



# FRANKLY SPEAKING **ABOUT CANCER**

A PROGRAM OF THE CANCER SUPPORT COMMUNITY



# MELANOMA





The Cancer Support Community, AIM at Melanoma, Melanoma International Foundation, Melanoma Research Alliance, and the Melanoma Research Foundation have developed this guide for people impacted by melanoma. It explains how melanomas arise, who is at risk, how the disease is detected and diagnosed, and the treatments available.

It also provides information about potential side effects and the emotional and social issues that people may encounter during their treatment for melanoma. We want everyone with a melanoma diagnosis, at any point in their experience, to know they are not alone.

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# Overview

“I think, in melanoma, an important part of our role today is explaining all these new approaches, and that we need to take the time with our patients to help them understand the options.”

—Lynn Schuchter, MD, University of Pennsylvania

Melanoma is usually, but not always, a cancer of the skin. It begins in melanocytes—the cells that produce the pigment melanin that colors the skin, hair, and eyes. Melanoma affects over 100,000 people (over 60,000 men and 40,000 women) in the United States every year. The average age for a melanoma diagnosis is 65. But people of any age, including teens and young adults, can get this disease.

The number of people who are living with melanoma has been on the rise in the US for the last 40 years. This increase is attributed to the use of tanning beds and other unsafe exposure to ultraviolet rays. Although the number of cases is on the rise, deaths from melanoma have decreased.

When detected early, melanoma is often highly curable. Melanoma is more likely than other skin cancers to spread to other parts of the body. It accounts for about 1% of all skin cancers but causes the majority of

skin cancer deaths. Until recently, there were few effective treatment options for advanced or metastatic melanoma. Recent years have seen the introduction of new and better treatments that are offering new options and hope for many. (See the Treatment chapter in this book, as well as updated information at [www.CancerSupportCommunity.org/melanoma](http://www.CancerSupportCommunity.org/melanoma).)

Most melanomas arise in moles on the surface of the skin and are first detected by patients themselves. People at higher risk for melanoma should be screened regularly by their doctors. You are at higher risk if you have:

- a sun-sensitive skin type that freckles easily
- many moles or dysplastic moles (moles with abnormal cells)
- a history of sun exposure
- a family history of skin cancer or melanoma.



The diagnosis of melanoma is usually made by biopsying (cutting out) the suspicious area. If cancer is found, it is important to determine how deeply the melanoma has grown into the skin. Your doctor will also see if it has spread to nearby lymph nodes or other organs in the body. The depth of the melanoma, the type, and its stage help determine the best treatment options.

Early melanomas are treated with outpatient surgery. Melanomas that are deeper or have spread to lymph nodes may require additional treatments after surgery. These treatments, also called adjuvant therapy, help reduce the risk that the melanoma will recur. There are

many treatment options for people with advanced melanoma, including targeted therapy and immunotherapy.

People with melanoma and their loved ones need support—both to understand treatment options and to deal with the emotional challenges of a diagnosis. This is a time to talk with your health care team and identify the resources that will help you.

Learning that you have melanoma can be a frightening and life-changing experience. It is important to know, that whatever the stage of your disease, there are treatment options available and resources for emotional and social support.

## **If you are facing a melanoma diagnosis, or being treated for this disease:**

- Learn about your melanoma.
- Talk to your doctors.
- Ask questions.
- Think about getting your treatment in a cancer center that has experts experienced in treating melanoma.
- Ask whether new treatments for melanoma or a clinical trial might be right for you.
- Take care of yourself.
- Talk to your health care team about getting the support you need right from the start.



# What is Melanoma?

“Early melanomas are very curable. I recommend that everyone gets naked and looks for things that are changing on their skin.”

—Lynn Schuchter, MD, Penn Medicine

Melanoma is cancer that begins in cells called melanocytes. Melanocytes make the pigment called melanin, which gives the skin its tan or brown color. Melanin also protects the deeper layers of the skin from the harmful effects of the sun.

Most of the melanin in our bodies is concentrated in the top layer of the skin (epidermis). For that reason, most melanomas develop on the surface of the skin. But, melanoma can arise in any tissue where pigment-producing cells are found, including the eye and the mucous membranes (the moist, inner lining of some organs and body cavities such as the nose, mouth, lungs, and stomach).

Melanomas are usually brown or black, but some can appear as tan, pink, or even white. They often arise in moles or nevi (a dark area that may be raised from the skin). This can occur in a pre-existing mole that suddenly begins to grow or change, or in a new mole. They are most common on the back, chest, and legs but can be found anywhere on the body. The neck and

face are other common sites. In rare instances, melanomas can form in the eyes (ocular melanoma), mouth, genitals, and anal area (mucosal melanoma).

