platelets:** A type of blood cell that forms blood clots to control bleeding

**Red blood cells:** A type of blood cell that carries oxygen from the lungs to all parts of the body

**Side effect:** An unplanned physical or emotional response to treatment

**Tumor markers:** Substances found in body fluid or tissue that may be a sign of cancer

**White blood cells:** A type of blood cell that fights disease and infection

## Imaging tests

When a tumor is suspected, doctors want to get a look at exactly where it is and how large it is. Imaging tests are used to take pictures of the inside of your body. They allow doctors to see the primary tumor, and also to see if there is evidence of cancer in other places in your body. Common imaging tests include x-rays; CT (**c**omputed **t**omography) scans, which use x-rays from many angles to make a picture of the inside of the body; MRI (**m**agnetic **r**esonance **i**maging) scans; and PET (**p**ositron **e**mission **t**omography) scans.

For most imaging tests, you just have to lie there and let the machine do the work. The hardest part is staying still and not getting bored. For some tests, you may also have to take a special contrast material that will highlight a particular part of the body so it shows up better on the scan. Sometimes this material is injected in a vein, sometimes it's given in an enema, and sometimes it's administered as a not-particularly-tasty drink called a barium swallow. A barium swallow is a liquid containing barium sulfate that is swallowed to coat and outline the walls of the esophagus and upper GI (**g**astro**i**ntestinal) tract so they can be seen on an x-ray. More often than not, there are no side effects after going through an imaging test. If radiation is used, the amount is small.

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

## Questions to ask your doctor about: Testing

Your doctor should provide you with information on the tests you will be having, including their potential risks and what you need to do to prepare. The questions below can serve as a guideline to help you fill in any gaps as you talk with your doctor.

- What tests will I have?
- Where and when will the tests take place?
- How long will they take?
- Will I be awake?
- Will it hurt?
- What are the risks?
- How do I prepare for testing?
- How soon will I know the results and who will explain them to me?
- Who will talk with me about the next steps? When?

# Part 2: Dealing with the diagnosis

## Biopsies

Blood tests and imaging studies can tell a doctor only so much about a potential cancer. The only way to be absolutely sure about what is going on is to look at the cells themselves. And that means taking a biopsy—removing some suspicious tissue so that it can be examined by a pathologist and tested for cancer cells. A pathologist is a doctor who's an expert in testing cells to find disease.

Biopsies often include removal of tissue from nearby lymph nodes (groups of special disease-fighting cells) to determine whether the cancer has moved beyond the original tumor. Once the biopsy has been completed, a pathologist will look at the tissue sample—or samples—under a microscope to determine:

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

The pathologist may also perform additional tests to see if the cancer cells contain specific genes (instructions in cells for making and controlling cells) or proteins that can help in understanding how the cancer is likely to behave and which treatments will be most effective.

Biopsies are usually performed by a surgeon, a doctor specially trained in performing surgical procedures. Biopsy techniques include bone marrow aspiration (removal of liquid bone marrow for testing), endoscopic biopsy, incisional biopsy (surgical removal of a sample of tumor tissue for testing), excisional biopsy (surgical removal of the entire tumor for testing), laparoscopic biopsy, laparotomy (a long surgical cut in the abdomen), lumbar puncture, needle biopsy, and thoracotomy.

Before undergoing a biopsy, you may be asked to stop eating or drinking for a period of time, stop taking some medicines, or stop smoking. Depending on the

### Definitions

**Endoscopic biopsy:** Use of a thin, lighted tube to remove tissue samples to test for disease

**Laparoscopic biopsy:** A thin, lighted tube inserted through a small cut in the belly to remove tissue to test for disease

**Lumbar puncture:** Use of a thin needle inserted into the lower part of the spine

**MRI scan:** A test that uses radio waves and powerful magnets to see the shape and function of body parts

**Needle biopsy:** Insertion of a needle into a tumor to remove tissue for testing

**PET scan:** A test that uses radioactive material to see the function of organs and tissues inside the body

**Thoracotomy:** Surgery done through a large cut in the chest to remove tissue

> You need to take time out and really do your research. No one is going to know who’s right for you. No one is going to know what’s comfortable for you. It’s so important to do your homework and put yourself first. Whether it means taking a week off work or focusing in and doing your research, just do it.”

Natasha
Hodgkin’s lymphoma survivor

type of biopsy, you may be given general anesthesia so you can sleep through the procedure, local anesthesia to numb the area being sampled, or a sedative that makes you feel drowsy and relaxed.

Biopsies are generally safe procedures. Some biopsies may be done in less than 30 minutes while others may require an hour or more. If your biopsy requires general anesthesia, you can expect to spend up to four hours in the recovery room after the surgery is complete, where a nurse will keep track of your blood pressure, pulse, and breathing.

Because the sedatives will take several hours to wear off completely, you will need to have someone there to drive you home. Depending on the type of biopsy, the incision site (or sites) could be sore for a while, and you may have to avoid physical activities such as heavy lifting while the incisions heal.

## Making sense of the diagnosis

Reviewing the test results marks the real beginning of your cancer journey. Since the information from your blood tests, imaging studies, and biopsy will determine the treatment you receive, it is particularly important that you understand what they mean.

Of course, the shock of hearing that you have cancer can make it hard to absorb all the technical and scientific information being thrown at you. Following a few simple rules can help prevent you from feeling overwhelmed.

- First and foremost, be sure to **have someone with you** when meeting with your doctors. Having another set of ears in the room will help ensure that you don't miss important information. You may also want to consider writing down or recording the conversation so you can review it later.
- **Get copies of** blood tests, imaging results, pathology reports, and information about the specific type of cancer you have. It will be helpful when getting a 2nd opinion (more on that later), and will make it easier to keep track of your progress.
- **Get organized.** As you go through treatment you are going to accumulate a lot of paper—insurance forms, medical records, tests results, etc. If you've never been particularly organized, this is the time to start. Come up with a plan before you're drowning in paperwork, and make sure you have easy access to crucial information like the names and contact numbers of everyone on your treatment team and the details on your insurance coverage. If possible, enlist a friend or family member to help you put a system together.
- **Be prepared.** Cancer doctors are often on very tight schedules, so you'll want to make the most of the time you have with your doctor. Make a list of the questions you want to have answered or issues you want to discuss before you go to each doctor's appointment. Share the list with your "extra set of ears" so he or she can help make sure your questions are answered. Many of your questions will

be answered by other members of the doctor's team (nurse practitioners, physician assistants, and other staff members).

### The pathology report

The pathology report is written by a doctor for a doctor, which can make it a bit of a challenge for patients to understand. Don't be afraid to ask your doctor questions. The report will cover everything from your name, age, and other details on who you are (check this carefully!) to details on how the biopsy sample looks, how the cancer seems to be growing, and what it's likely to do.

One of the most important items in the pathology report is information on the sample's tumor margins. When evaluating the biopsy samples the pathologist will examine the outer edges of the tissue to see whether cancer cells are present. Samples that have no cancer cells at the edges are considered to have negative margins, which may mean the surgeon may have removed all of the cancer. Samples that have cancer cells at the edges are said to have positive margins, which may indicate that cancer cells are still present.

### Staging

Staging is a sort of shorthand designed to quickly summarize the extent of a person's cancer. Your doctor will use information about the stage of your disease to determine your prognosis (the likely course the cancer will take) and to choose the best treatment for you.

The stage of the cancer may be expressed in several different ways. One approach is the summary staging system, which groups cancers based on their location in the body:

- **Carcinoma in situ** is limited to the layer of cells where it began.
- **Localized cancer** is limited to the organ where it began.

### Questions to ask your doctor about:
### Test results

When all of your test results are in, your doctor should go over them with you in detail. The questions below can serve as a guideline to help you fill in any gaps as you talk with your doctor.

- What type of cancer do I have?
- How aggressive is it?
- Have any cancer cells traveled away from the original tumor? Are lymph nodes involved?
- Were any of the results unclear, and if so, should the tissue be retested?
- Do I need more tests to tell whether the cancer has traveled to other parts of my body?

- **Regional cancer** has spread to nearby lymph nodes or organs.
- **Distant cancer** has metastasized to distant parts of the body.
- **Unknown** means that not enough information is available to determine the cancer's stage.

Tumors may also be described as stage 0 through IV:

- **Stage 0** is a very early form of cancer that has not yet invaded other areas.
- **Stage I–III** indicates increasingly extensive disease, including larger tumor size and greater spread of cancer to nearby organs or lymph nodes.
- **Stage IV** indicates that the cancer has spread to distant organs.

Some cancers are staged using the TNM system, which is based on the extent of the primary tumor (T), whether or not cancer was found in nearby/regional lymph nodes (N), and whether distant metastases are present (M). (Table 2)

## Table 2. The TNM staging system

| Primary Tumor (T) | Regional Lymph Nodes (N) | Distant Metastases (M) |
|---|---|---|
| TX: unable to evaluate | NX: unable to evaluate | MX: unable to evaluate |
| T0: no evidence of primary tumor | N0: no cancer found in lymph nodes | M0: no distant metastases found |
| T1-T4: size of primary tumor | N1-N3: cancer in lymph nodes | M1: distant metastases found |

Each type of cancer has a slightly different staging system, so the letters and numbers may mean something different for a person with ovarian cancer than they do for someone with lymphoma.

## Exploring your options

When you've been diagnosed with cancer it's perfectly natural to want to get the cancer out of your body right away. And in some cases—such as acute leukemia—time really is of the essence. But the truth is that most cancers are not that urgent, as long as treatment can begin within a few weeks of diagnosis. So it makes sense to take the time to get a 2nd opinion and be certain you are working with doctors who understand the unique needs of AYAs with cancer and have experience treating patients with the type of cancer you have.

### Getting a 2nd opinion

Even if you like and trust your doctor, it is usually a good idea to get a 2nd opinion. Evaluating a biopsy sample requires skill and a practiced eye, and there is always a possibility that another doctor will see something the first pathologist missed. A new oncologist may also be able to present a different perspective on the type of treatment that's best for you. For example, a surgical oncologist may suggest that surgery is your best option, while a medical oncologist may suggest chemotherapy.

If nothing else, a 2nd opinion can confirm that your first doctor and pathologist got it right. (Most doctors understand the importance of a 2nd opinion. If your doctor gets angry or insulted at the idea, it may be time for a new doctor.) Getting a 2nd opinion is particularly important if:

- Your doctor has limited experience treating the type of cancer you have,
- Your test results were borderline or inconclusive,
- You live in a rural area,
- You have a rare type of cancer,
- You are interested in enrolling in a clinical trial, or
- Your doctor has said there's nothing to be done.

Many insurance companies will pay for a 2nd opinion. Check with your insurance company about its rules on 2nd opinions—including potential out-of pocket costs if the doctors you choose are not part of your insurance plan.

# Part 2: Dealing with the diagnosis

Preferably, your “2nd opinion” doctor should not be connected to your current doctor in any way. When searching for a doctor to do a 2nd opinion, look for someone who:

- Has a higher level of expertise than your current doctor,
- Is associated with a hospital that has an AYA oncology program or has knowledge and experience in treating AYAs with cancer,
- Has been an author on scientific papers related to the cancer you have, or
- Has been involved in clinical trials related to the cancer you have and/or with AYA cancer patients.

Once you’ve found your 2nd opinion doctor, make arrangements to have copies of all your records sent to him or her. Do this well before your appointment! If you run into trouble having records sent, pick them up yourself and bring them with you.

If your 2nd opinion doctor offers different advice, make an appointment with your first doctor to discuss the differences. If you’re not sure what to do, get a 3rd opinion. Or a 4th. Do whatever you need to do to feel confident about your diagnosis and your treatment plan.

## Finding your 2nd opinion

**The R.A. Bloch Cancer Foundation (www.blochcancer.org/resources/multidisciplinary-second-opinion-centers/)** has compiled a list of institutions across the country that offer multidisciplinary 2nd opinions: consultations where a medical oncologist, radiation oncologist, and surgeon review a case and discuss it openly together in front of the patient.

**The Navigate Cancer Foundation (www.navigatecancerfoundation.org)** has experienced cancer nurses who can help you find a qualified doctor for a 2nd opinion.

### Choosing your doctor

Sometimes the doctor who diagnoses the cancer is not the right person to treat it. As we've seen, cancer is a different disease in AYAs than it is in people older than 40. If your doctor has limited experience in treating people your age or with the particular cancer you have, it might be best to seek out someone who has more experience. Look for someone who:

- Has expertise in treating the particular cancer you have (for example, a doctor who has published papers or participated in clinical trials related to that cancer),
- Is associated with a hospital that has an AYA oncology program, or
- Has extensive experience in treating AYAs with cancer.

### Questions to ask your doctor about:
### Your doctor

- How many patients have you treated with this kind of cancer?
- How many of them were my age?
- Does your hospital have a program for AYAs with cancer?
- If not, can you help me access resources designed for patients my age?
- Have you participated in research on this kind of cancer? On cancer in AYAs?
- Are you involved in any clinical trials on the treatment of this kind of cancer?

# Part 3: Preparing for the future

> "It was so overwhelming. I come from a big family and always wanted at least three kids. The cancer diagnosis alone was all-consuming—I didn't anticipate the decisions I'd have to make about a future family."

Arieana, diagnosed with Hodgkin's lymphoma at age 22

## Cancer treatment and fertility

It may seem weird to be thinking about babies when you're about to start doing battle with cancer. But the fact that you are at an age when you are able to have children is one of the many things that sets you apart from the majority of people who are diagnosed with cancer. That's important, because cancer and its treatment can damage your reproductive organs and make it difficult or impossible to have children once treatment is over.

Up until recently most young cancer patients—and their doctors—didn't think much about fertility (the ability to have babies) until treatment was already completed and the damage was done. But in 2006 the American Society of Clinical Oncology published guidelines recommending that oncologists talk with their AYA patients about fertility issues, inform them about options for preserving fertility, and provide referrals to fertility specialists when possible *before* starting treatment.

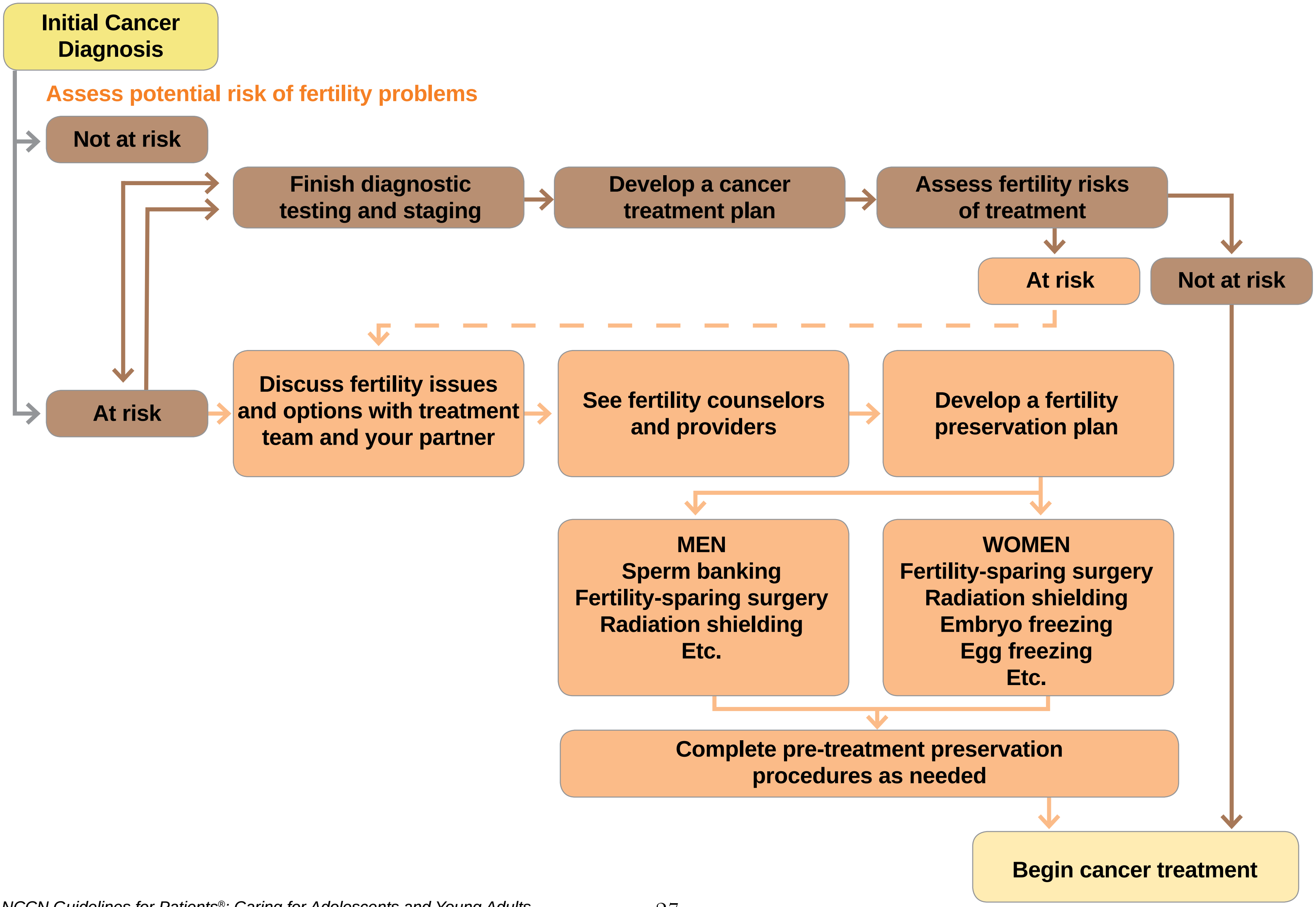
Unfortunately, not all oncologists are following these guidelines. In fact, some surveys indicate that only about half of oncologists talk about fertility with their patients, and even fewer are referring at-risk patients to reproductive specialists who can assist patients in understanding and preserving their fertility options.

So even if you've never really thought much about being a parent, it's important to talk to your doctors about fertility issues as soon as you're diagnosed, before treatment begins. (Figure 3 outlines how fertility preservation can be worked into the process of confirming your diagnosis and developing your treatment plan.)

If your treatment plan includes drugs or procedures that can have an effect on your fertility, you can work with your oncologist and a reproductive specialist to find ways to limit the damage or take steps so you can still have children in the future. If treatment absolutely can't be delayed, a reproductive specialist can help you to understand what your fertility options may be after treatment is completed. Your oncologist will carefully evaluate your case—including the risks of delaying treatment—to arrive at a decision regarding the timing of fertility preservation measures.

**Figure 3. Steps to protecting your fertility**

Adapted from Flemming F. Developing a community oncofertility program. Oncology Issues 2012; May-–June: 20-–28.



## Understanding the risks

The complete loss of the ability to have children is called infertility. In men, infertility happens when the testicles can no longer make sperm (a condition known as azoospermia) or when the pathways that sperm travel through are blocked or damaged. In women, infertility happens when:

- The ovaries can no longer make eggs: a condition called premature ovarian failure or early menopause,
- There is damage to the uterus (where babies grow during pregnancy) or other parts of the reproductive system that makes it impossible for eggs to become fertilized, or
- There is damage to the uterus or other parts of the reproductive system that makes it impossible for a fertilized egg to implant and grow inside the uterus.

Cancer treatment can lead to infertility because many cancer therapies are designed to attack cells that divide rapidly. Unfortunately, this includes a lot of normal, healthy cells that have a high turnover rate, such as hair follicles, the mucus membrane of the mouth and GI tract, and—you guessed it—the ovaries and testicles. Cancers that develop in the reproductive system also carry a risk for fertility problems.

The actual risk of infertility varies depending on the cancer, the treatment, treatment dosage, and the age of the person receiving cancer treatment. In general, the higher the dose and the older your age, the more likely you are to experience problems. High-risk treatment regimens include:

- **Radiation therapy** of the pelvis, abdomen/belly, brain (for women), testicles (for men), or whole body;
- **Combination therapy**, particularly if it includes alkylating agents such as cyclophosphamide, melphalan, or procarbazine; and
- **Conditioning regimens**, an aggressive form of chemotherapy used to suppress the immune system and kill as many cancer cells as possible in preparation for a stem cell (or bone marrow) transplant.

Treatment-related infertility isn't always permanent. Men tend to have a better chance of regaining their fertility, because the male body has stem cells that can be used to make more sperm. Women, on the other hand, have a limited supply of eggs, and if the ovaries are badly damaged they may not be able to recover. Because cancer treatments can decrease the overall number of eggs, the risk for premature ovarian failure can last for months or even years after completing chemotherapy, even if a woman had normal menstrual cycles during and after treatment.

### Assessing your risk

Fertile Hope—an initiative launched by the LIVE**STRONG** Foundation—offers online risk calculators that can help you figure out if your disease, or its treatment, will make it difficult for you to have children.

Go to www.fertilehope.org/tool-bar/risk-calculator.cfm for more information.

## Questions to ask your doctor about: **Fertility**

Your doctor should discuss fertility issues with you before beginning cancer treatment. The questions below can serve as a guideline to help you fill in any gaps as you talk with your doctor.

- Will the treatment you are recommending affect my ability to have children?
- If so, what is your best estimate for the chance I will become infertile due to cancer therapy?
- Are there other ways to treat this cancer that will not affect my fertility?
- Is there anything that can be done during treatment to protect my fertility?
- How long would it be safe to delay the start of my treatment, if I wanted to consider fertility preservation?
- Is there anything I can do after treatment to preserve my fertility?
- How will I know if I am fertile when treatment is over? Are there tests that I can take?
- For women: After my treatments are over, how long will it take for my periods to begin again? If I am not having periods, should I still use contraceptives?
- For women: Is pregnancy safe for me after treatment? If so, how long should I wait after treatment to become pregnant?
- Does this hospital have an oncofertility team?
- If not, where can I find support for coping with fertility issues?
- Can you refer me to a specialist who can help preserve my fertility?

## Definitions

**Alkylating agents:** Drugs that damage instructions in cancer cells so they can't grow and multiply

**GI tract:** Group of organs eaten food passes through

**Hair follicles:** Tube-like openings in the skin where hairs develop and grow

**Menopause:** Twelve or more months without a menstrual period

**Mucus membrane:** Layer of cells that moistens and lines surfaces in the body

**Ovaries:** Pair of female organs that make eggs and hormones

**Sperm:** Male reproductive cells formed in the testicles

**Stem cell transplant:** Replacing damaged immature blood-forming cells called stem cells with healthy cells

## Setting your priorities

Fertility preservation is all about keeping your options open. Whether you know you eventually want to have children or aren't really sure at the moment, reproductive specialists and the members of an oncofertility team can help you sort through what's important to you and understand your options.

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

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

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

- Have you always wanted children?
- How many children do you want to have?
- Does it matter if your children are biologically related to you?
- How do you feel about adoption?

# Part 3: Preparing for the future

- How would you feel about using donor sperm or donor embryos?
- How would you feel about having a surrogate bear your child?
- Do you have any religious or ethical concerns about technologies such as IVF (in vitro fertilization) or embryo transplantation?

You will also want to think about finances. All fertility preservation methods have an out-of-pocket cost, and many treatments are still considered experimental. You'll need to check with your insurance company about what they will cover. (Often a nurse navigator, case manager, or social worker can help get this information and deal with the insurance company.)

Fortunately, the LIVE**STRONG** Foundation's Fertile Hope program can help offset the cost of fertility preservation for many cancer patients. The program's Sharing Hope financial assistance program assists with access to discounted sperm, embryo, and egg banking services at participating centers throughout the U.S. Applications and information are available at www.fertilehope.org/financial-assistance/index.cfm.

## Understanding your options

Your fertility preservation options will vary depending on your age, your gender, the type of cancer you have, and the type of treatment you are going to receive. Most techniques that can increase your chances of having children must be done before treatment starts, and some—such as embryo freezing—may require delaying treatment for several weeks. If that isn't possible, your oncofertility team can counsel you on other options that can be done after treatment. (For a summary of fertility preservation methods and their costs, including experimental options, see Table 3.)

### Definitions

**Embryo:** A fertilized egg that has been dividing and growing for up to 8 weeks

**Gynecologic oncologist:** Doctor who's an expert in treating cancer that starts in the female organs involved in making babies

**Infertility:** The inability to become pregnant and have babies

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

**Oncofertility:** Approach when cancer doctors and reproductive specialists work together to preserve fertility (ability to have babies) in cancer patients

**Sperm:** Male reproductive cells that are formed in the testicles

## Before treatment

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

### *Damage prevention*

It's sometimes possible to protect reproductive organs through fertility-sparing surgery, in which the surgeon removes only the cancerous tissue and leaves as much healthy tissue in place as possible (for example, leaving the healthy ovary in place if you have early-stage ovarian cancer).

If you'll be receiving radiation therapy, radiation shielding (using special lead shields to prevent radiation from reaching the ovaries or testicles) can sometimes prevent fertility damage. If you're a woman, it may also be possible to surgically move the healthy ovary (or ovaries) out of the radiation field, a process called ovarian transposition.

There is also an experimental technique called ovarian suppression that uses a hormone-blocking drug to stop the ovaries from producing eggs. (Think of it as putting the ovaries to sleep until treatment is over.) Although ovarian suppression is sometimes used in the treatment of breast cancer, no scientific studies have been published on how well it works for protecting fertility.

### Exploring your choices

The LIVE**STRONG** Foundation's Fertile Hope program offers calculators (www.fertilehope.org/tool-bar/options-calculator.cfm) that can identify fertility preservation techniques that might work for you based on your gender, age, treatment stage, and the type of treatment you're receiving.

## Table 3. Fertility preservation methods

| Method | Description | Approximate Cost |
|---|---|---|
| **For Women** | | |
| Radiation shielding | Use of lead shields to protect ovaries during radiation treatment | Included in cost of radiation therapy |
| Embryo freezing | Use of hormone treatment, egg extraction, and IVF to produce embryos that can be frozen for later implantation | $12,000 per IVF attempt, plus storage fees |
| Ovarian transposition | Surgical repositioning of healthy ovaries so they are out of the radiation field | Variable—may be covered by insurance |
| ***Experimental Options*†** | | |
| Egg freezing | Extraction and storage of unfertilized eggs | $12,000 per extraction attempt, plus storage fees |
| Ovarian tissue freezing | Removal of healthy ovarian tissue (or whole ovary) for transplantation back into the body after treatment | $17,000 or more, plus storage fees |
| Ovarian suppression | Medication to stop the ovaries from producing eggs during the treatment process | Up to $1,000 per month |
| **For Men** | | |
| Radiation shielding | Use of lead shields to protect testicles during radiation treatment | Included in cost of radiation therapy |
| Sperm banking | Collection and storage of ejaculate | $675 to $2,000, plus storage fees |
| ***Experimental Options*†** | | |
| Testicular sperm extraction | Extraction of sperm from testicular tissue | Cost varies |

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

“[For most of my life] I felt that I lacked the ‘maternal gene’. . . Apparently things change when you hear the words ‘You have cancer’. . . Instantaneously, I had come to the realization that my evolutionary value would be compromised, and without my consent.”

Lauren
Hodgkin’s lymphoma survivor

### *Banking healthy cells*

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

Sperm banking is a fairly simple procedure that involves collecting and then freezing one or more samples of ejaculate. Embryo freezing is more complicated because it requires IVF, a process in which eggs are removed from the ovaries and fertilized in a lab. If you don't have a partner, IVF can be done with donor sperm.

Since IVF must be timed to your menstrual cycle and involves a series of hormone shots to prompt the ovaries to produce more than one egg, it could mean delaying treatment for several weeks.

Experimental options include:

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

## Definitions

**Ejaculate:** Mixture of sperm and other fluids released through the penis during orgasm

**Embryo:** A fertilized egg that has been dividing and growing for up to 8 weeks

**Hormones:** Chemicals in the body that activate cells or organs

**Ovaries:** The pair of female organs that make eggs and hormones

**Sperm:** Male reproductive cells that are formed in the testicles

**Testicles:** Two egg-shaped glands found inside the scrotum below the base of the penis that produce sperm and male hormones

## Acronyms

**IVF=** In vitro fertilization

### After treatment

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

- **Donor eggs or donor embryos** – Donor eggs are harvested from women who have volunteered to go through hormone treatment to produce multiple eggs, whereas donor embryos are donated by couples who have chosen not to use their frozen embryos. Donor eggs are fertilized through IVF using a partner's—or donor's—sperm. The cost can range from $5,000 to $15,000 (in addition to the cost of IVF), and there is a risk of having more than one baby since more than one embryo must be implanted.
- **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 5 years before adopting a child. And the adoption process itself can take up to 2 years. Costs can range from a few thousand dollars—when adopting through a public agency or foster care program—to as much as $40,000 for an international adoption.
- **Surrogacy** – If treatment-related damage to the reproductive organs makes it impossible to carry a child, couples who have frozen embryos may consider using a surrogate—a woman who volunteers to have the embryos inserted into her uterus and go through pregnancy and birth. Sometimes the surrogate is a relative or friend. Surrogacy can be expensive (anywhere from $10,000 to $100,000) and legally complicated, as the laws governing surrogacy vary from state to state. It can also result in more than one baby, since more than one embryo is usually implanted.

### Questions to ask your doctor about: Fertility preservation

- What are my fertility preservation options?
- Will any of the fertility-preservation options affect how well the cancer treatment works?
- Will using one of these options require that I delay cancer treatment? If so, for how long?
- What are the risks of delaying therapy?
- Will fertility treatments increase the risk that the cancer may return?
- For women: Will becoming pregnant increase the risk that the cancer may return?
- Am I eligible for a clinical trial for fertility preservation?
- How much will these fertility-preservation options cost?
- Are any of these fertility-preservation options covered by insurance?

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# Part 4: Navigating the treatment process

> “I remember having an appointment with my oncologist where I brought research that I wanted to review with him. I don’t think he’d had that happen before.”
>
> Kate

# Part 4: Navigating the treatment process

Getting treated for cancer can be a strange journey. You know where you want to end up—healthy—but it's not always clear how you're going to get there or how long it will take. Depending on your diagnosis, the process could take weeks, months, or years, hopefully to be followed by many more years as a cancer survivor.

## Stages of treatment

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

### Neoadjuvant or induction therapy

Neoadjuvant (from Latin words meaning "new aid") or induction ("to lead into") therapy is usually given to reduce the size of the cancer before cancer surgery. It can be particularly helpful for a large primary tumor, because shrinking the tumor may make the surgery less complicated. Induction therapy may also be used to prepare the body for a stem cell transplant (or bone marrow transplant) in patients with leukemia or lymphoma.

Neoadjuvant therapy may include radiation therapy, chemotherapy, or a combination of several different treatments. If the chosen treatment carries a risk of side effects such as nausea or fatigue, the treatment team should also set up a palliative care plan to prevent or relieve these symptoms.

If the cancer does not change or continues to grow during neoadjuvant treatment, your doctor may try a different therapy (for example, a different chemotherapy drug) or simply stop neoadjuvant therapy and move forward with surgery.

### Primary or first-line therapy

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

### A palliative care reality check

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

For years palliative care was thought of as the treatment of last resort—something that was done only when everything else had failed. Not anymore.

Today's clinical guidelines state that palliative care should be included in every stage of cancer treatment. Your treatment team should start evaluating your palliative care needs as soon as you're diagnosed, and re-evaluate them regularly as you move through the treatment process.

# Part 4: Navigating the treatment process

Local therapies include surgery and radiation therapy, while systemic treatments include chemotherapy, targeted therapy, and immune therapy (treatment that uses the immune system to fight disease), all of which will be discussed in Part 5. For some patients, the best option for primary therapy may be a clinical trial of a new treatment or medication.

After the primary therapy is complete, your doctor will run many of the same tests used during diagnosis to see whether the treatment has succeeded in removing or controlling the cancer. If there are no signs of cancer, you may be declared to be in complete remission. If some, but not all, signs and symptoms of cancer have disappeared it may be called a partial remission. If the cancer has grown or spread to other places in your body, it means the cancer has progressed.

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

## Adjuvant therapy

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

## Consolidation therapy

Consolidation therapy—sometimes called intensification or postremission therapy—is meant to consolidate (or strengthen) the success of primary therapy and sustain the remission. Consolidation therapy may include radiation therapy, chemotherapy, or a stem cell transplant, and is usually given for a relatively brief time.

## Definitions

**Chemotherapy:** Drugs that kill all rapidly dividing cells in the body, including cancer cells and normal cells

**Leukemia:** Cancer of the blood-forming tissue (bone marrow)

**Lymphoma:** Cancer that begins in cells of the immune system

**Radiation therapy:** Use of high-energy rays to kill cancer cells

**Side effect:** An unplanned physical or emotional response to treatment

**Stem cell transplant:** Replacing damaged stem cells (immature blood-forming cells) in the bone marrow with healthy cells

**Targeted therapy:** Drugs that specifically target and kill cancer cells

### Maintenance therapy

Like consolidation therapy, maintenance therapy is given after successful primary treatment to keep the cancer from coming back. Unlike consolidation therapy, maintenance therapy can be taken for years and typically uses relatively low doses of targeted therapy, chemotherapy, or immune therapy. For example, if you have been treated for breast cancer, your doctor may recommend maintenance therapy with a drug that interferes with estrogen—a hormone that some forms of breast cancer need to survive.

### Second-line therapy (and beyond)

If cancer does not respond to initial therapy—or reappears after a period of remission—it's time for second-line therapy. Some people may have many remissions and recurrences, and require third, fourth, or even more lines of therapy. Treatment options in these situations may include another round of the therapy used initially, surgery, radiation therapy, immune therapy, targeted therapy, chemotherapy, or a combination of all the above.

If there are no evidence-based recommendations for second-line (or later) treatment for the cancer you have, you may be enrolled in a clinical trial of an experimental treatment option.

### Survivorship care

When treatment results in remission (or no evidence of disease) you're on your way from cancer patient to cancer survivor. Life as a cancer survivor will not be quite the same as life before your diagnosis. Cancer and its treatment can't help but leave their mark—on your body, on your emotions, and on your mind. Dealing with these effects can be a challenge for even the most hardy of cancer survivors.

According to recommendations from the Institute of Medicine, every cancer patient should have a survivorship care plan that includes guidelines for monitoring and maintaining health in the months and years post-treatment. Part 8, *Moving Beyond Treatment*, will include detailed information on survivorship issues, including how to ensure you have the information and support you need to make the transition to the brave new world of cancer survivorship.

### Recurrence (or relapse) vs. progression

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

### End-of-life care

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

Although it's natural to want to avoid thinking about death, most cancer experts recommend completing an advance directive of your preferences for end-of-life care sooner rather than later. Doing this will give you one less thing to worry about. An advance directive does not mean you have given up. However, it ensures that your treatment team and your loved ones understand what you want. This leaves you free to focus on your treatment and making the most of every day. (More details on advance directives and dealing with end-of-life issues are provided in Part 9, *Thinking About the Unthinkable*.)

## Working with a treatment team

To get the highest level of care possible, it's important to work with health care providers who will not only care for your physical health, but also can help you with the psychological, emotional, and social effects of dealing with cancer.