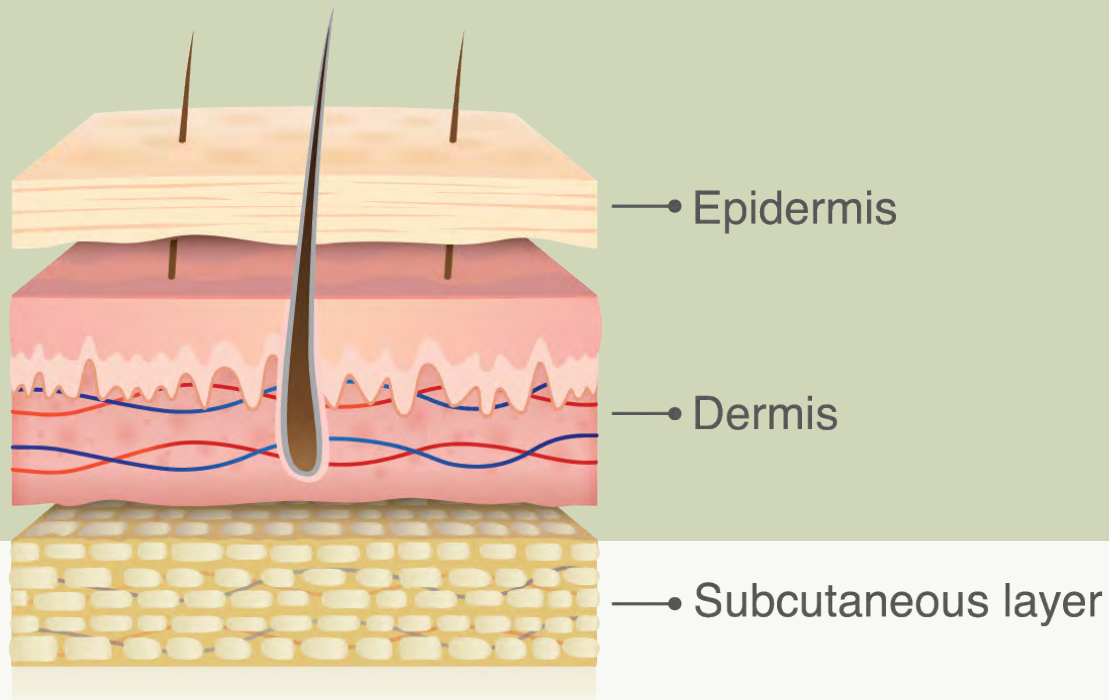
Who is at risk for melanoma?

Anyone can get melanoma, but some people are at higher risk of developing this cancer and they include:

- Individuals who have fair skin, lots of freckles, and light hair.
- Anyone who has a first-degree relative who has had melanoma. A first-degree relative means a mother, father, or sibling.
- Anyone who has already had melanoma.
- People with multiple moles (more than 50). This can be hereditary and is often linked to specific syndromes or conditions.
- People who have a history of blistering sunburns during childhood or adolescence or a history of chronic sun exposure.
- People who have a weakened immune system.



# Your Skin has Three Layers



- 1** The epidermis or top layer. This is where melanocytes are found along with several other types of skin cells.
- 2** The dermis or middle layer. This layer contains hair follicles, sweat glands, blood vessels, and nerves held in place by collagen, which gives the skin its elasticity and strength.
- 3** The subcutis or deepest layer is formed by a network of collagen and fat cells. It helps the body conserve heat and acts as a shock absorber.

As with any risk factors, having one or more of these does not mean that you will develop melanoma. But, it does mean you should check your own body once a month and have a yearly skin screening from your dermatologist. Individuals with large numbers of moles should discuss with their dermatologist a technique called “whole body photography” which provides a way of examining and comparing moles over time.

For people with multiple moles doing a full body check may be difficult. Those individuals should try to look for the “ugly duckling,” the mole that appears suddenly, begins to grow or change color or shape.



## Prevention

Most melanomas are caused by damage from ultraviolet light—either from natural or artificial sources. It is very important for everyone to take precautions to protect themselves. This includes:

- ❑ Using sunscreen—at least 30 SPF, broad-spectrum and water resistant. Apply every two hours, and more often if you are swimming or sweating.
- ❑ Wearing protective clothing and wide-brimmed hats.
- ❑ Taking advantage of the shade as much as possible when you are outdoors. An umbrella or a tree can help protect your skin.
- ❑ Saying no to tanning beds. Indoor tanning has been shown to increase the risk of melanoma by up to 75%.

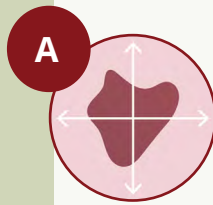




# When to Worry about a Mole

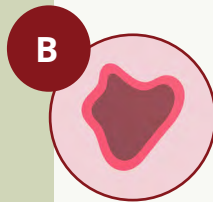
Doctors use what they call the **A-B-C-D-E system** to describe worrisome moles—the ones that may be or are cancerous.

If you notice any of these warning signs, see a dermatologist and have the mole or lesion evaluated as soon as possible.



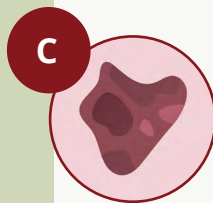
## **ASYMMETRY**

Imagine folding the mole in half. If the two halves are not the same size or shape, it is asymmetrical and of more concern.



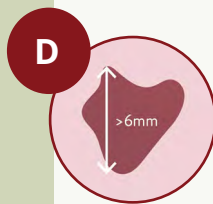
## **BORDER**

Melanomas often have irregular borders.



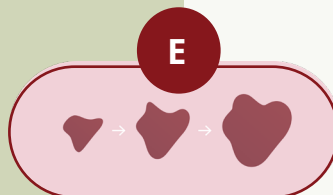
## **COLOR**

Melanomas are often darker than other moles and have different colors within their borders.



## **DIAMETER**

Melanomas are often—but not always—larger than other moles.



## **EVOLVING OR ELEVATED**

A mole that grows or changes size or appearance or begins to bleed is of more concern.

## A Little History

Melanoma is an ancient disease. The first recorded description of the dark tumor, “melas” and “oma” are found in the writings of Hippocrates in the 5th century B.C. The earliest physical evidence comes from the skeletons of Pre-Columbian mummies estimated to be at least 2,400 years old.

Over the years, physicians and researchers studied these mysterious tumors. They learned that melanomas often originated in moles, yet understood little about how cancers grow and spread, so the only treatment was to cut or burn the mole off and hope that was enough.

It is only in the last decade that a new understanding of the relationship between cancer cells and the immune system has resulted in new treatment options for people with advanced melanoma.

The other significant contribution to treating advanced melanoma was the discovery of “driver mutations.” These are changes that occur in tumors and fuel the growth and spread of the cancer cells. These known mutations occur in more than half of all melanoma patients and can now be targeted with agents that either turn off or block their activity.



# Diagnosis and Staging

“The most challenging time for me was the initial diagnosis.

I recommend taking someone with you to the appointments to help digest information, to take notes on different treatments. It tends to be overwhelming and you just don’t hear very much.” – Melanoma survivor

## DIAGNOSIS

Melanomas are usually diagnosed when either the person or the doctor notices a suspicious mole or area on the skin. The next step is a biopsy, a procedure in which the surgeon removes either the entire suspicious area or a sample for examination under the microscope. The exact type of biopsy and its extent depend on the size and appearance of the lesion. Biopsies are generally done under local anesthesia on an outpatient basis. The different types of biopsies include:

**Shave biopsy**—The doctor shaves off the top layers of the skin, usually just the epidermis and dermis. This is appropriate when the risk of cancer is very low and is not recommended when there is a higher chance of cancer.

**Punch biopsy**—This involves the use of a tool that resembles a tiny round cookie cutter to remove a deeper sample of skin.

This technique may not provide as much tissue to examine the margins as other approaches.

**Excisional and incisional biopsies**—These procedures are used to examine lesions that are suspected of having invaded deeper into the skin. The excisional biopsy removes the entire tumor, while the incisional biopsy removes only a portion of the tumor. Both procedures are done with surgical instruments and local anesthesia.

In other cases, the tumor causes symptoms in the areas that are affected. It may also appear as a lump or enlarged lymph node in the neck, groin, or elsewhere. When this happens, the diagnosis is made by biopsying the lump or the mass detected in another organ, such as the lung, liver, or brain. Depending on the location of the tumor, the diagnosis can be done either with fine needle aspiration, by removing the entire lymph node, or by a surgical or endoscopic biopsy.



## NEXT STEPS

If the biopsy results come back as melanoma, a number of additional tests and procedures are needed to determine how deeply the melanoma has invaded and whether it has spread to other sites in the body.

Some melanomas are diagnosed after they have spread to lymph nodes or to another organ. This can happen if the original melanoma on the skin is not found or is so small that it goes undetected.

Imaging tests may be used to determine if cancer has spread to another organ or part of the body. Most patients will have a CT scan as part of their diagnostic workup. Doctors may also use MRI, PET scans, or ultrasound for this purpose. People with melanoma that has spread have regular imaging tests to see how their tumors are responding to therapy.

## THE PATHOLOGY REPORT

The pathology report contains all of the critical information about the tumor and the cells that make it up. It is a very detailed and technical document. Some people want to understand every line in the report and what it means to their treatment and prognosis, while others would prefer to have their doctors explain

what is important to them. Regardless of how you approach the pathology report, it is important to have at least a basic understanding of the diagnosis, its extent, and treatment options available to you.

**“Scanxiety”** is a term used to describe the anxiety and fear individuals may have when waiting for the results of imaging tests. While there is no antidote to this common experience, there are ways to help reduce your level of anxiety:

- Try to have a short waiting period between the time you schedule the scan or tests and when you have them.
- Talk to your doctors and let them know you want the results of the scan as soon as possible, the same day if they can make it happen.
- Take a family member or friend with you to the scan and the appointment in which you learn the results.
- Even though it may be hard, do something to distract yourself from thinking about the scan both before you get it, and while you wait for the results.
- Know that your feelings are normal.



A guide to the type of information you will find on your pathology report is on page 14.

## TYPES OF MELANOMA

There are several types of melanoma, each with unique features related to their shape, color, location, and growth pattern.

- **Superficial spreading** melanoma resembles a brown or black stain that appears to come out of a mole. This is the most common type of melanoma and tends to occur in skin that has been exposed to ultraviolet light.
- **Nodular** melanoma is a more pronounced, firm, dome-shaped bump. This type of melanoma tends to spread more rapidly into the dermis.
- **Lentigo maligna** melanoma looks like a dark stain and is not associated with a mole. It is the slowest growing type of melanoma.
- **Acral lentiginous** melanoma occurs on the soles of the feet, palms of the hands, or under the nails. It looks like a dark spot on the skin or under the nail that doesn't go away. It is the most common type of melanoma in African-Americans.