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

Some members of your treatment team will be with you throughout the cancer journey, while others will only be there for parts of it. Understanding who your team members are and what they do will make it a lot easier to make the most of each person's skills and knowledge. Key players are likely to include:

### Definitions

**Chemotherapy:** Drugs that kill all cells that grow rapidly, including cancer cells and normal cells

**Immune therapy:** Treatment that uses the immune system to fight disease

**Radiation therapy:** Use of high-energy rays to destroy cancer cells

**Targeted therapy:** Drugs that specifically target and kill cancer cells

- A **primary care practitioner** (family doctor, internist, general practitioner, etc.) who handles medical care that isn't related to the cancer. This person should be kept up to date on your cancer care and receive summaries of your progress.
- A **medical oncologist** or **hematologist** who specializes in the systemic treatment of cancer. This person will be the one who prescribes chemotherapy. Often, he or she will also coordinate the overall treatment team and keep track of tests and exams performed by other specialists.
- **Oncology nurses** who will provide much of your hands-on care, including administering chemotherapy, coordinating care, answering questions, and helping you cope with treatment side effects. Oncology nurse practitioners and physician assistants may also perform health assessments and physical exams, order and interpret diagnostic and laboratory tests, prescribe medications, and order chemotherapy.
- **Social workers** who provide counseling, help with discharge planning and home care, and help with finding community resources.
- A **patient navigator** who can help with arranging financial support, transportation, and child care during treatment; coordinating care among several doctors; and providing emotional support.
- A **dietitian** or **nutritionist** to provide nutritional advice and help you plan menus to meet your nutritional needs during cancer treatment.

Depending on your diagnosis your team may also include:

- A **surgical oncologist** who will perform any surgical procedures,
- **Anesthesiologists** who will provide anesthesia during surgery or procedures such as bone marrow aspiration or some forms of endoscopy,
- A **radiation oncologist** who will prescribe and oversee radiation therapy,
- A **gynecologic oncologist** who specializes in treating cancer of the female reproductive system,
- A **urologist** who specializes in treating cancer of the male reproductive system,
- A **pathologist** who interprets laboratory tests and evaluates cells, tissues, and organs removed during a biopsy or cancer surgery,
- A **diagnostic radiologist** who reviews and interprets the results of x-rays and other imaging tests,
- A **psychiatrist** or **clinical psychologist** who can help you cope with the psychological and emotional effects of dealing with cancer and who will also monitor your overall psychological well-being as you go through treatment (psychiatrists are medical doctors and can also prescribe medication as needed), and
- **Physical, occupational, speech,** and **respiratory therapists** who can help you with specific problems related to the cancer, its treatment, and recovery from side effects.

# Part 4: Navigating the treatment process

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**.

Whether you’re 16 or 36, as the person who actually has the cancer you know your body better than anyone. You’re in the best position to help other team members understand how you feel, what you need, and what’s working. You should never hesitate to ask questions, seek other opinions, or let the team know when you’re feeling overwhelmed or just need a break.

Your team may get larger the further along you are in treatment. To keep track of them, consider putting together a written or electronic “cancer address book,” with the names and contact information of every member of your treatment team, and a brief explanation of what they’re responsible for. (If they have business cards, grab them and make a cancer Rolodex.) It will make it easier for you—and any loved ones involved in your care—to know who to contact when problems or questions arise.

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

## Definitions

**Anesthesia:** Loss of feeling with or without loss of wakefulness

**Biopsy:** Removal of small amounts of tissue or fluid to be tested for disease

**Bone marrow aspiration:** The removal of a small amount of liquid bone marrow or solid bone marrow tissue to examine for disease

**Radiation therapy:** Use of high-energy rays to destroy cancer cells

**Reproductive system:** The organs and tissues involved in the process of pregnancy and child bearing—the vagina, cervix, uterus, fallopian tubes, and ovaries in women, and the penis, testicles, and prostate in men

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## Developing a treatment plan

### Setting treatment goals

Deciding on a treatment goal may seem like a no-brainer: you want to get better. But when dealing with something as complicated as cancer, “getting better” can mean different things to different people. Treatment goals typically fall into several basic categories:

- Cure – The complete elimination of the cancer.
- Remission – No detectable evidence of the cancer.
- Disease control – Preventing the cancer from getting worse.
- Symptom control – Preventing and treating symptoms caused by cancer or its treatment.

To decide on your personal treatment goals, you and your team will consider many different factors, including:

- The type and stage of the cancer,
- The prognosis of the cancer—what the cancer is likely to do with or without treatment,
- The treatment options available for this type of cancer, including clinical trials,
- The potential side effects of each treatment option, including long-term effects,
- Your overall health,
- Your personal definition of “good quality of life,”
- Your feelings about side effects, and
- Your spiritual beliefs.

Even if your initial goal is to cure the cancer, it’s possible that it will change over time. Make sure that you and your team revisit your treatment goals regularly to ensure that everyone is on the same page and working toward the same goal.

### Treatment planning

A treatment plan is a written course of action that covers every stage of the treatment process, from neoadjuvant therapy onward. It serves as a guideline for everyone involved in your care, reminding them of decisions that have already been made, and guiding future discussion and changes to your care plan.

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

The specifics of your treatment plan will be based on the nature of the cancer you have, the various treatments available, and your personal resources, beliefs, wishes, and values.

# Part 4: Navigating the treatment process

As a young adult with cancer, you may have treatment options that children and older adults do not. For example:

- Depending on your diagnosis, you may do better with a pediatric treatment protocol than one designed for adults.
- Since you're most likely in better shape than many older patients, you can probably tolerate more aggressive treatment approaches, including high-dose systemic therapies.
- As a young, relatively healthy person (other than the cancer, of course!), you're also an excellent candidate for enrollment in a clinical trial.

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

Cancer treatment is always evolving, and it's not always easy for doctors to keep up. That's why organizations such as the American Cancer Society, the National Cancer Institute, and NCCN offer clinical guidelines for the treatment of specific cancers. These guidelines are based on the best available scientific evidence on cancer and its treatment, and are important tools in coming up with the right treatment plan for your diagnosis. You can access NCCN Guidelines on specific cancers—and on other aspects of care of AYAs with cancer—on the NCCN Web sites, www.nccn.org and www.nccn.com.

## The pros and cons of doing your own research

When it comes to treatment planning, the more you understand about the cancer you have and its treatment, the easier it will be to work with your treatment team. On the other hand, it's also possible to get overwhelmed by a tidal wave of statistics, scientific jargon, and drug names. Striking a balance between blissful ignorance and TMI is one of the major challenges of being a cancer patient.

**Notes:**

Whether you go hunting for information yourself or hand the job over to a computer-savvy friend or relative, you should take some time to figure out what you'll be searching for. Start with the information you already have about the cancer—the diagnosis, the stage, the histologic grade, etc. You'll want to look for information that applies to the specific cancer you have, and weed out information that doesn't. For example, if you have a stage 2 breast cancer that will not respond to estrogen, there's not much point in pulling up information on stage 4 breast cancer that's hormone receptor-positive.

The Internet can be an incredible resource, but it's also littered with inaccurate information and scams, including Web sites promoting unproven or downright dangerous "alternative" therapies. Some of the most obvious "red flags" include:

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

In general, government-based (.gov) and university-based (.edu) Web sites are reliable sources of information and are less likely to be trying to sell you something than commercial (.com) sites. Not-for-profit organizations (.org) also tend to be good sources, but it's always a good idea to check on who is funding the organization. Some not-for-profits may have political, social, or religious points of view that influence the Web site's content. If a site doesn't provide information on its sponsors, advertisers, or funding source, you may want to take it with quite a few grains of salt. Other questions to consider are:

- **Who's checking the information?** Reliable health Web sites will have an editorial or advisory board that reviews and approves the site's contents. The site should include the full names, credentials, and contact information for each of these individuals.
- **Where are the references?** Medical claims and scientific information should always be supported by a reference from a scientific journal. (Think *Lancet* or *The New England Journal of Medicine*, not *National Enquirer*.) If the site is reference-free, there's no way to check on the accuracy of the information.
- **How current is the information?** The Internet is forever, and there are a lot of sites floating around that may have been current 5 or 10 years ago, but are now woefully out of date. Since cancer research

is constantly evolving, trustworthy sites will regularly update their content, and include a timestamp on every page indicating the date of the most recent update.

Forums, bulletin boards, and chat rooms are great places to share ideas and get support, but are less-than-ideal sources of medical information. Just because a treatment worked for a person on your favorite cancer bulletin board doesn't mean it will work for you.

## Sticking with the plan

Research has shown that treatment can give AYAs with cancer a very good chance of living for a very long time. But getting there means sticking with the treatment plan—a task that many AYAs find difficult. In fact, some surveys have found that more than half of AYAs with cancer stray from their treatment plan at one time or another—whether it's not taking medication as prescribed, not showing up for a chemotherapy or radiation treatment, or taking recreational drugs that can interfere with treatment effects.

There's no doubt that cancer treatment can be tough. But there are things you can do to make it easier to stick with your plan and increase the likelihood that treatment will be effective.

- **Take all of your medications as prescribed.** That means taking them in the right amounts, at the right time. Skipping or delaying doses may interfere with a drug's effects. If you're having trouble paying for your medication, ask your treatment team for help. They may be able to refer you for financial aid or special

## Definitions

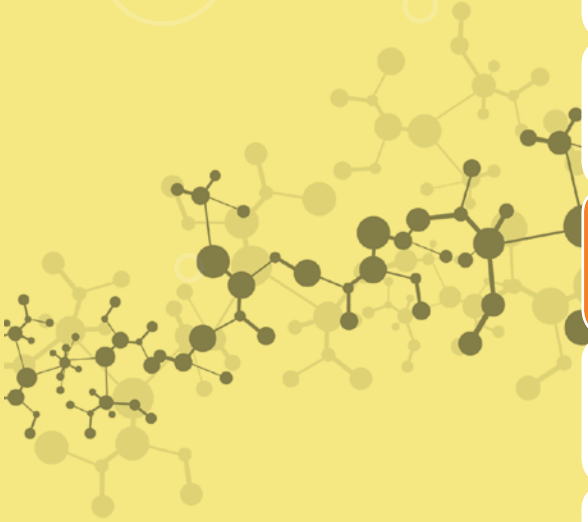
**Histologic grade:** A measure of how much tumor cells resemble healthy cells of the same tissue type

**Hormone receptor-positive:** Cancer cells that use hormones (chemicals in the body that activate cells or organs) to grow

**Stage:** A rating of the extent of cancer in the body drug company programs designed to help people who cannot afford cancer treatment. (For more on financial issues, see Part 7.)

- **Talk to your treatment team.** Your team can do more than hand out pills and stick you with needles. If you're having trouble coping with the treatment plan, let them know. They can give you a hand with accessing psychological, financial, and practical help for sticking with treatment while living your life. They'll also work with you to schedule treatments in a way that works with your day-to-day responsibilities and needs.
- **Stick with your appointments.** Although your team will try to be flexible when timing your appointments, most cancer facilities have pretty tight schedules. If you miss a scheduled appointment it may not be possible to get a new one right away—which could delay treatment by days or longer.
- **Be honest.** Your treatment team can't help you if they don't know what's going on. If you're experiencing side effects or symptoms, talk to your doctor or oncology nurse. If you're drinking or using recreational drugs, tell them.

# Part 5: Understanding your treatment options



> “The uncertainty is the hardest part—not knowing what’s coming next. What’s the chemo going to feel like—will I sleep through the whole thing or will I puke my guts out? Will I have any energy at all or will there still be a spring in my step? When will I be able to go back to work? How long will I be stuck at home? . . . So many unknowns.”

Robin,
diagnosed with non-Hodgkin’s lymphoma
at age 29

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

## Clinical trials

A clinical trial is a research study that tests a new treatment to see if it is safe and effective. Treatments that have been approved as a result of clinical trials are said to be “evidence-based”—meaning that they have been shown to have an effect on cancer and that any risks are outweighed by the treatment’s beneficial effects.

Clinical trials are often the best option for cancer treatment, particularly for AYA patients. For one thing, you are certain to receive excellent care. All clinical trials are designed to compare the new treatment against the current standard of care, so even patients who aren’t receiving the experimental drug will get the most cutting-edge treatment available. Second, you will be treated by experts. Third, the results of your treatment—both good and bad—will be carefully tracked. Fourth, you may help other patients with cancer.

Clinical trials may have risks too. Like any test or treatment, there may be side effects. Also, there is always a possibility that the new treatment might not help. Another downside may be that paperwork or more trips to the hospital are needed.

### Phases of clinical trials

New cancer treatments aren’t offered to the public as soon as they’re created. They need to go through a series of trials to make sure they’re safe and work. Clinical trials have four phases. They are labeled with Roman numerals I–IV.

- **Phase I** trials test a drug’s safety and determine the best dose of a new drug with the fewest side effects. The drug has already been tested in lab and animal studies, but now it needs to be tested in patients. Doctors start by giving very low doses of the drug to the first group of patients. Higher doses are given to the next groups until side effects appear or the desired effect is seen. If a drug is found to be safe enough, it can be tested in a phase II clinical trial. Phase I trials are usually offered to patients only if standard therapies have not worked, or if there is no known effective therapy available to treat that patient’s cancer.

- **Phase II** trials assess if a drug works for a specific type of cancer. They are performed in larger groups of patients for whom standard treatments aren’t working. Often, new combinations of drugs are tested. Patients are closely watched to see if the drug works. The treatment team also looks for side effects. If a drug is found to work, it can be tested in a phase III clinical trial.

- **Phase III** trials include large numbers of patients. Often, these trials are randomized. This means that patients are put into a treatment group by chance. There can be more than two treatment groups in phase III trials. The control group gets the standard treatment and the other groups get a new treatment. Neither you nor your doctor can choose your group. Every patient in phase III studies is watched closely. The study will be stopped early if the side effects of the new drug are too severe or if one group has much better results than the other group. Phase III clinical trials are often needed before the U.S. FDA (**F**ood and **D**rug **A**dministration) will approve the use of a new drug for the general public.
- **Phase IV** trials test new drugs approved by the FDA. The drug is tested in many patients with different types of cancer. This allows for better research on short-lived and long-lasting side effects and safety. For instance, some rare side effects may only be found in large groups of people. Doctors can also learn more about how well the drug works and if it's helpful when used with other treatments.

## Finding a Clinical Trial

The National Institutes of Health maintains a searchable database of publicly and privately supported clinical trials, including enrollment requirements and contact information. You can access the database at www.clinicaltrials.gov.

The National Cancer Institute's Cancer Information Service can also provide information on clinical trials. The service is available in English and Spanish, Monday through Friday 8:00 AM to 8:00 PM ET at 1-800-4-CANCER (1-800-422-6237).

**Notes:**

## Joining a clinical trial

When deciding on your treatment plan, it is always a good idea to ask your team whether clinical trials are available for the treatment of the particular cancer you have, and to do some digging around yourself. Because clinical trials are not available at all treatment centers, you may want to consider traveling if a promising trial is available at a center other than the one closest to you.

To join a clinical trial, you must meet the conditions of the study. Patients in a clinical trial are often alike in terms of their tumor type and general health. This helps researchers ensure that any changes in the cancer are because of the treatment and not because of differences between patients.

If you meet the conditions of the study, you will be asked to review a paper called an informed consent form. This form describes the study in detail, including the risks and benefits. Also, your doctor will explain why the clinical trial may be right for you. You will be able to fully read the form and have all your questions answered. Afterward, you may decide to sign the form and start in the study. If you are younger than age 18, your parents will need to review the form and provide consent for you to participate in the trial.

### Questions to ask your doctor about:
### Clinical trials

The clinical trial process is designed to make sure that every patient involved in the trial understands what's going to happen and the possible risks and benefits. The questions below can serve as a guideline for talking with your doctor about joining a trial.

- Are there clinical trials available for the type of cancer I have?
- Is this center involved in any of these trials?
- If not, where is the nearest center that offers enrollment in a trial?

# Part 5: Understanding your treatment options

## Treatment types: Local therapies

As noted in Part 4, cancer therapies can be lumped into two basic groups: local therapies that remove or destroy individual tumors or cancerous tissues, and systemic therapies that go after cancer cells throughout the body.

### Surgery

Surgery can serve many purposes in the treatment of cancer. **Curative surgery** is done when the cancer is in just one area of the body and can likely be completely removed by a surgeon with very little chance that it has spread to other parts of the body. Sometimes radiation therapy may be done at the same time as the surgery to make sure that all cancer cells have been destroyed. This procedure is called **intraoperative radiation therapy**.

If the surgical margins and nearby lymph nodes show no signs of cancer, curative surgery may be the end of your cancer treatment. However, many oncologists recommend adjuvant radiation or systemic therapy just to make sure that no cancer cells are left elsewhere in the body.

**Debulking (or cytoreductive) surgery** is done when cancer is too advanced or widespread to remove completely. In these cases, the surgeon removes as much of the cancerous tissue as possible and treats what is left with radiation or systemic therapy.

**Palliative surgery** is not focused on cure. Like debulking surgery, palliative surgery may attempt to remove as much cancerous tissue as possible, but the goal is to correct situations that are causing pain or other problems. For example, palliative surgery may be used to remove part of a tumor that is pressing on other organs and causing pain, or that is blocking part of the digestive tract.

**Supportive surgery** includes procedures that make it easier to give other types of treatment. If you are going to be receiving intravenous chemotherapy, for

## Definitions

**Adjuvant treatment:** A treatment given after the main treatment used to cure disease

**Intravenous chemotherapy:** Drugs given by a needle or tube inserted into a vein

**Lymph nodes:** Small groups of special disease-fighting cells located throughout the body

**Radiation therapy:** Use of high-energy rays to destroy cancer cells

**Surgical margin:** Normal tissue around the edge of a tumor removed by surgery

**Systemic therapy:** Drugs used to treat cancer cells throughout the body example, a surgeon may insert a CVC (**c**entral **v**enous **c**atheter) or venous access port into one of your large veins so your treatment team can give medication and draw blood without constantly sticking you with needles.