- **Ocular** melanoma is a rare form of melanoma that begins in the eye. It behaves and is treated differently than melanomas that arise on the skin.
- **Mucosal** melanoma is a rare form of melanoma that occurs in the mucous membranes of the nasal passages, mouth, and genitals.

A small number of melanomas arise in mucous membranes or in the palm/sole, fingernail bed, or in the eye. Their cause is not known, but they don't necessarily carry a higher risk if caught early and treated properly.



## A GUIDE TO INFORMATION ON YOUR PATHOLOGY REPORT

All of this information comes together to form a profile of your cancer. Your doctors use this information to recommend treatments for your situation. You can always ask for a copy of your pathology report and to discuss it with your doctor.

**Diagnosis:** The type of melanoma.

**Tumor size:** Your pathologist will measure the tumor's length, height, and width.

**Tumor location:** Where on the body was the tumor found.

**Breslow thickness:** How deep the melanoma has grown in the skin. This is measured in millimeters.

**Ulceration status:** Has the top layer of the tumor begun to break up and pull apart.

**Dermal mitotic rate:** This measures the number of melanoma cells that are actively growing and dividing.

**Clark Level:** This uses a five-point scale to assess the depth to which the tumor has invaded the skin. Clark Level is different than the stage. Clark Level I involves only the epidermis, while a level V has invaded tissue below the skin. Clark Level has been replaced by the Breslow Thickness in many clinics.

**Peripheral margin status:** Did the surgeon get a clean margin around the edge of the tumor?

**Deep margin status:** Did the surgeon get a clean margin under the tumor?

**Microsatellitosis:** Does the tumor have microscopic satellites within two centimeters of the primary tumor? This means there are no cancer cells in the tissue surrounding the tumor.

**Tumor infiltrating lymphocytes (TIL):** Are any white cells or immune cells found in the tumor? This can be a sign of an immune response. The more TIL, the better.

**Radial growth phase:** The tumor in the earliest phase with little chance of metastasis.

**Vertical growth phase:** The direction of the tumor's growth into the skin. The report will indicate whether this is present or absent.

**Regression:** This means that the tumor has disappeared, perhaps because of destruction by the immune system. It is listed as either present or absent. If present, the extent of the regression is described.

**Angiolymphatic invasion:** Has the tumor invaded blood cells?

**Histologic subtype:** This groups cancer cells by certain qualities or characteristics.

## STAGING

Melanoma is staged from 0 to IV, with stage 0 being the earliest and stage IV the most advanced. As with most cancers, melanomas are staged using the TNM system:

**T** refers to the tumor—its size, thickness, and depth

**N** refers to nodal status—the presence or absence of positive lymph nodes

**M** refers to metastases—whether the tumor has spread to other organs

Doctors look at the TNM numbers as a group. Because of this, it is hard to describe the stages in just a few words.

In general, the stages of melanoma are as follows:

- **Stage 0:** Cancer cells are only found on the outer layer of the skin.
- **Stage 1A (T1a):** The tumor is no more than 0.8 millimeters (about 1/30th of an inch) thick, without ulceration of the skin. (Ulceration can only be seen under a microscope.)
- **Stage 1B (T1b or T2a):** The tumor is no more than 0.8 millimeters (1/30th of an inch) thick, with ulceration of the skin. Or, the tumor is no more than 2.0 mm (1/25th of an inch in thickness)

without ulceration.

- **Stage 2A (T2b or T3a):** The tumor is at least 1-2 millimeters thick with ulceration or between 2-4 mm thick without ulceration.
- **Stage 2B (T3b or T4a):** The tumor is 2-4 millimeters thick with ulceration. It also has an ulceration. Or, it is more than 4 mm thick without ulceration.
- **Stage 2C (T4b):** The tumor is more than 4 millimeters thick with ulceration.
- **Stage 3:** Cancer cells have spread to nearby lymph nodes or tissues.
- **Stage 4:** The cancer has spread to other parts of the body, including organs such as bones, lungs, or the liver.

Staging takes into account many factors. The stage of melanoma guides the treatment and generally predicts the prognosis. Most early-stage melanomas can be treated with surgery and have a good prognosis.

Melanomas that are thicker, ulcerated, have certain biologic features, or have spread to the lymph nodes are at higher risk for recurrence and require more extensive treatment, as do those that arise in the head and neck area. Melanomas that have spread



to other sites in the body are treated with a number of therapies, including targeted agents and immunotherapy.

More information about stage III melanoma can be found in CSC's *Frankly Speaking About Cancer: Putting the Focus on Stage III Melanoma*, available at [www.CancerSupportCommunity.org/melanoma](http://www.CancerSupportCommunity.org/melanoma).

## OTHER TESTS AFTER A DIAGNOSIS

**Blood Tests**—These tests are not typically used to diagnose melanoma. They may be used to monitor melanoma once it has spread to another part of the body.

**Biomarker Testing**—Biomarker testing helps your doctor better understand your cancer. A biomarker is a sign that can be measured. It describes proteins or genes that may be driving the melanoma to grow or spread. A tumor that tests positive for a biomarker has a good chance of responding to a certain treatment.

A sample of your blood or tissue may be sent to a lab for biomarker testing. Often, the sample is removed during surgery or a biopsy.

It may take a few weeks for the test results to come back. Biomarker testing is also called molecular testing, tumor profiling, or genomic testing.

If you have melanoma, talk to your health care provider about getting Comprehensive Biomarker Testing (including BRAF, C-KIT, NRAS, and PD-L1 or TMB [Tumor Mutational Burden]) before starting treatment.

### Who should get Biomarker Testing?

Comprehensive Biomarker Testing (including BRAF, C-KIT, NRAS, and PD-L1 or Tumor Mutational Burden) is recommended for everyone with Stage IV melanoma. BRAF testing is recommended for all patients with Stage III melanoma. Stage II melanoma patients interested in clinical trials may also consider BRAF testing. About half of all melanomas are BRAF positive (BRAF+).

The need for biomarker testing is not based on any risk factors. For example, it does not matter if you smoked or didn't smoke.

For additional information visit [www.CancerSupportCommunity.org/biomarkers](http://www.CancerSupportCommunity.org/biomarkers)







## Early Melanoma

Anne was 32 years old, the mother of two very young children, when she noticed a mole on her back that was “darker and uglier” than the few others she had. Her doctor was concerned as soon as he saw it and sent the punch biopsy for rush pathology.

The diagnosis was melanoma.

“It turned my life upside down,” she says. “For weeks, it consumed all my thoughts. I was so stressed out.”

Anne had a wide excision and a sentinel node biopsy, which showed that her nodes were clear of cancer.

“I feel braver than I was before this happened, and more of an advocate,” she says.

“It has been very helpful to reach out and talk to others.”



Michael Wernette (Melanoma Survivor) and his wife, Sue.

# Coping with a Melanoma Diagnosis

Any diagnosis of cancer is a life-changing event. From the day you hear those words, you enter a world in which you have to learn a new language, make decisions, and deal with issues you never imagined would be part of your life.

You are suddenly faced with multiple doctor's appointments, tests, procedures, and possibly treatment sessions. Your family life, your friends, your job, your financial situation—everything may be impacted. It can seem overwhelming—and that is normal. You are not alone. You are not powerless.

There are people there to support you, and steps you can take to help navigate this new world and to make your journey more manageable.

## THE BENEFITS OF TAKING CARE OF YOURSELF

There are positive benefits to taking an active approach to living with your cancer. Many people do better

physically when they take care of their emotional and social needs. You may experience less fatigue, anxiety, or depression, or be better able to tolerate your therapies.

Taking care of your emotional needs also provides you with more control over your life, regardless of where you are in your treatment. It is not unusual for people with cancer to discover new meaning in their lives or to develop a deeper appreciation for the people and things that are important to them.

Many people find that connecting with other people with cancer helps both in what you receive in those interactions, and what you give.



Colleen and Frank (pictured above) were young and going through cancer with their three kids. Colleen said, “I was on auto-drive with getting Frank



to his appointments and taking care of the kids.” It is so important to reach out for help and meet with other caregivers. There is no time to worry, you can’t stop your life with kids. I did a lot of research and getting our kids in a support group was so important to us. We have met some great friends through melanoma conferences, support is so important, it is absolutely necessary.

There is no right way to approach your situation, but it is very helpful to understand enough about your disease so you can be an informed,

active participant in your treatment. Knowing the stage of your disease and the treatment options available to you will help assure that your life and your goals are part of the discussion. Never hesitate to ask questions or raise issues with your team. You are the expert on your life and your body—and your own best advocate.

**Contact CSC’s Cancer Support Helpline at 888-793-9355 if you need information, support, or help communicating with your cancer care team.**

## Cost Concerns

Unfortunately, the cost of cancer care is an issue for many people. It can add more stress to an already stressful time. Costs can be direct—bills that result from treatment such as copays, or indirect—losing work, paying for childcare, gas money, parking for treatment. Questions about what your insurance covers or how to get insurance coverage may also come up. Whatever your situation, there are resources and organizations that can help. Ask to sit down with the financial or insurance counselor at your cancer center. They can work with you to understand what the costs may be and develop a plan to pay for it.



## What you can do:

### ❑ **Learn about your cancer.**

Melanoma is a complicated disease. Your experience and your treatment will depend on the stage of your melanoma.

### ❑ **Communicate.**

Good, open communication with your health care team is key. It is important to try to find a doctor and treatment center experienced in treating melanoma. It is also key to find a team who will answer your questions and address your issues. Don't be afraid to ask questions or let your team know if you are experiencing side effects or struggling with the emotional impact of your cancer. Make a list before your appointment of the issues you want to discuss. Take someone with you to your appointments to help listen and respond to what you learn.

### ❑ **Be your own best advocate.**

Some people want to know everything about their cancer and its treatment. They pour over their pathology report and research new developments in the field. Others are more comfortable knowing the basics and relying

on their doctors to tell them what they need to know. Even if you only want to know the basics, consider getting a second opinion from another doctor. A second opinion can help reconfirm your diagnosis and treatment options. It can also give you the chance to see if there is another health care team that you would like to work with.

### ❑ **Get a second opinion.**

Talk through options with your treatment team. There are multiple settings in which you can receive excellent treatment for your cancer. Consider getting a second opinion if you are unsure of your doctor, hospital, or the options available to you.