**Restorative (or reconstructive) surgery** is used to repair damage caused by other cancer treatments. The most familiar example of this kind of surgery is breast reconstruction, in which a surgeon restores the appearance of the breast after the removal of breast cancer.

**Preventive (or prophylactic) surgery** removes tissue that carries a high risk of becoming cancer, such as precancerous polyps in the colon. Preventive surgery is also an option 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) to ensure that cancer won't develop.

### Radiation Therapy

Radiation therapy uses high-energy particles or rays to kill cancer cells and/or damage the cells' DNA so they can no longer grow or divide. Radiation can be administered in three ways: external beam radiation, internal radiation (also known as brachytherapy), and systemic radiation therapy.

## Treatment types: Systemic therapies

Systemic therapies are the ground troops of the cancer treatment world. Some go after all rapidly dividing cells in the body (chemotherapy), some zero in on particular characteristics of cancer cells (targeted therapy), and some recruit your body's natural defenses to recognize and destroy cancer (immune therapy).

Because systemic therapies go after cancer in a many different ways, doctors will often use different medications in combination to get the biggest treatment effect. This strategy can increase the chances of getting rid of the cancer, but it also increases the risk that healthy cells will get caught in the crossfire, leading to side effects that may make it necessary to stop or delay treatment or change the treatment approach.

### Chemotherapy

Chemotherapy, or chemo, is the mainstay of systemic cancer treatment. All chemotherapy drugs interfere with the genetic machinery that cells use to grow and divide. Some damage DNA directly; others get in the way of processes that help cancer cells build DNA (Table 4).

Many chemotherapy drugs are given as liquids that are slowly injected into a vein, a CVC, or a port. Some are pills that are given by mouth. Chemotherapy may also be placed directly into a body cavity (such as the bladder, abdomen, or the space around the brain and spinal cord) so it can be delivered straight to the cancer cells without having to go through the bloodstream.

## Table 4. Chemotherapy drugs

| Drug Class | What They Do |
|---|---|
| *Alkylating agents* | Damage DNA so cancer cells can’t multiply |
| *Antimetabolites* | Kill cancer cells by getting in the way of the “building blocks” of DNA |
| *Anticancer antibiotics* | Interfere with enzymes that help cancer cells build DNA |
| *Plant alkaloids* | Block mechanisms that help cancer cells to divide |

Chemotherapy is usually given in cycles of treatment days followed by days of rest. These cycles vary in length depending on which drugs are used. Often, the cycles are 14, 21, or 28 days long. These cycles give the body a chance to recover before the next treatment.

### Immune therapy

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

Immune therapies are designed to boost immune activity and help the immune system recognize and attack cancer cells. Currently available immune therapies include:

- **Nonspecific immune therapies** (eg, interleukins, interferons) that produce an overall boost in immune function that can increase immune activity against cancer cells,
- **Monoclonal antibodies**—called MABs—(eg, ipilimumab, rituximab), man-made versions of proteins that recognize and attach to special molecules on the surface of cancer cells. (Kind of like a key fitting into a lock.) Once MABs link up with the cancer cell, other immune cells are able to recognize and attack the cancer, and
- **Cancer vaccines** (eg, Sipuleucel-T) that act in much the same way as vaccines against the flu or chicken pox: they teach the immune system to recognize cancer cells so the immune system can start defending itself against the cancer.

### Targeted therapy

Unlike chemotherapies, which go after just about any fast-dividing cell, targeted therapies seek out specific molecules on cancer cells that play a role in tumor growth and development. Targeted therapies are usually grouped on the basis of what they do or the part of the cell they target.

- **Hormone modifiers** (eg, tamoxifen, anastrozole) block the production or the activity of estrogen, a hormone that some cancers of the breast and uterus need to survive.
- **Enzyme inhibitors** and **growth factor inhibitors** (eg, trastuzumab, erlotinib) block specific enzymes and growth factors that cancer cells need to grow and spread. These drugs may also be called small-molecule drugs or signal transduction inhibitors.
- **Apoptosis-inducing drugs** (eg, bortezomib, pralatrexate) alter parts of the cancer cell that control survival and death, essentially causing the cell to kill itself.

## A word on corticosteroids

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

Corticosteroids can be given orally (as a pill or a liquid), intravenously, as a cream, or by injection. They may be used as an anticancer treatment, often in combination with chemotherapy, or on a short term-basis to relieve side effects of treatment, such as:

- Nausea,
- Swelling,
- Allergic reactions, and
- Reduced appetite.

Corticosteroids can be enormously helpful, but they do have side effects, including:

- Indigestion or heartburn,
- Swollen hands, feet, or ankles,
- Increased risk of infection,
- Changes in blood sugar levels with high-dose or long-term treatment,
- Changes in mood, and
- Difficulty sleeping—taking your tablets early in the day may help.

If your doctor prescribes corticosteroids, be sure to take them *exactly* as prescribed.

## Definitions

**Chemotherapy:** Drugs that kill all cells that grow rapidly, including cancer cells and normal cells

**Enzymes:** Proteins that speed up chemical reactions in the body

**Hormones:** Chemicals in the body that activate cells or organs

**Intravenous:** Administration of a drug through a vein

**Side effects:** An unplanned physical or emotional response to treatment

- Tumors need a blood supply in order to grow. **Angiogenesis inhibitors** (eg, bevacizumab, sunitinib) target growth factors that allow cancer cells to build new blood vessels, cutting off the tumor's blood supply and basically starving it to death.
- **Antibody-drug conjugates** (eg, tositumomab, ibritumomab tiuxetan) are a combination of a MAB and a toxin or radiopharmaceutical that enters and kills the cell after the MAB latches on.

Because these drugs zero in on molecular targets found mostly in cancer cells, targeted therapies are less likely to damage healthy cells and cause side effects.

Some targeted therapies are given as pills; others must be given into a vein. Some IV medicines can be given in the outpatient clinic, while others require admission to the hospital. Intravenous methods include:

- An IV push, in which the drug is injected quickly over a few minutes.
- An IV infusion that can last from 30 minutes to several hours. The medication flows through a tube that is attached to the catheter. The flow may be controlled by a machine called an IV pump.
- A continuous infusion that can last up to 7 days. Continuous infusions are always controlled by electronic IV pumps.

## Complementary and alternative medicine (CAM)

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

- **Alternative therapies** are treatments and techniques that are used instead of conventional treatments such as chemotherapy or radiation. Some alternative medicines are sold as cures even though they haven't been proven to work. If there was solid scientific proof that an alternative treatment or technique was effective against cancer, it would be included in this guideline. In general, if something is being promoted as a substitute for regular medical care, steer clear.
- **Complementary therapies** are meant to be used alongside conventional therapies, most often to prevent or reduce side effects. Complementary therapies can be very helpful for dealing with side effects such as pain or nausea, and will be discussed in greater detail in Part 6.

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

# Part 5: Understanding your treatment options

## Questions to ask your doctor about:
## Your treatment options

Ideally, your doctor will keep you involved and informed of all decisions concerning your treatment. The questions below can serve as a guideline to help you fill in any gaps as you talk with your doctor about your treatment option.

- Based on current research and clinical guidelines, what is the best treatment for this cancer when it occurs in someone my age?
- Does this hospital (or center) offer the best treatment for me?
- Is a pediatric or adult protocol better for me?
- Are there any advantages to me being treated at a pediatric versus an adult facility?
- What side effects am I likely to experience?
- Will using higher doses or a more intensive protocol increase my chances of cure or remission? If so, what additional risks or side effects might I experience?
- Can you provide me with more information on the research that supports this treatment plan?
- Are there any complementary therapies that may help me cope with cancer treatment?
- How much time do I have to think about my options or get a 2nd opinion?

## Definitions

**Catheter:** A flexible tube used to give treatments, such as liquid drugs, or drain fluid from the body

**Radiopharmaceutical:** A drug that contains a radioactive substance

**Side effect:** An unplanned physical or emotional response to treatment

**Toxin:** A poison produced naturally by certain bacteria, plants, or animals, including insects

## Acronyms

**IV=** Intravenous

**MAB=** Monoclonal antibody

# Part 6: Coping with side effects

61 **Why side effects happen**
A brief explanation of what cancer treatments can do to healthy cells, and what it means for you

61 **What you can do: The basics**
Simple steps you can take to prevent—or relieve—the unwanted side effects of cancer treatment

65 **What you can do: Specifics**
Quick tips on coping with some of the most common treatment side effects

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

Curtis B., Cancer Survivor

# Part 6: Coping with side effects

Side effects are a fact of life when you're being treated for cancer. With some treatments, side effects are relatively mild and don't interfere much with day-to-day life. With others, side effects can make it hard to do much of anything—at least in the days right after treatment.

Fortunately, a better understanding of just why side effects happen has made it easier to prevent side effects, like nausea and vomiting, and to treat such problems when they do arise. Also, newer drugs and improved technology are making it easier to target cancer cells with less damage to healthy tissues, which can help prevent side effects from happening.

## Why side effects happen

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

Side effects can also be caused by your body's reaction to this damage. When healthy cells are hurt or die, for example, the immune system sends in special cells to deal with the threat, leading to inflammation and more cell damage. (Kind of like what happens when the skin around a small cut gets red and puffy as it heals.)

Most side effects tend to be worst in the days right after treatment is given and subside once treatment is complete. But some treatment-induced damage does not heal when treatment is over, leading to long-term problems such as early menopause and infertility (see Part 3) and an increased risk of later health problems, including some forms of leukemia. Since you may be living for many, many years after treatment is over, your oncology team will carefully consider the risk of long-term side effects when developing your treatment plan.

The side effects you're likely to face will depend on your treatment plan. In general, drugs that have broad effects—such as some chemotherapies—tend to cause more side effects than drugs designed to zero in on cancer cells, such as targeted therapy drugs and immune therapy drugs. Higher doses may also cause more severe side effects.

## What you can do: The basics

Taking good care of yourself is the first and most important thing you can do to prepare for the treatment process. The healthier you are before and during treatment, the easier it will be to recover from unwanted side effects. So if you're already fairly athletic and a fan of fruits, vegetables, and other healthy foods, you'll want to continue those healthy behaviors. And if you lean more towards the couch potato end of the spectrum, it may be time to make a few basic changes to maximize your general health during cancer treatment.

### Feed yourself well

Keeping yourself well-fed can help ward off fatigue and weight loss during treatment and help you bounce back when treatment is done. If your treatment team doesn't already include a nutritionist or dietician, ask for one, and set up a meeting to work out a nutritional plan that takes into account your unique needs, including:

- Your lifestyle (work, school, parenting, etc.),
- Your living situation (how much help you have for cooking, shopping, etc.),
- Your personal tastes (if you've never liked broccoli, having cancer isn't going to magically make you crave it), and
- The types of side effects you're likely to experience.

Nutritional counseling is particularly important because it's likely that nearly everyone is going to have an opinion about what you should eat. But when it comes to cancer, standard nutritional advice may not apply. If you' re dealing with nausea, mouth sores, or other side effects of the GI tract, maintaining your energy and a healthy weight may mean eating lots of rich, high-calorie items and steering clear of "healthy" foods that might irritate sensitive tissues. So listen to your body, your doctors, and your nutritionist and do what works for you.

### Drink water. A lot.

Your body is 70% water, and it needs a steady supply to function at its best. Getting enough fluids (staying hydrated) is even more important during cancer treatment. Side effects such as vomiting and diarrhea rob your body of fluids, and the drier you get the worse your nausea will become. Drinking plenty of fluids will also help prevent constipation (difficulty going to the bathroom), protect your bladder and kidneys from the damaging effects of systemic therapy, and help flush out the chemical byproducts of your treatment.

Your treatment team can give you guidance on exactly how much you should be drinking, but a good general rule is to get at least 64 ounces (2 liters) of noncaffeinated liquids every day. (Although a little caffeine is okay, keep in mind that it has dehydrating effects.)

Keeping a water bottle with you at all times will make it easier to track how much you're drinking over the course of the day. Other ways to meet your liquid quota include:

- Watermelon,
- Ice pops or sherbets,
- Sports drinks,
- Juices,
- Jell-O,
- Soups or broths,
- Fruit smoothies,
- Caffeine-free herbal teas, and
- Caffeine-free sodas (including ginger ale).

There is now a great deal of research data linking regular alcohol intake to the risk for multiple forms of cancer. Based on research, both men and women are advised to drink only moderate amounts of alcohol, or no alcohol at all. Regular drinking of alcohol has been clearly shown to increase the risk for cancers of the breast, esophagus, stomach, colon, rectum, liver, pancreas, lung, bladder, and kidney. Increased cancer risks have been observed for all types of alcoholic beverages, including wine.

### Keep moving

Staying physically active is one of the most effective ways to fend off treatment-related fatigue, and exercise can also help boost a finicky appetite and help you sleep better at night. And you don't need to be a tri-athlete to enjoy the benefits of exercise. Even a short walk can go a long way toward making you feel better.

Pay attention to your body. When your energy level is good, take advantage and do some activity you already enjoy. Ask your treatment team whether there are any exercise programs available through the hospital or center where you are receiving treatment. Many large cancer centers offer yoga and other exercise programs designed specifically for patients being treated for cancer.

### Cooking tips

If you—or someone who wants to cook for you!—needs help in planning some treatment-friendly menus, check out Rebecca Katz's *The Cancer-Fighting Kitchen: Nourishing, Big-Flavor Recipes for Cancer Treatment and Recovery*. (Berkeley, CA: Celestial Arts, 2009.) It's filled with tips and recipes designed specifically for people dealing with the side effects of cancer treatment.

The American Cancer Society's "Eat Healthy" Web page (www.cancer.org/healthy/eathealthygetactive/eathealthy/index) also offers a range of healthy eating resources, including recipes and shopping lists.

### Definitions

**GI tract:** The group of organs that food passes through when you eat

**Side effect:** An unplanned physical or emotional response to treatment

**Systemic therapy:** Treatment to destroy cancer cells throughout the body

### Acronyms

**GI=** Gastrointestinal

## Get enough sleep

Sleep gives your body and mind a chance to rest and recover from stress. As you may have noticed, dealing with cancer and its treatment is pretty stressful, which can make sleep a challenge. Over time, sleep deprivation can mess with your mood, your relationships, and your ability to function.

Your treatment team can help if you're having trouble sleeping—and can even refer you to a sleep specialist if sleep problems are really interfering with your life. There are also a few simple steps you can take that may make it easier to sleep:

- **Set a sleep schedule.** Many people find it easier to sleep when they go to bed and get up at around the same time every day.
- **Nap when you need to**, but try to limit naps to less than an hour so you can still fall asleep at night.
- **Exercise during the day.** Improved sleep is just one of the many benefits of physical activity. Just make sure that you exercise at least three hours before bedtime so you're not too revved up to sleep.
- **Relax in the evening.** Give yourself some time to wind down and relax before trying to sleep. Limit screen time. Take a bath. Listen to music. Read a good (but not too exciting!) book. Whatever works to slow you down.
- **Steer clear of caffeine and alcohol** at the end of the day, both of which can make it more difficult to fall—and stay—asleep.

## Make use of your team

Your oncology treatment team has a wealth of experience and information, and you should draw on them every chance you get. This is particularly true if you are being treated at a center that has an AYA cancer program, which should have lots of resources to help you deal with the physical, emotional, and day-to-day challenges of cancer treatment.

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

Your team will want to monitor the types of side effects you experience, how severe they are, and how they are affecting your overall health and well-being. You may be asked to keep a diary tracking your side effects and other information such as your temperature, and be given instructions on when to call the doctor. Be honest about what you're experiencing—this isn't the time to put on a brave face or play down how bad you're feeling. If the side effects are too severe or if they threaten your long-term health, the team can modify the treatment plan.

# Part 6: Coping with side effects

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

## What you can do: Specifics

There are some side effects that occur with many different types of cancer treatment. Although an exhaustive review is beyond the scope of this booklet, the following pages offer tips for coping with some of the most common side effects.

### Nausea and vomiting

*Why it happens*

The nausea and vomiting you may experience during cancer treatment have more to do with your brain than with your stomach. Cancer treatment can stimulate a section of the brain called the CTZ (**c**hemoreceptor **t**rigger **z**one), which helps the body recognize and get rid of toxic or dangerous substances. (If you've ever had food poisoning or felt queasy at the sight of something disgusting, you've experienced the CTZ in action.) Since most cancer treatments are toxic, they tend to trigger the CTZ.

*What you can do*

The cardinal rule of dealing with treatment-induced nausea is to stay ahead of it. It's a lot easier to prevent vomiting than it is to stop vomiting once you've started. So be sure to let your treatment team know if you experience nausea or vomiting, including during the hours before treatment—a condition known as anticipatory nausea.

## Definitions

**Complementary therapy:** Treatments given along with standard treatment

**Hypnotherapy:** The use of hypnosis to put patients into a trance-like state of deep relaxation during which they are more accepting of suggestions

**Integrative medicine:** Combining standard treatment with complementary therapies that have been shown to be safe and effective

**Side effect:** An unplanned physical or emotional response to treatment

Medications that can prevent "puke now" signals from reaching the CTZ include ondansetron (Zofran), granisetron (Kytril), dolasetron (Anzemet), prochlorperazine (Compazine), promethazine (Phenergan), metoclopramide (Reglan), and aprepitant (Emend). When given before chemotherapy—either by mouth or in a vein—these drugs may prevent nausea for up to 24 hours. Another option, palonosetron (Aloxi), is given intravenously and can work for up to five days. Other medications that can help prevent or ease nausea include:

- Steroids such as dexamethasone (Decadron and Hexadrol),
- Tranquilizers such as lorazepam (Ativan),
- Antihistamines such as diphenhydramine (Benadryl), and
- Antacids.