Carla Rake, Melanoma survivor

# Treating Melanoma

“We have seen a firestorm of progress in understanding and treating melanoma.” —Meenhard Herlyn, PhD, The Wistar Institute

The right treatment for your melanoma depends on the stage of the cancer, your overall health, and results of biomarker testing. Your care will be provided by a team of doctors, nurses, and other health care professionals. They will work with you to find you the right treatment. Your care team may include a dermatologist, a pathologist, a surgeon, imaging specialists, nurses, and possibly a medical oncologist, a radiation therapist, a social worker, and other medical staff.

## EARLY STAGE MELANOMA

Melanoma in stages 0 to III is considered early stage. Almost all people with early stage melanoma will have surgery to remove the primary tumor. More than 8 of 10 melanomas are diagnosed at an early stage. These are highly curable. Surgery is often the only treatment required.

Surgery is also used when melanoma is found at a later stage. It is often followed by other treatments to prevent the cancer from coming back or spreading.

## WIDE EXCISION SURGERY

Melanoma is diagnosed with a biopsy. During this procedure, some of the cancer cells are removed. Once you have been diagnosed with melanoma, another surgery may be needed to remove all the cancer cells from the biopsy area. This is called a wide excision. The surgeon removes the tumor and an area around it. The goal is to leave a “clean margin” of normal tissue, both at the edges and below the tumor.

The amount of tissue removed depends on the size of the melanoma, its thickness, and where it is located. Thicker melanomas need wider margins, as do those that have spread more on the skin’s surface. Skin from another part of the body may be used to close the wound and minimize scarring.

## SENTINEL NODE BIOPSY

Your doctor may recommend testing to see if the melanoma has spread to the lymph nodes. This will depend on the features of your melanoma. They



learn this by removing and looking at just one or two lymph nodes close to the primary tumor. These are the nodes that are likely to be affected first if the cancer begins to spread. They are known as sentinel nodes. Finding these nodes is called sentinel node mapping. If the sentinel nodes are free of cancer, further surgery or testing may not be needed. This spares the patient more major surgery. It also helps determine treatment options.

Sentinel lymph node biopsy is used to determine if the cancer has spread to the lymph nodes.

A sentinel lymph node biopsy is most often used when the melanoma is more than 1.0 mm thick or has ulceration (breaks). Your doctor may consider other features of the tumor as well. The sentinel lymph node biopsy is usually performed at the same time as the wide excision surgery.

To do a sentinel node biopsy, the doctor first injects a small amount of radioactive dye into the area around the melanoma. They then use a special camera to see if the dye collects in one or more nodes (the sentinel nodes). The patient then goes to surgery where a blue dye is injected into the

same place as the radioactive dye as a double-check. The sentinel lymph nodes that are both blue and detected with the special camera are removed for biopsy.

Some people will not need a sentinel node biopsy. Their melanomas are thin and have not invaded the layers of the skin deeply. Others will have an enlarged lymph node near the site of the tumor. This situation usually calls for a procedure called a full lymph node dissection.

## **LYMPH NODE DISSECTION**

In a lymph node dissection, a surgeon removes the lymph nodes next to the primary cancer. They are sent to a lab to determine if they contain cancer cells. Lymph node dissections have been part of melanoma treatment for many years. In recent years, doctors have used them less often. Research has found that they may not improve the cure rate or help people with melanoma live longer.

Full lymph node dissections often involve major surgery that increases the risk of lymphedema. Lymphedema is a long-term side effect marked by fluid build-up and swelling. For more information about lymphedema see page 38.





There are studies underway to determine if full lymph node dissections are ever needed. More and more centers are using the sentinel node biopsy for patients at all stages.

You should make sure to discuss any potential lymph node surgery with your surgeon.

### **HIGH-RISK MELANOMAS**

“The goal of treating melanomas is to minimize their risk of recurrence without causing unnecessary side effects or expense to our patients. We don’t want to overtreat people who can be cured with surgery. The key is finding ways to identify those patients who really will benefit from adjuvant or neoadjuvant therapies.” —April Salama, MD, Duke University

### **TREATMENT AFTER SURGERY (ADJUVANT THERAPY)**

Surgery is used to remove the primary tumor. Melanomas that are deeper or wider may require treatment after surgery. The goal is to prevent the cancer from coming back or spreading. Your doctor may recommend further

treatment if your melanoma is:

- stage III or IV and can be removed surgically, or
- stage II with high-risk features.

Treatment after surgery is called adjuvant therapy. Three types of therapy are often used:

- Immunotherapy (see page 30),
- Targeted therapy drugs (see page 29),
- Radiation therapy.

Radiation therapy is sometimes considered after surgery. When it is used, the goal is to help keep the cancer from coming back. Your doctor will tell you if radiation is recommended in your case.

Radiation is also often used to treat cancer that spreads (metastasizes) to other parts of the body. It can shrink tumors in the bones or brain that are causing pain or other symptoms.

More information on stage III melanoma can be found in CSC’s *Frankly Speaking About Cancer: Putting the Focus on Stage III Melanoma*, available at [www.CancerSupportCommunity.org/melanoma](http://www.CancerSupportCommunity.org/melanoma).



## QUESTIONS TO ASK YOUR DOCTOR ABOUT EACH TREATMENT THEY RECOMMEND:

What type of treatment do you recommend for me?

Why do you think this type of treatment would be better for me than others?

Tumor location: Where on the body was the tumor found.

Do you recommend taking this treatment in combination with another type of treatment?

Am I eligible to participate in a clinical trial?

What are the common side effects of the treatment(s) you're recommending?

When will side effects occur?

What can be done to help prevent or manage side effects?

How will this treatment be given?

Will I get it intravenously (through a needle in a vein) or orally (in a pill)?

Will I need a port (a small device placed under the skin to make it easier to get intravenous treatments)?

How often will I receive treatment?

Where will I go for treatment? How long will a treatment session take?

How will we know if this treatment is working?

## TREATMENTS FOR ADVANCED OR METASTATIC MELANOMAS

Some people are diagnosed with melanoma that has already spread to other organs of the body. Others have melanomas that recur after surgery, sometimes years after treatment. This is known as stage IV, advanced, or metastatic melanoma.

Once a melanoma has spread to other organs, it can no longer be cured with surgery. A systemic (whole body) treatment is needed. Systemic drugs are used to try to control the cancer for as long as possible. They can destroy cancer cells almost anywhere in your body.

In the past, doctors had few options to treat advanced melanoma. Today, immunotherapies and targeted therapy drugs can be effective in keeping the cancer from growing or spreading for years. Even though the disease is likely to require ongoing treatment, there is real hope for people with advanced melanoma.

## COMBINING THERAPIES FOR BETTER OUTCOMES

Doctors have found that cancer treatments sometimes work better when used together. Combination therapy can mean two or more drugs or two or more treatments

given at the same time. Some recent studies in melanoma test “triplets”— combinations of three drugs.

Be sure to ask about the side effects of any and all drugs you consider, when given on their own or in combination. More information on the side effects of immunotherapy can be found in CSC’s *Frankly Speaking About Cancer: Immunotherapy for Melanoma* booklet. (Available at [www.CancerSupportCommunity.org/melanoma](http://www.CancerSupportCommunity.org/melanoma) or by calling our Helpline at 888-793-9355.)



“Since 2011, at least 11 new drugs have been approved for use in patients with advanced melanoma. This has transformed the way we care for patients with advanced disease. These treatments generally fall into three categories: immunotherapy, targeted therapy, and oncolytic virus therapy.” —Evan Thomas Hall, MD, Stanford University

## TARGETED THERAPY DRUGS

Targeted therapy is a type of cancer treatment that targets a specific change in some cancers that helps them grow, divide, and spread. Targeted therapy drugs keep cancer from growing and spreading with less harm to cells that are not cancer. These drugs “target” specific melanoma subtypes. They are only likely to work in those specific subtypes. They may have fewer side effects than other treatments because they are better able to attack your cancer cells and leave healthy cells alone.

These drugs can work in several ways:

- They can find cancer cells.
- They can destroy cancer cells directly.
- Or they can cut off the blood supply that tumors need to grow and survive.

Your doctor will use biomarker testing to see if you have a melanoma subtype for which targeted therapy is a good

option. It can also be called molecular testing, genetic testing, or genomic testing. For more information about biomarker see page 16.

The table lists targeted therapy drugs by type and their possible side effects. These drugs may be given alone or in combination. Keep in mind that you may not get any or even most of the possible side effects of a drug. It is important to let your health care team know immediately if you notice any change in side effects or symptoms. Most side effects can be managed if they are treated early.

These are the classes of targeted therapy drugs that are FDA-approved to treat melanoma as of September 2021. This list changes often. For information on specific drugs and the latest approvals for melanoma, go to [www.CancerSupportCommunity.org/melanoma-treatments](http://www.CancerSupportCommunity.org/melanoma-treatments).



TARGETED THERAPY DRUGS		
<p><b>MEK Inhibitors</b> – for MEK+ melanoma</p> <p>These drugs are given as a pill.</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Liver problems</li> <li>• Low albumin (a protein needed for blood)</li> <li>• Anemia (low red blood count)</li> <li>• Diarrhea Rash</li> <li>• Lymphedema (swelling in the arms or legs)</li> <li>• Kidney problems</li> <li>• Muscle damage</li> </ul>	<ul style="list-style-type: none"> <li>• Diarrhea</li> <li>• Low white blood count</li> <li>• Tiredness</li> <li>• Sensitivity to the sun</li> <li>• Nausea and vomiting</li> <li>• Low sodium levels</li> <li>• Fever</li> <li>• Chills</li> <li>• Blurred vision</li> </ul>
<p><b>BRAF Inhibitors</b> – for BRAF+ melanoma</p> <p>These drugs are given as a pill.</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Tiredness</li> <li>• Nausea and vomiting</li> <li>• Abdominal pain</li> <li>• Joint pain</li> <li>• Kidney problems</li> <li>• High blood sugar</li> <li>• Headache</li> </ul>	<ul style="list-style-type: none"> <li>• Thickening of the outer layer of the skin</li> <li>• Low level of phosphate in the blood. Symptoms may include weakness, trouble breathing, and loss of appetite</li> <li>• Rash</li> <li>• Sensitivity to sun</li> <li>• Hair loss</li> <li>• Nausea</li> </ul>
<p><b>C-KIT Inhibitors</b> – for C-KIT+ melanoma</p> <p>These drugs are given as a pill.</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Low blood counts</li> <li>• Rash</li> <li>• Headache</li> <li>• Nausea and vomiting</li> </ul>	<ul style="list-style-type: none"> <li>• Muscle cramps</li> <li>• Bone pain</li> <li>• Diarrhea</li> <li>• Fever</li> <li>• Swelling (edema)</li> </ul>

## IMMUNOTHERAPY

Immunotherapy uses the body’s natural defenses (the immune system) to identify, attack, and kill cancer cells. Not all people get side effects. If you are on immunotherapy, it is important to let your health care team know immediately if you notice any change in side effects or symptoms. Most side effects can be managed if they are treated early.