If medications don't seem to be working, you might want to consider asking your oncologist to prescribe

## Questions to ask your team about: **Side effects**

Your doctor or oncology nurse should give you a pretty complete picture of the side effects you may experience and what can be done to prevent or relieve them. The questions below can serve as a guideline to help you fill in any gaps.

- What side effects should I expect during this treatment?
- When are they likely to occur?
- How long could they last?
- Are there any medications that can prevent or relieve these side effects?
- Is there anything I can do (other than medication) to prevent or relieve these side effects?
- Are there any complementary treatments that have been shown to help with the side effects of this treatment? Can you refer me to a person or place that offers these treatments?
- Are there any particular activities I should do—or avoid—to take care of myself while on this treatment?
- When should I call the doctor about my side effects?
- If the side effects cause too many problems, can I take a break from treatment? Can the dose be lowered? Is there a different treatment we could try?
- Are there any long-term effects associated with this treatment?
- Is there anything that can be done to prevent or reduce the risk of long-term side effects?

medical marijuana. The active substance in marijuana—a chemical called THC (**t**etra**h**ydro**c**annabinol)—has been shown to relieve nausea and stimulate appetite in people receiving chemotherapy. Your doctor can also prescribe a medication that contains THC such as dronabinol or nabilone. If you choose to go the more traditional route of smoking an occasional joint (or snacking on the occasional pot brownie), be sure to let your treatment team know, and educate yourself about state and federal laws related to the medicinal use of marijuana.

There are also some natural and complementary therapy options for preventing and calming nausea and vomiting that can be used alongside antinausea medications, including acupuncture and ginger root (as candy or tea). Staying well hydrated and eating frequent, small meals can also help.

## Hair, skin, and nail changes

### *Why it happens*

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

### *What you can do*

If your treatment plan includes medications that can cause hair loss, you'll want to make plans on how to deal with it before treatment starts. (Wig shopping can be emotionally much easier when you still have your own hair.) Some people find it helpful to pre-emptively shave their heads or cut their hair short. If you'd rather preserve as much of your hair for as long as possible, be gentle with it—baby shampoo, no harsh chemicals, and no blow drying.

### Definitions

**Chemotherapy:** Drugs that kill all cells that grow rapidly, including cancer cells and normal cells

**Complementary therapy:** Treatments given along with standard treatment

**Intravenous:** Drugs given into a vein

**Oncologist:** A doctor who specializes in treating cancer

### Acronyms

**CTZ=** Chemoreceptor trigger zone

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

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

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

- Wigs for Cancer Patients at the Cancer and Careers Web site (www.cancerandcareers.org/en/at-work/Managing-Treatment-Side-Effects/Wigs-for-Cancer-Patients)
- Wigs and Hair Donation on the American Cancer Society's Web site (www.cancer.org/myacs/california/areahighlights/wigshairdonation)
- The American Cancer Society's "tlc"™ Tender Loving Care catalog (www.tlcdirect.org/)
- Look Good Feel Better (www.lookgoodfeelbetter.org/)

If you experience severe skin reactions, your treatment team may try prescription medications or creams, or revise the treatment plan to give your skin time to recover.

## Mucositis and stomatitis

### *Why it happens*

Your GI tract—from the mouth right through to the other end—is lined with cells that are constantly dividing and replacing themselves every four or five days, which makes them vulnerable to being damaged by chemotherapy. Cancer treatment can lead to inflammation throughout the GI tract (mucositis)—often with pain and diarrhea—and inflammation and sores in the mouth (oral mucositis or stomatitis).

### What you can do

Be kind to your mouth and the rest of your GI tract. Keep your mouth clean and well lubricated, and avoid products and foods that can irritate inflamed tissues and open sores.

- Suck on ice chips or ice pops (not citrus!) before and during chemotherapy to help prevent oral mucositis from developing.
- Switch to the softest toothbrush possible, and brush your teeth within 30 minutes of every meal. If your mouth is very sensitive, try a sponge-tipped swab.
- Avoid products that contain alcohol, which can irritate and dry your mouth.
- Try a specialty toothpaste—such as Biotene—that does not contain sodium lauryl sulfate.
- Rinse your mouth regularly with a lubricating mouthwash (such as Biotene) or a diluted solution of baking soda and warm water.
- Steer clear of spicy or acidic foods (such as chili and lemonade).

If you're experiencing diarrhea, be sure to increase your intake of fluids to make up for what you're losing. To prevent diarrhea, try the following:

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

Let your treatment team know if you have more frequent bowel movements or severe diarrhea for two or more days in a row. If you become dehydrated you may require fluid replacement, including IV administration of fluids.

## Definitions

**Chemotherapy:** Drugs that kill all cells that grow rapidly, including cancer cells and normal cells

**GI tract:** The group of organs that food passes through when you eat

## Acronyms

**GI=** Gastrointestinal

**IV=** Intravenous

> I suppose most women would prefer to shave off their hair in private or to wait for it to fall out on its own, but I wanted to beat the chemo to it.”

Jen,
non-Hodgkin’s lymphoma survivor, on her head-shaving party

# Part 6: Coping with side effects

## Fatigue

### *Why it happens*

The fatigue that comes with cancer is a completely different animal than run-of-the-mill tiredness. As one blogger on Planet Cancer (www.planetcancer.org) described it, "It's like you're so tired that it makes you tired."

Fatigue can be the result of treatment's effects on the red blood cells that carry oxygen to your tissues, side effects of other medications, pain, dehydration, stress, sleeplessness, inadequate nutrition, or any combination of the above. If you experience fatigue, you may find that it is most severe in the days right after you receive treatment.

### *What you can do*

How your fatigue is managed will depend on its underlying causes. If you have anemia, your treatment team may give you a transfusion of red blood cells. If your fatigue can be traced to factors such as pain, sleeplessness, or nutritional problems, you may be referred to specialists with expertise in those areas.

In addition to eating well and staying as active as possible, you can work around treatment-related fatigue by paying attention to when fatigue tends to hit and managing your time accordingly. If you tend to feel wiped out in the days immediately following treatment, avoid making too many commitments during those times. When you do have energy, pace yourself and feel free to change or cancel plans if you're just not up to it.

## Immunosuppression

### *Why it happens*

Cancer treatment can damage your bone marrow, temporarily suppressing the cells your body needs to form red blood cells, platelets, and white blood cells called neutrophils that defend the body against infection. A severe drop in neutrophils is known as neutropenia.

## Definitions

**Bone marrow:** Soft tissue found in the center of most bones where blood cells are formed

**Platelet:** A type of blood cell that forms blood clots to control bleeding

**Side effect:** An unplanned physical or emotional response to treatment

**White blood cell:** A type of blood cell that fights disease and infection

*What you can do*

Be vigilant. Frustrating though it may be, you really need to protect yourself from viruses, bacteria, and other germs that your system just isn't prepared to fight. After all, the last thing you need while battling cancer is a severe case of the flu. Basic protective measures include:

- Buy a good thermometer. When you're immunosuppressed, or neutropenic, even a small spike in temperature may indicate the beginning of an infection. Monitoring your temperature can help detect infections before they become serious.
- When your counts are at their lowest, stay away from young children if you can. They're cute, but they're germ factories. If you're a parent, encourage your kids to be extra careful about hand washing and covering sneezes and coughs to help mommy or daddy stay well.
- Wash your hands. A lot. Carry hand sanitizer and try to use it whenever you touch potentially germy surfaces such as doorknobs. (And try to avoid shaking hands.)
- Avoid salad bars and buffets (they can be almost as germy as children!).
- Ask friends and family to stay away if they're feeling even a little bit under the weather, or if they've been exposed to someone who is sick.
- If your neutrophil count is low, ask your doctor if you should stay home from work or school. If you have to go in to the office or school, be sure to wash your hands often and well.
- Get a flu shot every fall. Discuss the timing of the shot with your treatment team, so you can be immunized when your immune system is relatively strong.

If your bone marrow is suppressed for a long time, your treatment team may prescribe injections of a G-CSF (**g**ranulocyte **c**olony-**s**timulating **f**actor) drug, such as Neupogen or Neulasta, that will prompt your bone marrow to produce more neutrophils.

## Nerve damage (neuropathy)

*Why it happens*

Several common chemotherapy drugs can cause neuropathy—damage to nerve cells that interferes with normal nerve signals. Peripheral neuropathy affects the hands and feet and can manifest as an increased sensitivity to cold, pain, burning, numbness, or a "pins and needles" tingling.

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

Neuropathy usually subsides once treatment is over, but permanent nerve damage can occur, so your treatment team will want to monitor these side effects very closely.

*What you can do*

If your treatment plan includes a drug that is known to cause neuropathy, your treatment team may try to limit your risk by reducing or skipping one or more doses. Other treatments that may reduce your risk of neuropathy include the nutritional supplements glutamine and alpha lipoic acid. Supplementation with calcium and magnesium may prevent the neuropathy associated with oxaliplatin.

If you do develop neuropathy, there are several medications and complementary therapies that can help:

- Gabapentin (Neurontin)—a drug to prevent convulsions—can ease the symptoms of peripheral neuropathy,
- Antidepressants such as amitriptyline (Elavil) and venlafaxine (Effexor) can alter the level of brain chemicals that control pain signals,
- Over-the-counter pain relievers such as acetaminophen (Tylenol) and ibuprofen (Motrin, Advil) are often effective at relieving the pain of neuropathy, and in severe cases, prescription pain killers may also be prescribed,
- Acupuncture,
- Massage, and
- Physical therapy.

## Definitions

**Bone marrow:** Soft tissue found in the center of most bones where blood cells are formed

**Chemotherapy:** Drugs that kill all cells that grow rapidly, including cancer cells and normal cells

**Neutrophils:** A type of white blood cell that fights infections in the body

# Part 7: Living your life

> When I was diagnosed with lymphoma, I was 18. I had just finished my freshman year of college. I had to come home and go back into my parents’ house and become dependent on them. I think being a young adult, you’re gaining your independence. You gain control over your life, and lose control over your life once you’re diagnosed. I’d been independent for a year and doing what I wanted to do when I wanted to do it. Now I was at the hold of what the doctor said and my parents.”

Tenise - Lymphoma survivor

# Part 7: Living your life

Going from "your basic American teen (or 20-something or 30-something)" to "your basic American teen (or 20-something or 30-something) with cancer" can throw your entire life off kilter. Whatever your plans may have been before your diagnosis, for the next year or more a big chunk of your time is going to be occupied with tests, treatments, insurance issues, and just plain holding it together.

This doesn't mean that you have to put your entire existence on hold. With the right support and a little planning you can keep your life from being all about the cancer.

## Holding your own

### Coping with moving back home

If getting cancer also means moving back in with your parents or other family members, the shock of your diagnosis may be mixed with a lot of other feelings, from frustration at losing your independence to relief at having the help, to a strange combination of the two.

Although the love and support of your family can be one of your most valuable assets, it's important that they—and you—understand that you're the one in charge when it comes to treatment. Parents and other family members can help you with research, support you during doctor visits, and offer their opinions, but ultimately it's your body, and it is important that your voice be heard and understood. Although it's not always easy to ask loved ones to back off, if you feel that your opinions aren't being heard you may need to let people know. Be loving but firm in setting boundaries, and let your family know if they are crossing the line from supportive to controlling.

### Maintaining a sense of control

It's not always easy to feel in control when cancer has hijacked your body. But even when surrounded by uncertainty there's plenty you can do to maintain a sense of control over your life and future.

- **Get organized.** As noted in Part 2, you'll be dealing with a LOT of paper and information on your cancer journey. Staying on top of it from the very beginning can save you from feeling overwhelmed and can do wonders for your sense of control. The Cancer101 Web site offers a comprehensive planner that can get you started. It includes sections for test results, research, insurance information, symptom tracking, appointments, and more. You can order the planner at www.Cancer101.org or by calling 646.638.2202.
- **Take control of your environment.** If you're going to be spending more time at home, you might as well enjoy it. If your bedroom (or apartment, or dorm room) isn't particularly comfortable or welcoming, try your hand at interior design. Set up a refuge where you can retreat and relax.
- **Set your priorities.** This is a good time to think about what's really important to you and where you want to invest your time and energy during treatment. What gives you satisfaction? Makes you happy? Makes you laugh? Is there anything you've always wanted to do, but haven't because you were

always on the go? Make these things a priority as you plan the days, weeks, and months ahead.

- **Give yourself some goals.** Your plans for the future don't have to come to a screeching halt just because you're being treated for cancer. In addition to your bigger life goals, try setting some short-term goals that you can work toward during the treatment phase—whether it's writing in your journal every day, finally getting to level 21 in Angry Birds, or reading that book that everyone's been talking about.

## Dealing with doubts

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

- **Give yourself permission to feel bad.** Cancer stinks. You have every right to feel scared or angry.
- **Talk about it.** Keeping negative feelings bottled up will just make them grow and heighten your sense of being out of control. Let friends and family know when you're feeling down or frightened. You don't always have to be brave.
- **Work with a professional.** If doubts and fears become difficult to manage, reach out to a social worker or psychologist. They can help you work through your feelings and find ways to cope. If you'd prefer, you can also talk to a minister, rabbi, or other clergyperson you trust. Your treatment team can also refer you to a psychiatrist if you feel that it will be helpful.
- **Connect with others who are in the same boat.** There are some things only another person with cancer can really understand. If your hospital or community doesn't have support groups for young adults with cancer, check out the online communities at Planet Cancer (www.planetcancer.org) or Stupid Cancer (www.stupidcancer.org). For more one-on-one support, try Imerman Angels (www.imermanangels.org/), an organization that matches and individually pairs a person touched by cancer (a cancer fighter or survivor) with someone who has fought and survived the same type of cancer.

## To party, or not to party . . .

Having a social life can be a bit more complicated while being treated for cancer, but it's not impossible. Getting out and spending time with friends will provide a much-needed reminder that there's life beyond needles and IVs and blood tests, and that not everything revolves around the cancer. But if your pre-diagnosis social life was filled with late nights and interesting substances, you're going to have to make some changes.

- **Tell your friends what they need to know**—this doesn't necessarily mean every gory detail of your cancer and its treatment. Share whatever information will help friends understand your new needs and limitations and so they can help you out if you are feeling sick or depressed.

- **Keep your plans flexible.** It may be hard to predict how you'll be feeling from one day to the next, particularly in the early phase of treatment. Let friends know that all plans are conditional on how you're feeling on any given day.
- **Be selective.** When your energy is limited, it makes sense to spend it on events and activities that are really special.
- **Expand your horizons.** Consider incorporating stress-reducing activities into your social life. Ask friends to join you for yoga class and brunch instead of a night at the bar.
- **Don't be afraid to bow out.** It's better to opt out of a planned activity than to push yourself when you're feeling fatigued or ill.
- **Be aware of your risks.** If your treatment plan includes drugs that suppress your immune system, you'll want to avoid large group situations that can expose you to germs your immune system can't fight when your blood counts are at their lowest.
- **Think before you drink.** (Or smoke. Or whatever.) Alcohol and other drugs may interact with your cancer treatment and cause potentially serious side effects. Be sure to talk to your treatment team about whether—or how much—alcohol is safe for you, and about the risks of other recreational drugs. Keep your treatment team informed of how much you are drinking, smoking, or using.

**Notes:**

### A primer on cancer etiquette

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

> It’s really helpful to know someone else your age who’s going through, or has gone through, what you’re experiencing. In my case, it was a family friend who’d been diagnosed several months prior. I would get in touch with my friend whenever I had questions. Or simply to vent about the whole situation!!! There’s nothing like having a person around who gets the dark humor that inevitably takes over when your life is on the line.”
>
> Allyson
> non-Hodgkin’s lymphoma survivor, diagnosed at age 37

## Navigating relationships

Friends and family can react to a cancer diagnosis in some very strange ways. Some take it in stride, achieving the perfect balance of support and normalcy. Others are so freaked out or unsure of what to say that they basically disappear. Still others become so focused on the cancer that they can’t seem to talk about anything else. And all of them mean well.

Navigating your relationships with friends and family members requires a mix of honesty, diplomacy, and self-protection. Having to tell your story over and over again tends to get old fast. To keep people in the loop consider one or all of the following options.

- Ask a friend or family member to serve as information central, keeping people updated on your condition and fielding questions and messages so you don’t get overwhelmed.
- Start a blog. The Web site www.familypatient.com is a free service that you or your information central person can use to post regular updates in a simple message format.
- Send out mass e-mail updates on how you’re doing and what you need.

# Part 7: Living your life

### Talking with your partner

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

Before you begin treatment, sit down with your partner and your physician to discuss what side effects you can expect, the impact they may have on your sexuality, and whether there is anything that can be done to help. As you go through treatment, be honest with your partner about what you are going through physically and emotionally. Even if sexual intercourse is not possible, you can maintain your physical intimacy by continuing to caress, hold, and kiss one another.

### Books that can help

Peter VanDerNoot. *Helping Your Children Cope with Your Cancer* (Second Edition): A Guide for Parents and Families. Long Island City, NY: Hatherleigh Press, 2006.

Kathleen McCue, Ron Bonn. *How to Help Children Through a Parent's Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist*. New York, NY: St. Martin's Griffin, 2011.

**Notes:**

### Talking with children

If you're a parent, telling your children about your cancer can be one of the most challenging things about the disease. It may be tempting to put on a brave face and try to protect them from the news—but this is almost always a mistake. Kids are observant, and are likely to know that something is wrong whether you tell them or not.

There's plenty of information out there on how to talk to children about cancer and help them cope with a parent's illness. The Web site Telling Kids About Cancer (www.tellingkidsaboutcancer.com/) offers a wealth of age-appropriate tips and resources for parents. Key recommendations include:

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

## Navigating home

If you're living on your own or caring for a family, juggling home life and treatment can be a struggle. Staying on top of things like laundry, cleaning the bathroom, or grocery shopping gets a lot more difficult when you're also battling treatment side effects and trying to go to school, maintain a job, and/or care for children.

This is an excellent time to take people at their word and accept offers of help. Go ahead and delegate tasks that you don't feel up to doing. Most importantly, ask for help when you need it.

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

# Part 7: Living your life

## Navigating school

The combination of cancer and the social jungle that is school can be particularly challenging. In addition to constantly being exposed to the germfest of classrooms, locker rooms, and communal bathrooms, side effects like fatigue and chemobrain can make it harder to keep up with coursework.

No matter how much you may want to keep your condition under wraps, it's important to let your teachers/professors and school counselor know about your cancer. Have a talk with each teacher as soon as you're diagnosed (and at the beginning of each semester) about the side effects you're likely to experience and how they may affect your ability to attend class or meet deadlines. Discuss how—and when—you should request extensions if needed.

## Navigating work

Since cancer treatment can last for months to years, it's likely that you'll be working for much of the time you're in treatment. Before treatment begins, make time to talk with your boss and get a clear understanding

**Notes:**

of your company's policies on things like flex time, telecommuting, qualifying for Family Medical Leave Act benefits, and short- and long-term disability.

If you have other questions, check out Cancer and Careers (www.cancerandcareers.org), a one-stop-shop for all things cancer- and work-related. Founded in 2001, the Cancer and Careers site is dedicated to eliminating fear and uncertainty for working people with cancer. It contains expert advice on everything from selecting a wig to disability law, as well as interactive tools and educational events on how people with cancer can thrive in the workplace.

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

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

## Dealing with finances

Sadly, financial problems are all-too-common among AYAs with cancer. If you're facing financial stresses such as unemployment or inadequate health insurance, talk with your team's social worker, patient navigators, and hospital financial services about options for getting better control of your finances.

An excellent source of support and information is the not-for-profit Patient Advocate Foundation (www.patientadvocate.org, 800.532.5274), which provides professional case managers who serve as advocates for patients dealing with insurance companies, employers, and/or creditors.

For information on pharmaceutical companies' patient assistance programs—which provide free or discounted medications to patients in financial need—try the searchable online databases at Rx Assist (www.rxassist.org/patients) or Needy Meds (www.needymeds.org/indices/pap.htm). Other sources for help with medication costs include:

- The Patient Access Network Foundation (www.panfoundation.org; 866.316.7263, 9:00 AM to 5:00 PM, ET), which 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.
- The Patient Advocate Foundation's Co-Pay Relief Program (www.copays.org/), which provides direct financial support for pharmaceutical co-payments to insured patients who financially and medically qualify.

# Part 7: Living your life

> “The first couple of years, I ignored all of these insurance things, because I had too much on my mind with regard to what I was dealing with. That came back to bite me because then it goes to the creditors and your credit gets screwed up . . . When I resigned, I got COBRA insurance, which I can have for up to 18 months. That's always been a very difficult thing. It's a pain. At 25 years old, you don't really know how to deal with it.”
>
> Tim - Testicular cancer survivor.

**Notes:**

# Part 8: Moving beyond treatment

> “I underestimated life after treatment and thought things were going to be just like they were before my cancer, but I'm finding out it's a lot tougher than I expected.”

Breast cancer survivor, diagnosed at age 27

# Part 8: Moving beyond treatment

Finishing treatment is a major milestone in your cancer journey: a time to say goodbye to the cycle of treatments, side effects, and tests and to get back to normal.

But the “normal” of post-treatment life won’t be quite the same as life before your diagnosis. Cancer changes you. Some people have described survivorship as “being disease free, but not free of disease.” As a cancer survivor, you have a new perspective, new worries, and new strengths that will influence every day of your life.

Adjusting to this “new normal” isn’t always easy, but preparation and planning can smooth the transition and help you make the most of the next phase of the journey.

> I remember being told, ‘You’re cured. Go home. Get on with your life.’ Evidently, that’s not necessarily the end of the story for me or millions of others like me. I do not deny that the physical malignancy is gone. It’s been 11 years and there is still no evidence of biological recurrence. So everything is hunky dory, right? Ummm . . . no.”
>
> Matthew, brain cancer survivor, diagnosed at age 21

## Preparing for the transition

During treatment, your oncology team, family, and friends likely were a pretty constant source of information and support. Even though you’re no longer actively fighting cancer, you’ll need many of these supports as you continue along the road of cancer survivorship.

After months of spending way too much time with various medical people, you may want to take a break from doctors for a bit. That’s understandable. But regular follow-up is critical to protecting your long-term health.

Your physician will probably want to check for recurrences and other medical problems every month or two for the first year or so. If all goes well, that may eventually drop down to once a year.

Follow-up is important because treatment-induced damage can cause health problems that last long after treatment is over. Depending on your treatment plan, survivorship problems may include:

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

In addition, many cancer treatments have been linked to late effects that may not become obvious until years after you've finished treatment, including:

- Secondary cancers,
- Heart problems,
- Lung problems,
- Hearing problems,
- Cataracts (clouding of the eye lens),
- Stroke,
- Kidney problems, and
- Osteoporosis.

Cancer leaves its mark in other ways, as well. You may find that you experience nagging worries, doubts about the future, and concerns about school, work, and relationships.

Dealing with these effects will take time, patience, and plenty of support. So instead of a cancer treatment team, you now will need a cancer survivorship team.

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

- Your **family medical history** (eg, blood relatives who have had diabetes, heart conditions, cancer, stroke, and other conditions),
- All v**accinations and immunizations** you have had,
- Any **past injuries or surgeries**—including details on the treatment and results,
- Information on any **ongoing health problems** you have other than cancer, including dental issues,
- A complete list of all **medications** you are currently taking, including over-the-counter drugs—the list should specify drug names, doses, and the name of the prescribing doctor,
- Notes about any **side effects or reactions** you have had to medicines or medical treatments,

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

- The LIVE**STRONG** Foundation's "Aftereffects of Cancer Treatment" Web page (www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Aftereffects-of-Cancer-Treatment).
- Cancer.Net's "Late Effects" Web page (www.cancer.net/survivorship/late-effects).

- History of **pain problems** including treatments and results,
- Information about **specific cancer treatments** and side effects, and
- A list of **allergies and sensitivities**.

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

- A record of pertinent diagnostic tests and their results,
- The specifics of your diagnosis, including the type and location of the cancer, stage, histologic grade, hormonal status, and markers,
- History of your cancer treatments and hospital stays including dates, medications given, doses used, treatment response, and any reactions or side effects,
- Records of any other health care services you received such as physical therapy, psychosocial counseling, and nutritional services, and
- Names and contact information for all health professionals involved in your treatment.

This information can be used to develop a comprehensive survivorship care plan for the days, months, and years ahead.

## Your survivorship care plan

The goal of a treatment plan is the elimination and/or control of cancer. The goals of a survivorship care plan are different, and are sometimes referred to as the "three Ps":

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

### Definitions

**Histologic grade:** A measure of how much tumor cells resemble healthy cells of the same tissue type

**Osteoporosis:** A disease causing thinning, weakened bones

**Secondary cancers:** Cancers that develop as a result of damage caused by the treatment of the original cancer

**Side effect:** An unplanned physical or emotional response to treatment

**Stage:** A rating of the extent of cancer in the body

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

- A summary of your cancer treatment history. This will ensure that other doctors you work with have a complete understanding of your case.
- Detailed recommendations for follow-up care, including:
    - Names and contact information for follow-up physicians, including who is responsible for which aspects of your care,
    - A schedule for follow-up visits with an oncology specialist,
    - Tests that should be done to check for recurrence, and
    - Recommendations and guidelines for identifying and managing long-term and late effects.
- Health promotion recommendations, including:
    - Smoking cessation,
    - Limiting your alcohol use,
    - Eating a healthy diet,
    - Regular weight-bearing exercise,
    - Regular tooth brushing, flossing, and dentist visits, and
    - Receiving an annual flu shot.
- Information on available resources that can help you deal with physical problems, psychological and emotional stress, financial issues, insurance issues, and other survivorship challenges.

Ideally, your treatment team will take the lead in putting together a survivorship care plan before you're even finished with treatment. If they don't, the LIVE**STRONG** Foundation has partnered with OncoLink (from Penn Medicine) to provide the LIVE**STRONG** Care Plan (www.livestrongcareplan.org/). This interactive Web site uses your answers to a brief questionnaire to produce a basic individualized care plan.

To use the site you will need information from your treatment record, including your diagnosis and details on the treatment you received. The resulting care plan can then be shared with your oncology team and used as a start for putting together your personal survivorship care plan.

Many large cancer centers offer dedicated survivorship programs to help patients make the transition from patient to survivor. If your treatment center is one of them, be sure to take advantage of as many survivorship resources as possible.

# Part 8: Moving beyond treatment

## Questions to ask your team about: **Survivorship**

- What treatments and drugs have I been given?
- What are the long-term and late effects of the treatment I received?
- Are there interventions I can use to relieve or prevent these effects?
- What are the chances that my cancer will come back or that I will get another type of cancer?
- What symptoms should I watch for? If I develop any of these symptoms, whom should I call?
- How often should I see my doctor for follow-up?
- Who should I see for cancer follow-up?
- What tests, if any, should I have to monitor my health?
- How often will I need these tests?
- Will I have trouble getting health insurance or keeping a job because of the cancer?
- Can you recommend any support groups or other resources that can help me with survivorship issues?

**Notes:**

## Adjusting to a new normal

Being a cancer survivor adds new layers of complexity to things like school, career, and personal relationships. There are often nagging questions about who to tell about your history, how much they need to know, and when you should tell them.

Many people also underestimate just how long it can take to recover from the effects of cancer treatment. Survivors may take on too much. Friends and family may not realize their support is still needed. Romantic partners may have trouble adjusting to sex after cancer.

On the plus side, surviving cancer can give you a whole new perspective on life and what you want from it. After facing your own mortality, you may find it's easier not to sweat the small stuff, and to take advantage of the opportunities life brings your way.

### At school

Lingering problems with concentration and memory can be frustrating when trying to get back into the swing of things at school. If you continue to experience chemobrain, try cutting back on your course load and scheduling more time to study and to complete assignments. If chemobrain or other treatment-related side effects are interfering with your ability to keep up, let your doctors know. Neuropsychological testing can identify your specific limitations, and your doctors can work with your school to create a plan to compensate for them as much as possible. You can also talk with your professors or school counselor about modifying your schedule and adjusting deadlines.

If you're facing financial challenges, consider applying for some of the many scholarships and grants that are available to students who are cancer survivors, including the SAMFund for Young Adult Survivors of Cancer (www.thesamfund.org). You can find a comprehensive listing of cancer-related scholarships on the Web site FinAid! The Smart Student Guide to Financial Aid (www.finaid.org/scholarships/cancer.phtml).

### At work

Research has shown that cancer survivors are just as productive in the workplace as employees who haven't had cancer, but you may find that some co-workers (and employers) have their doubts about your ability to work. It's even possible that you have some worries about how you'll cope when returning to full-time work.

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

That said, you should always feel free to talk to your employer if you need to make adjustments at work because of ongoing side effects. Under Federal law, employers are required to make reasonable accommodation to help you do your job during or after cancer treatment. Reasonable accommodation is loosely defined as changes in work arrangements (schedule, office location, etc.) that will allow a qualified person to continue to do his or her job without causing a significant hardship for the employer. For more information on laws related to survivorship and the work place, visit the Cancer Legal Resource Center (www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm) or Cancer and Careers (www.cancerandcareers.org/en/at-work/Back-to-Work-After-Cancer). Both sites include a wealth of information on getting back to work after cancer treatment, including regularly updated information on legal and insurance issues.

### In your relationship

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

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

If you're currently single, try not to put too much pressure on yourself to find "the one," or to hide from potential relationships. Gradually lower yourself back into the dating pool, by getting involved in social activities you know you enjoy. Let dating be a by-product of the social life you are already enjoying.

**Notes:**

For more on navigating life after treatment, check out *The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer* (New York, NY: Marlowe & Company, 2006). Written by psychologist and cancer survivor Michael Feuerstein and social worker Patricia Findley, *The Cancer Survivor's Guide* offers 7 distinct steps to help survivors chart the course of their post-treatment life and answer their personal "Now whats?"

When you do start dating, wait until you have a sense of trust and connection with the other person before telling him or her about your cancer. For more on sexual issues during survivorship, see the American Cancer Society's Web pages on sexuality for the woman (www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/sexualsideeffectsinwomen/sexualityforthewoman/sexuality-for-women-with-cancer-cancer-sex-sexuality) and man (www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/sexualsideeffectsinmen/sexualityfortheman/sexuality-for-men-with-cancer-intro) with cancer.

As discussed in Part 3, many cancer treatments damage cells in the testicles and ovaries and can lead to problems with fertility. In men, treatment-related infertility is often temporary. Unfortunately that's rarely the case with women. In fact, women may develop premature ovarian failure months, years, or even decades after treatment is over. These uncertainties make it particularly important that you get regular checkups to determine if you are still fertile, and that you use birth control if you don't want a child in the near future. If you're a woman and are still having periods, you may want to ask your doctor whether the treatment you received is associated with an increased risk of delayed premature ovarian failure.

## Coping with recurrence

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), in the same general vicinity as the original cancer (regional recurrence), or in a completely different part of the body (distant recurrence or metastasis).

Recurrences are scary and frustrating but they aren't the end of the road. Advances in cancer treatment have made it possible to cure many local and regional recurrences, and even a distant recurrence can sometimes be successfully treated or kept in check for years. The exact treatment for the recurrence will be based on the same factors that were considered after your first diagnosis, including the availability of clinical trials. (See Part 5.)

Finding out that your cancer has come back can really pull the rug out from under you, and it's natural to feel all sorts of complicated emotions. As before, give yourself permission to express your feelings and reach out for help as needed. Above all, try not to waste valuable time and energy looking backward or second-guessing yourself. Take a deep breath and move forward. After all, this time around you have quite a few advantages that you didn't have when you first were diagnosed.

- **You know more.** First time out, everything was a surprise. Now, you're a veteran. Central venous catheter? Been there, done that. Chemotherapy side effects? Check. Very loud MRIs? Piece of cake. The fact that you've already been through treatment can make it easier to plan, to cope, and to work with the treatment team.
- **You've built relationships.** If you're being treated by the same basic oncology team, you also have the advantage of working with people you already know and trust.
- **You know what works for you.** Instead of trial and error, you can draw on your first experience when making decisions about dealing with side effects, planning your life, and making use of available supports.

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

## Definitions

**Central venous catheter:** A thin, flexible tube that is placed into a vein in the upper arm, neck, thigh, or below the collarbone

**Chemotherapy:** Drugs that kill all cells that grow rapidly, including cancer cells and normal cells

**MRI:** A test that uses radio waves and powerful magnets to see the shape and function of body parts

**Side effect:** An unplanned physical or emotional response to treatment

## Acronyms

**MRI=** Magnetic resonance imaging

# Part 9: Thinking about the unthinkable

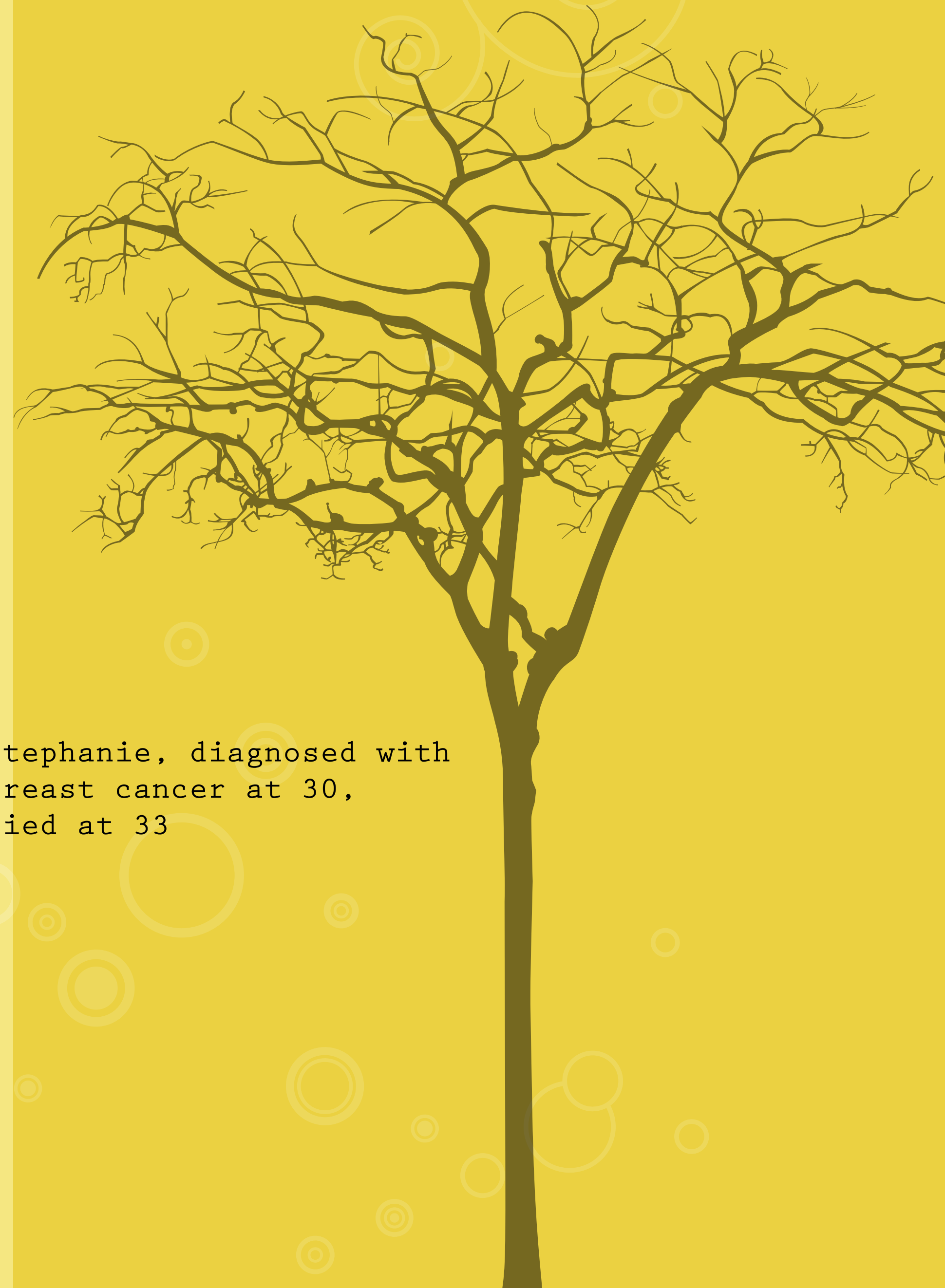
95 **Advance care planning**
Making sure your wishes are known and respected

96 **Making the most of your time**
Enjoying life when time is limited

97 **Hospice care**
Facing the end in comfort and with dignity

> “When I asked my doctor how much time I had left, she often responded, ‘You never know. Heck, I could get hit by a bus tomorrow.’ Sure she could. But I always wanted to tell her that it’s a little different when there’s a maniacal driver out there, gunning for you.”

Stephanie, diagnosed with
breast cancer at 30,
died at 33



# Part 9: Thinking about the unthinkable

Most people with cancer go into treatment determined to “beat this thing.” And lots of them do—at any given time there are more than 13 million cancer survivors in the U.S., alone.

But sometimes beating cancer isn’t an option. When cancer is diagnosed very late or keeps progressing despite all treatment efforts, it may be time to set some new goals. If it becomes clear that cure is not possible, treatment becomes about making the most of your time and assuring that you can meet death on your own terms.

## Advance care planning

Advance care planning is all about making sure that your wishes are understood and respected and that you receive the best possible care at the end of your life. Research has shown that when patients with incurable cancer set up an advance care plan early on, they feel less stressed and better able to cope with their condition.

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

Once you’ve made these decisions, they will be incorporated into an advance directive—a legal document that lays out what you want done if you aren’t able to tell the doctors yourself. Doctors are required to follow the care instructions in an advance directive when you are too ill to give instructions about your care. The advance directive will include information on how much you want your doctors to do if your heart or lungs stop working or if you are no longer able to eat. Many advance directives include DNAR (**D**o **N**ot **A**ttempt **R**esuscitation) or DNI (**D**o **N**ot **I**ntubate) orders, which specifically forbid medical providers from reviving you with CPR (**c**ardio**p**ulmonary **r**esuscitation) or hooking you up to a breathing machine. It will be important to keep your advance directive on hand because in the absence of these papers, health care professionals are legally required to do everything possible to keep your heart beating and lungs breathing. Make sure everyone on your team—and in your family—knows about your advance directive and its contents.

> “
>
> Willing yourself to live often takes sheer guts and a willingness to ‘do what it takes.’ Living without being afraid to die takes being at peace with where you are in life . . . It gave me a great feeling of peace to be ready to die. It finally allowed me to ‘live’ in some ways.”
>
> Patti, diagnosed with
> breast cancer at 24, died at 29

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

Your advance directive should also identify your health care proxy, a person who is authorized to make decisions on your behalf it you can't communicate. This person may one day have to make some very tough decisions, so you should think carefully when selecting your proxy. Pick someone who knows you well but who will be able to follow your wishes when the time comes, even if your wishes don't mesh with that person's personal beliefs.

Researchers from the National Institutes of Health recently developed the Voicing My Choices Planning Guide for Adolescents and Young Adults (www.agingwithdignity.org/voicing-my-choices.php), a simple but incredibly complete template for laying out your end-of-life wishes. In addition to forms for selecting your health care proxy and your instructions regarding life support and resuscitation, Voicing My Choices includes sections on how you like to be comforted, your spiritual beliefs, and even what you want done after you have died.

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

- Clear up any insurance questions. Find out what 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 (bank accounts, insurance policies, mortgages, etc.) and make sure your family knows where everything is. The National Cancer Institute's booklet, Coping with Advanced Cancer (www.cancer.gov/cancertopics/coping/advancedcancer.pdf), includes a detailed worksheet that can help.
- If you wish to have a funeral or memorial service, consider making the arrangements in advance.

## Making the most of your time

Realizing that your time on this earth is limited can be a strange combination of devastating and liberating. Some patients with incurable cancer note that the loss of the future can give back the present, freeing you to focus on relationships and activities that bring you the most joy, fulfillment, and satisfaction. As one young breast cancer patient put it, "Instant gratification? For me, there's no other kind."

Use the times when you are feeling relatively well to pursue the hopes and dreams that are still within your grasp, to enjoy the company of the people you love, and to build positive memories that will last when you are gone. Some people use this time to build a sort of legacy, by preparing something special that they can leave behind for their loved ones, such as:

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

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

> “Being this sick made me realize that too many of us wait forever to start our lives. So I took a deep breath and moved forward . . . For what it's worth, and it's worth a lot, I've had two great years of really living.”
>
> Stephanie, diagnosed with breast cancer at 30, died at 33

This can also be a time to mend fences and work through painful emotions associated with leaving the people you love behind. If your treatment center doesn't have an end-of-life program, ask about a referral to a counselor with experience in end-of-life issues or to a support group for patients who are dealing with incurable illnesses. Having a safe place to vent your fear, guilt, grief, sadness, and just plain anger will make it easier to talk about these issues with family and friends.

## Hospice care

Hospice (from the Latin for “guesthouse”) is a type of care designed to provide medical, psychological, social, and spiritual support to terminally ill patients and the people who love them. The goal is comfort, not cure. Many insurance plans will only cover hospice services if your doctor has said that your life expectancy is 6 months or less and that you will not be receiving treatment designed to cure cancer. Of note, some forms of chemotherapy 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 clarify these issues before making your decision.

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

# Part 9: Thinking about the unthinkable

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

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

> “I look at it this way—at least I have a chance to say ‘hello’ and a chance to say ‘good-bye.’ Lots and lots of people don't get that chance.”
>
> Annette

## Questions to ask your team about: **End-of-life care**

- Based on what you know of this cancer, what symptoms will I experience as the cancer progresses?
- How will it affect my ability to do things? Drive a car? Will I be able to walk? Will it make it difficult for me to eat?
- What sort of pain am I likely to experience?
- What medications can I take to relieve this pain?
- Are there any complementary treatments that can help? If so, can you refer me to a practitioner who has worked with cancer patients?
- Am I eligible for hospice care? Will it be covered by my insurance?
- Does this hospital have an end-of-life support program for people my age? If not can you refer me to a counselor or support group?

# Part 10: Resources

# Part 10: Resources

## GENERAL INFORMATION ON CANCER IN AYAS

### *Web Resources*

**The 15-40 Connection**
www.15-40.org/

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

**Critical Mass: The Young Adult Cancer Alliance**
www.criticalmass.org

**Planet Cancer**
www.planetcancer.org/

A community of peer support and advocacy for AYAs with cancer, designed to connect and empower AYAs and help them access support and resources.

**Seventy K: Survival Up**
www.seventyk.org/

Not-for-profit organization dedicated to improving cancer care by educating patients, families, and their health care providers about age-appropriate treatment and the unique needs of AYA cancer patients.

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

The nation's largest online support community for AYAs affected by cancer.

**Teens Living With Cancer**
www.teenslivingwithcancer.org/

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

**Ulman Cancer Fund for Young Adults**
www.ulmanfund.org/

Grassroots organization dedicated to supporting, educating, connecting, and empowering AYA cancer patients and survivors.

### *Print Resources*

Kris Carr. Crazy Sexy Cancer Tips. Guilford, CT: skirt!, 2007.

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

# Part 10: Resources

Kairol Rosenthal. Everything Changes: The Insider's Guide to Cancer in Your 20s and 30s. Hoboken, NJ: John Wiley & Sons, Inc. 2009.

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

Heidi Schultz Adams & Christopher Schultz. Planet Cancer: The Frequently Bizarre Yet Always Informative Experiences and Thoughts of Your Fellow Natives. Guilford, CT: Lyons Press, 2010.

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

## CANCER DIAGNOSIS AND TREATMENT

### *Web Resources*

**American Cancer Society**

*Understanding Your Diagnosis*
www.cancer.org/Treatment/UnderstandingYourDiagnosis/index

*Chemotherapy*
www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/Chemotherapy/index

*Guide to Cancer Drugs*
www.cancer.org/Treatment/TreatmentsandSideEffects/GuidetoCancerDrugs/index

*Radiation Therapy*
www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/Radiation/index

*Immunotherapy*
www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/Immunotherapy/index

*Targeted Therapy*
www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/TargetedTherapy/index

*Understanding Cancer Surgery: A Guide for Patients and Families*
www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/Surgery/index

**MyCancerGenome.org**

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

# Part 10: Resources

**National Cancer Institute**

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

www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility

*Fact Sheets*

Bone Marrow Transplantation and Peripheral Blood Stem Cell Transplantation

www.cancer.gov/cancertopics/factsheet/Therapy/bone-marrow-transplant

*Targeted Cancer Therapies*

www.cancer.gov/cancertopics/factsheet/Therapy/targeted

**National Center for Complementary and Alternative Medicine**

www.nccam.nih.gov/

**National Comprehensive Cancer Network**

*Cancer Staging Guide*

www.nccn.com/understanding-cancer/cancer-staging.html

**Navigate Cancer Foundation**

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

This free, online program provides consultation services by experienced cancer nurses who can translate pathology reports, scans, and medical documents and help patients find a qualified doctor for a 2nd opinion.

**Ulman Cancer Fund for Young Adults**

*Patient Navigation Services*

www.ulmanfund.org/patientnavigation.aspx

On-site (Baltimore, MD) and remote program to help young adults manage their cancer experiences through increased knowledge and effective communication with their clinical care team, family, friends, and community.

**U.S. National Institutes of Health**

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

## Print Resources

Andrew Ko, Ernest H. Rosenbaum, & Malin Dollinger. Everyone's Guide to Cancer Therapy: How Cancer Is Diagnosed, Treated, and Managed Day to Day. Riverside, NJ: Andrews McMeel Publishing, 2008.

Gerald P Murphy, Lois B. Morris, and Dianne Lange. Informed Decisions: The Complete Book of Cancer Diagnosis, Treatment, and Recovery. Atlanta, GA: American Cancer Society, 2011.

# Part 10: Resources

## FERTILITY ISSUES

### *Web Resources*

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

**Fertile Hope**
www.fertilehope.org

> Fertile Hope 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. Useful sections include:
>
> > **Fertility Resource Guide** – A searchable database of doctors and services, including reproductive endocrinologists, sperm banks, financial assistance, adoption agencies, and legal resources.
> >
> > **Insurance Coverage** – An overview of the insurance issues involved in fertility preservation and treatment, including links to additional resources.
> >
> > **Options Calculators** – Calculators for identifying potential fertility preservation techniques based on your gender, age, treatment stage, and the type of treatment you're receiving.
> >
> > **Risk Calculators** – Risk calculators that can help you figure out if your disease, or its treatment, will make it difficult for you to have children.
> >
> > **Sharing Hope Financial Assistance Program** – Sharing Hope has worked with companies and clinics to arrange for discounted services and donated medications for eligible female cancer patients. The page includes a searchable database for finding providers in your area.

**MyOncofertility.org**
www.myoncofertility.org/

> Patient education resource provided by the Oncofertility Consortium.

**The Oncofertility Consortium**
www.oncofertility.northwestern.edu/

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

### *Print Resources*

Lindsay Beck, Kutluck H. Oktay, & Joyce Dillon Reinecke. 100 Questions & Answers About Cancer and Fertility. Sudbury, MA: Jones and Bartlett Publishers, 2008.

Gina M. Shaw . Having Children After Cancer: How to Make Informed Choices Before and After Treatment and Build the Family of Your Dreams. Berkeley, CA: Celestial Arts, an imprint of Ten Speed Press, 2011.

Leslie R. Schover. Sexuality and Fertility after Cancer. Hoboken, NJ: John Wiley & Sons, Inc., 1997.

## MANAGING SIDE EFFECTS

### *Web Resources*

**American Cancer Society**
*Chemotherapy Side Effects Worksheet*
www.cancer.org/acs/groups/content/@nho/documents/document/acsq-009502.pdf

*Nutrition for the Person with Cancer During Treatment: A Guide for Patients and Families*
www.cancer.org/acs/groups/cid/documents/webcontent/002903-pdf.pdf

*"tlc"™ Tender Loving Care catalog*
www.tlcdirect.org/

*Understanding Chemotherapy: A Guide for Patients and Families*
www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/Chemotherapy/

*Wigs and Hair Donation*
www.cancer.org/myacs/california/areahighlights/wigshairdonation

**Cancer and Careers**
*Wigs for Cancer Patients*
www.cancerandcareers.org/en/at-work/Managing-Treatment-Side-Effects/Wigs-for-Cancer-Patients

*Look Good, Feel Better*
www.lookgoodfeelbetter.org (for women)
www.lookgoodfeelbetterformen.org/ (for men)

> Program dedicated to improving the self-esteem and quality of life of people undergoing cancer treatment. Includes information on how to manage the appearance-related side effects of treatment.

**National Cancer Institute**
*Coping with Cancer: Managing Physical Effects*
www.cancer.gov/cancertopics/coping/physicaleffects/

*Nutrition in Cancer Care*
www.cancer.gov/cancertopics/pdq/supportivecare/nutrition/Patient/page1/

**University of California San Francisco Medical Center**
*Diet for Cancer Treatment Side Effects*
www.ucsfhealth.org/education/diet_for_cancer_treatment_side_effects/index.html

*Nutrition and Coping with Cancer Symptoms*
www.ucsfhealth.org/education/nutrition_and_coping_with_cancer_symptoms/index.html

# Part 10: Resources

## *Print Resources*

Judith McKay, Tammy Schacher. The Chemotherapy Survival Guide: Everything You Need to Know to Get Through Treatment (Third Edition). Oakland, CA: New Harbinger Publications, Inc., 2009.

Roxanne Brown, Barbara Mastej, John S. Link, MD. Chemo: Secrets to Thriving From Someone Who's Been There. Bedford, IN: NorLightsPress, 2011.

Rebecca Katz.The Cancer-Fighting Kitchen: Nourishing, Big-Flavor Recipes for Cancer Treatment and Recovery. Berkeley, CA: Celestial Arts, 2009.

## DEALING WITH LIFE (DURING AND AFTER TREATMENT)

### *Web Resources*

**Cancer101**
www.cancer101.org/

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

**Cancer and Careers**
www.cancerandcareers.org

> Web site dedicated to helping people with cancer thrive in the workplace by providing expert advice, interactive tools, and educational events. Also offers free publications, career coaching, and a series of support groups and educational seminars for employees with cancer and their health care providers and coworkers.

**Cancer Care**
www.cancercare.org/

> Provides free professional support services to anyone affected by cancer. All services—including counseling and support groups, education, financial assistance, and practical help—are provided by professional oncology social workers and are completely free of charge.

**Cancer Legal Resource Center (CLRC)**
www.disabilityrightslegalcenter.org/about/cancerlegalresource.cfm
Phone: 866.843.2572 or 213.736.1455

> Provides information about cancer-related legal issues, including health insurance, employment, government benefits, advanced directives, and more. Services are free, confidential, and available in both English and Spanish.

**Cancer.Net**
*Late Effects*
www.cancer.net/survivorship/late-effects

**CaringBridge.org**
www.caringbridge.org/

> Online space where cancer patients and their friends and family can connect, share, and receive support–kind of like a personalized social network. Available 24/7 to anyone, anywhere at no cost.

# Part 10: Resources

**Family Patient Online Patient Update Reports**
www.familypatient.com/

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

**FinAid! The Smart Student Guide To Financial Aid**
*Cancer Scholarships*
www.finaid.org/scholarships/cancer.phtml

Information about scholarships for cancer patients, cancer survivors, children of a cancer patient or survivor, students who lost a parent to cancer, and students pursuing careers in cancer treatment.

**Imerman Angels**
www.imermanangels.org/

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

**Job Accommodation Network**
www.jan.wvu.edu/

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

LIVE**STRONG Foundation Resources**
www.livestrong.org/gethelp

LIVE**STRONG Navigation Services** – Get free, confidential support through education, referrals, and counseling services at any point in your cancer experience. Call toll free 1.855.220.7777 or complete the online intake form at www.livestrong.org/Get-Help/Get-One-On-One-Support.

LIVE**STRONG Guidebook Planner and Journal** – Free two-volume set provides information and journal spaces to help you navigate the physical, emotional, and practical concerns you may have during the cancer journey.

LIVE**STRONG Cancer Guide and Tracker iPad App**– Lets you store and access information relevant to your treatment and survivorship electronically. The Cancer Guide will help you know what to expect, learn what questions to ask, and connect to resources.

LIVE**STRONG Educational Topics include:**
*After Effects of Cancer Treatment*
www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Physical-Effects-of-Cancer/Aftereffects-of-Cancer-Treatment

*Cancer Survivorship After Treatment*
www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Practical-Effects-of-Cancer/Cancer-Survivorship-After-Treatment

# Part 10: Resources

LIVE**STRONG Care Plan**

www.livestrongcareplan.org/

Interactive program that uses answers to a brief questionnaire to produce a basic survivorship care plan. The LIVE**STRONG** Care Plan is meant to be shared with the oncology team and used as a start for putting together a personal survivorship care plan.

**Lotsa Helping Hands**

www.lotsahelpinghands.com/

Free service designed to help friends and family organize support efforts. Includes a help calendar to schedule and sign up for specific report activities (shopping, rides to medical appointments, meal preparation, etc.) as well as a message board for sharing information.

**MyLifeLine.org**

www.mylifeline.org

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

**National Cancer Institute**

*Adolescents and Young Adults with Cancer: Survivorship*

www.cancer.gov/cancertopics/aya/survivorship

**Facing Forward: Life after Cancer Treatment**

www.cancer.gov/cancertopics/coping/life-after-treatment/

**National Coalition for Cancer Survivorship**

www.canceradvocacy.org

877.NCCS.YES (622.7937)

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

**Needy Meds**

www.needymeds.org/indices/pap.htm

Searchable online database of pharmaceutical companies' patient assistance programs.

**The Patient Access Network Foundation**

www.panfoundation.org

866.316.7263, 9:00 AM to 5:00 PM, ET

Provides help to underinsured patients for out-of-pocket expenses for life-saving medications. Patients must complete an application and meet certain insurance and income criteria to qualify for aid.

**Patient Advocate Foundation Co-Pay Relief Program**

www.copays.org/

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

**Patient Advocate Foundation**
www.patientadvocate.org
800.532.5274

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

**Rx Assist**
www.rxassist.org/patients

> Searchable online database of pharmaceutical companies' patient assistance programs.

**Surviving And Moving Forward: The SAMFund for Young Adult Survivors of Cancer**
www.thesamfund.org

> Non-profit organization that helps young adult survivors of cancer with a successful transition into their post-treatment life, by providing financial support through the distribution of grants and scholarships.

**Telling Kids About Cancer**
www.tellingkidsaboutcancer.com/

Comprehensive, user-friendly site with a wealth of age-appropriate tips and resources for parents.

**Young Survival Coalition**
www.youngsurvival.org/

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

### *Print Resources*

Lori Hope. Help Me Live, Revised: 20 Things People with Cancer Want You to Know. Berkeley, CA: Celestial Arts, 2011.

Kathleen McCue, Ron Bonn. How to Help Children Through a Parent's Serious Illness: Supportive, Practical Advice from a Leading Child Life Specialist. New York, NY: St. Martin's Griffin, 2011.

Peter VanDerNoot . Helping Your Children Cope with Your Cancer (Second Edition): A Guide for Parents and Families. Long Island City, NY: Hatherleigh Press, 2006.

Michael Feuerstein, Patricia Findley The Cancer Survivor's Guide: The Essential Handbook to Life After Cancer. New York, NY: Marlowe & Company, 2006.

## END-OF-LIFE ISSUES

### *Web Resources*

**American Cancer Society**
*Nearing the End of Life*
www.cancer.org/treatment/nearingtheendoflife/nearingtheendoflife/index

**Caring Connections**
www.caringinfo.org/i4a/pages/index.cfm?pageid=1

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

# Part 10: Resources

**Hospice Education Institute**
www.hospiceworld.org

Operates HOSPICELINK, a directory of all hospice and palliative care programs in the U.S. HOSPICELINK also provides information about the principles and practices of good hospice and palliative care.

**National Cancer Institute**

*Advance Directives*
www.cancer.gov/cancertopics/factsheet/support/advance-directives

*Coping with Advanced Cancer*
www.cancer.gov/cancertopics/coping/advancedcancer.pdf

*End-of-Life Care for People Who Have Cancer*
www.cancer.gov/cancertopics/factsheet/Support/end-of-life-care

*Hospice*
www.cancer.gov/cancertopics/factsheet/Support/hospice

*Last Days of Life (PDQ®)*
www.cancer.gov/cancertopics/pdq/supportivecare/lasthours/patient

**Voicing My Choices Planning Guide for Adolescents and Young Adults**
www.agingwithdignity.org/voicing-my-choices.php

Planning tool designed to help young people living with a serious illness to communicate their preferences to friends, family, and caregivers.

## *Print Resources*

Patti Balwanz, Kim Carlos, Jennifer Johnson, Jana Peters. Nordie's at Noon: The Personal Stories of Four Women "Too Young" for Breast Cancer. Philadelphia, PA: De Capo Press, 2006.

David B. Feldman, S. Andrew Lasher, Jr. The End-of-Life Handbook: A Compassionate Guide to Connecting with and Caring for a Dying Loved One. Oakland, CA: New Harbinger Publications, Inc., 2008.

# Part 11: A cancer dictionary

**Alkylating agents**
Drugs that damage the instructions in cancer cells so they can't grow and multiply.

**Angiogenesis**
The growth of new blood vessels inside a cancerous tumor that is crucial to the growth of tumors.

**Apoptosis**
Cell death as a result of instructions that are built into the cell's genetic code. Also called programmed cell death.

**Barium swallow**
A liquid containing barium sulfate (a silver-white metallic substance) that is swallowed to coat and outline the walls of the esophagus and the upper GI tract so that they can be seen on an x-ray.

**Bone marrow**
Soft tissue found in the center of most bones where blood cells are formed.

**Bone marrow aspiration or biopsy**
The removal of a small amount of liquid bone marrow or solid bone marrow tissue to examine for disease.

**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.

**Central nervous system (CNS)**
The brain and spinal cord.

**Central venous catheter (CVC)**
A thin, flexible tube that is placed into a vein in the upper arm, neck, thigh, or below the collarbone.

**Cervical cancer**
Cancer of the cervix, the structure that connects the uterus and vagina.

**Chemotherapy**
Drugs that kill all cells that grow rapidly, including cancer cells and normal cells.

**Colorectal cancer**
Cancer that develops in the colon (digestive organ that changes eaten food from liquid into solid form) and/or the rectum.

**Computed tomography (CT) scan**
A test that uses x-rays from many angles to make a picture of the inside of the body.

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

**Ejaculate**
Mixture of sperm and other fluids released through the penis during orgasm. Also called semen.

**Embryo**
A fertilized egg that has been dividing and growing for up to 8 weeks.

**Endoscopic biopsy**
Use of a thin, flexible tube with a light and camera at the end to look inside the body and take small tissue samples to test for disease.

**Enzymes**
Proteins that speed up chemical reactions in the body.

**Excisional biopsy**
Surgery that removes the entire tumor to test for cancer cells.

**External beam radiation therapy**
Radiation therapy received from a machine outside the body.

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

# Part 11: A cancer dictionary

**Gastrointestinal (GI) tract**
The group of organs that food passes through when you eat.

**Germ cells**
Cells that develop into sperm (in men) or eggs (in women).

**Gynecologic oncologist**
Doctor who's an expert in treating cancer that starts in the female reproductive organs (organs involved in making babies).

**Hair follicles**
Tube-like openings in the skin where individual hairs develop and grow.

**Histologic grade**
A measure of how much tumor cells resemble healthy cells of the same tissue type.

**Hormones**
Chemicals in the body that activate cells or organs.

**Hypnotherapy**
The use of hypnosis to put patients into a trance-like state of deep relaxation during which they are more accepting of suggestions.

**Immune therapy**
Treatment that uses the immune system to fight disease.

**Incisional biopsy**
Surgery that removes a tissue sample from the tumor to test for cancer cells.

**Integrative medicine**
Combining standard treatment with complementary therapies that have been shown to be safe and effective.

**Intensity-modulated radiation therapy (IMRT)**
Radiation therapy that uses small beams of different strengths based on the thickness of the tissue.

**Internal radiation therapy**
Radiation received from a radioactive 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.

**Laparoscopic biopsy**
Use of a thin, long tube with a light and camera at the end inserted through a small cut in the belly area to view and remove tissue to test for disease.

**Laparotomy**
Surgery with a long surgical cut made in the wall of the abdomen.

**Leukemia**
Cancer of the blood-forming tissue (bone marrow).

**Lumbar puncture**
Use of a thin needle inserted into the lower part of the spinal column to remove a small amount of cerebrospinal fluid (CSF) for examination or to give drugs. Also called a spinal tap.

**Lymph**
A clear fluid containing white blood cells.

**Lymphedema**
Swelling due to buildup of lymph.

**Lymph nodes**
Small groups of special disease-fighting cells located throughout the body.

**Lymphocytes**
A type of white blood cell.

**Lymphomas**
Cancer that begins in cells of the immune system.

**Magnetic resonance imaging (MRI)**
A test that uses radio waves and powerful magnets to see the shape and function of body parts.

**Medical oncologist**
A doctor who's an expert in treating cancer with drugs.

**Melanoma**
A cancer of the cells that give skin its brownish color.

**Menopause**
Twelve or more months without experiencing a menstrual period.

**Monocyte**
A type of white blood cell.

**Mucus membrane**
A thin layer of cells that line passages and open spaces inside the body and produce a slick substance called mucus that keeps the membranes moist and helps protect against infection.

**Needle biopsy**
Insertion of a needle into a tumor to remove tissue for testing.

**Neutrophil**
A type of white blood cell.

**Normal range**
A set of values that doctors use when evaluating patients' test results that is based on the results seen in 95% of healthy individuals.

**Oncofertility**
A team approach when cancer doctors and reproductive specialists work together to preserve fertility in cancer patients.

**Oncologist**
A doctor who specializes in treating cancer.

**Osteoporosis**
A disease causing thinning, weakened bones.

**Ovaries**
The pair of female organs that make 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 blood clots to control bleeding.

**Positron emission tomography (PET)**
A test that uses radioactive material to see the function of organs and tissues inside the body.

**Radiation field**
In radiation therapy, the area(s) of the body targeted with beams of radiation.

**Radiation therapy**
Use of high-energy rays to destroy cancer cells.

**Radiologist**
A doctor who's an expert in reading imaging tests.

**Radiopharmaceutical**
A drug that contains a radioactive substance.

**Red blood cell**
A type of blood cell that carries oxygen from the lungs to all parts of the body.

**Reproductive system**
The organs and tissues involved in the process of pregnancy and child bearing—the vagina, cervix, uterus, fallopian tubes, and ovaries in women, and the penis, testicles, and prostate in men.

**Sarcomas**
A group of cancers that develop in the bone or soft tissues of the cartilage, fat, muscle, blood vessels, and other connective or supportive tissue.

**Secondary cancers**
Cancers that develop as a result of damage caused by the treatment of the original cancer.

# Part 11: A cancer dictionary

**Side effect**
An unplanned physical or emotional response to treatment.

**Sperm**
Male reproductive cells that are formed in the testicles.

**Stem cell**
An immature cell from which other types of cells develop.

**Stem cell transplant**
A method of replacing damaged stem cells (immature blood-forming cells) in the bone marrow with healthy cells harvested from the patient or another person, called a donor.

**Stereotactic radiosurgery**
Radiotherapy that uses precise, high-dose photon beams to treat tumors.

**Surgeon**
A doctor who specializes in operations to remove or repair a part of the body.

**Surgical oncologist**
A doctor who's an expert in surgical procedures for cancer patients.

**Systemic radiation therapy**
The use of radioactive drugs (radiopharmaceuticals) to deliver radiation to cancer cells throughout the body.

**Targeted therapy**
Drugs that specifically target and kill cancer cells.

**Testicles**
Two egg-shaped glands found inside the scrotum below the base of the penis that produce sperm and male hormones.

**Thoracotomy**
Surgery done through a large cut in the chest to remove tumors or tissue.

**Three-dimensional conformal radiation therapy (3D-CRT)**
Radiation therapy that uses beams that match the shape of the tumor.

**Thyroid**
A gland located in the throat, just beneath the larynx (voice box) that makes thyroid hormone to help control growth and metabolism.

**Toxin**
A poison produced naturally by certain bacteria, plants, or animals, including insects.

**Tumor markers**
Substances found in body fluid or tissue that may be a sign of cancer.

**Uterus**
The female organ where a baby grows during pregnancy.

**Venous access port**
A medical appliance that can be inserted underneath the skin and connected to a major vein to deliver medicine directly into the bloodstream.

**White blood cells**
A type of blood cell that fights disease and infection.

**X-ray**
The use of controlled beams of radiation to make pictures of organs and structures inside the body.

# Credits

NCCN aims to improve the care given to patients with cancer. NCCN staff work with experts to create helpful programs and resources for many stakeholders. Stakeholders include health providers, patients, businesses, and others. One resource is the series of booklets for patients called the NCCN Patient Guidelines. Each booklet presents the standard of care for a type of cancer.

## NCCN abbreviations and acronyms

**NCCN®**
National Comprehensive Cancer Network®

**NCCN Patient Guidelines®**
NCCN Guidelines for Patients®

**NCCN Guidelines®**
NCCN Clinical Practice Guidelines in Oncology®

The patient booklets are based on guidelines written for doctors. These guidelines are called the NCCN Guidelines. They give a step-by-step course of care that many cancer doctors follow. Panels of experts create the NCCN Guidelines. Most of the experts are from the 21 NCCN Member Institutions. Panelists may include surgeons, radiation oncologists, medical oncologists, and patient advocates. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists.

The people involved in the making of the guidelines for patients and doctors are listed next, starting with NCCN staff:

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# NCCN Member Institutions

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

**Dana-Farber/Brigham and Women's Cancer Center**
**Massachusetts General Hospital Cancer Center**
Boston, Massachusetts
800.320.0022
dfbwcc.org
massgeneral.org/cancer

**Duke Cancer Institute**
Durham, North Carolina
888.275.3853
www.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 • fhcrc.org

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

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

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

**Moffitt Cancer Center**
Tampa, Florida
800.456.3434
moffitt.org

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

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

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

# NCCN Member Institutions

**St. Jude Children's Research Hospital/ The University of Tennessee Health Science Center**
Memphis, Tennessee
888.226.4343 • stjude.org
877.988.3627 • utcancer.org

**Stanford Cancer Institute**
Stanford, California
877.668.7535
cancer.stanfordhospital.com

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

**UCSF Helen Diller Family Comprehensive Cancer Center**
San Francisco, California
800.888.8664
cancer.ucsf.edu

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

**UNMC Eppley Cancer Center at The Nebraska Medical Center**
Omaha, Nebraska
800.999.5465
unmc.edu/cancercenter

**The University of Texas MD Anderson Cancer Center**
Houston, Texas
877.632.6789
mdanderson.org

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

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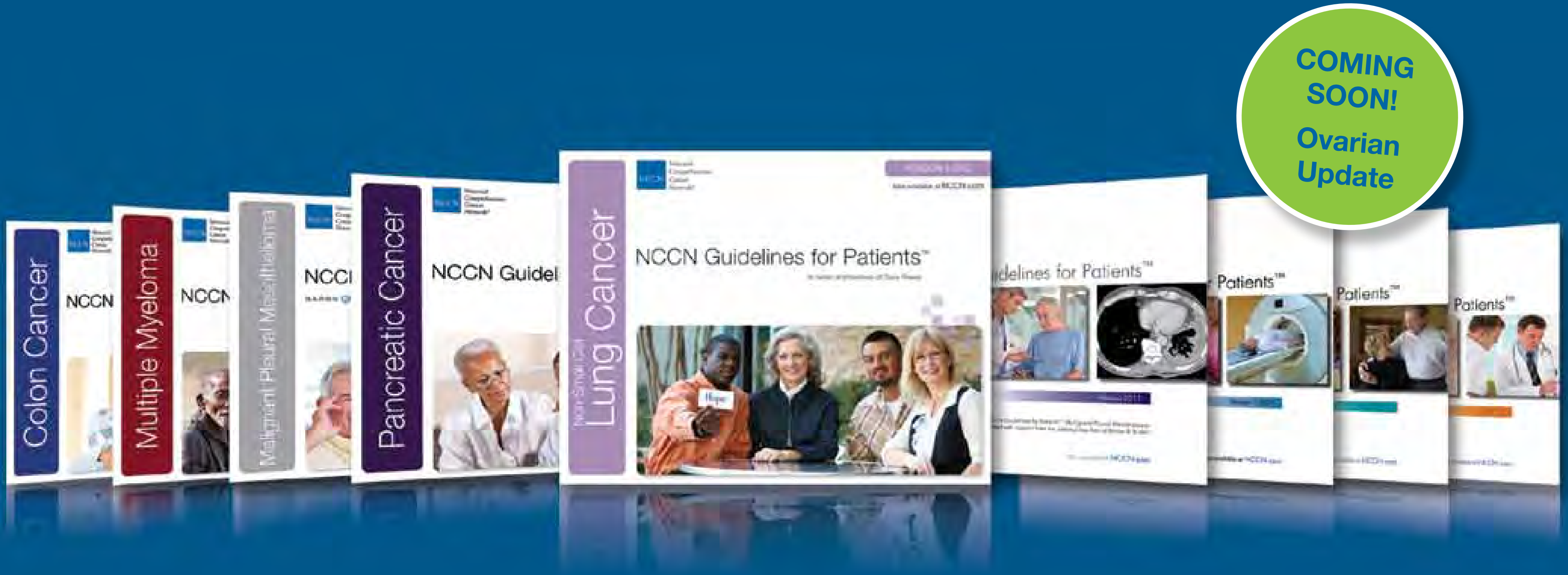

The same authoritative source referenced by physicians and other health care professionals is available for patients.

**To request a printed copy: patientguidelines@NCCN.org**

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# Caring for Adolescents and Young Adults

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