These are the classes of immunotherapy drugs that are FDA-approved to treat melanoma as of September 2021. This list changes often. Approvals for these drugs expand to include more types of melanoma. For information on specific drugs and the latest approvals for melanoma, go to [www.CancerSupportCommunity.org/melanoma-treatments](http://www.CancerSupportCommunity.org/melanoma-treatments).



IMMUNOTHERAPY		
<p><b>Checkpoint Inhibitors</b></p> <p>These drugs are given by IV (into the vein)</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Dry, cracked, scaly skin</li> <li>• Mouth sores</li> <li>• Dry eyes or mouth</li> <li>• Poor appetite</li> <li>• Feeling tired or weak</li> <li>• Joint, back, jaw, or bone pain</li> </ul>	<ul style="list-style-type: none"> <li>• Muscle pain or weakness</li> <li>• Rash</li> <li>• Cough</li> <li>• Shortness of breath</li> <li>• Fever</li> </ul>
<p><b>Interleukin-2 (IL-2)</b></p> <p>These drugs can be given by IV (into the vein) or injected into the tumor.</p> <p>Patients being given these drugs in high doses may be treated in the hospital and watched carefully. This is to help manage possible side effects.</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Flu-like symptoms (headache, muscle aches, tiredness, and fever)</li> <li>• Generalized flushing (redness) of the face and body, or skin rash</li> <li>• Nausea or vomiting</li> <li>• Lowered blood pressure</li> <li>• Diarrhea</li> <li>• Low blood counts</li> </ul>	<ul style="list-style-type: none"> <li>• Changes in mental status, such as confusion, drowsiness, or memory loss</li> <li>• Fast heartbeats</li> <li>• Decrease urine output</li> <li>• Changes in liver function</li> <li>• Swelling of the face, ankles, or legs (edema or water retention)</li> </ul>
<p><b>Oncolytic Virus Therapy</b></p> <p>These drugs are injected into the tumor</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Flu-like symptoms (headache, muscle aches, tiredness, and fever)</li> <li>• Fatigue</li> <li>• Chills</li> <li>• Nausea</li> </ul>	
<p><b>Topical Immunotherapy</b></p>	<ul style="list-style-type: none"> <li>• This is a cream that is used for early stage (stage 0) melanoma that has not spread to other parts of the body.</li> </ul>	

## CHEMOTHERAPY

Chemotherapy (also called chemo) uses drugs to destroy or damage fast-growing cells like cancer cells. It is used to shrink tumors, slow cancer's growth, relieve symptoms, or help people live longer.

Chemotherapy is not often used to treat melanoma. When it is used, it is most often used after other treatments have been tried first. Most chemotherapy drugs are given

intravenously (through a vein). Some drugs can be given as a pill or by injection. These drugs continue to work for days or weeks after they are taken. Because of this, a period of rest of one to three weeks follows each dose or cycle. This gives your body a chance to recover from some side effects.

You may get one type of chemotherapy at a time (single-agent therapy) or several drugs



in combination (combination therapy). You also may get chemo in combination with other types of treatment.

Your doctor will discuss with you the best medications for your cancer. It is important to let your health care team know immediately if you notice any change in side effects or symptoms.

Most side effects can be managed if they are treated early.

These are the classes of chemotherapy drugs that are FDA-approved to treat melanoma as of September 2021. This list changes often. For information on specific drugs and the latest approvals for melanoma, go to [www.CancerSupportCommunity.org/melanoma-treatments](http://www.CancerSupportCommunity.org/melanoma-treatments).

CHEMOTHERAPY	
<p><b>Alkylating Agents</b> These drugs may be given by IV (into the vein) or as a pill.</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Low blood counts (white blood cells, red blood cells, and platelets)</li> <li>• Nausea and vomiting</li> <li>• Taste changes</li> <li>• Hair loss</li> <li>• Weakness</li> <li>• Constipation</li> </ul>
<p><b>Plant Alkaloid</b> These drugs are given by injection or infusion.</p>	<p>Common Side Effects:</p> <ul style="list-style-type: none"> <li>• Low blood counts</li> <li>• Hair loss</li> <li>• Peripheral neuropathy (numbness and tingling of hands and feet)</li> <li>• Abnormal heart rate, rhythm, or heart function</li> <li>• Nausea, vomiting, diarrhea</li> <li>• Weakness and fatigue</li> <li>• Diarrhea</li> <li>• Poor appetite</li> <li>• Pain in the joints and muscles</li> <li>• Edema (swelling of feet, ankles, or hands)</li> <li>• Fever</li> <li>• Increases in blood tests measuring liver function (these return to normal once treatment is stopped)</li> </ul>

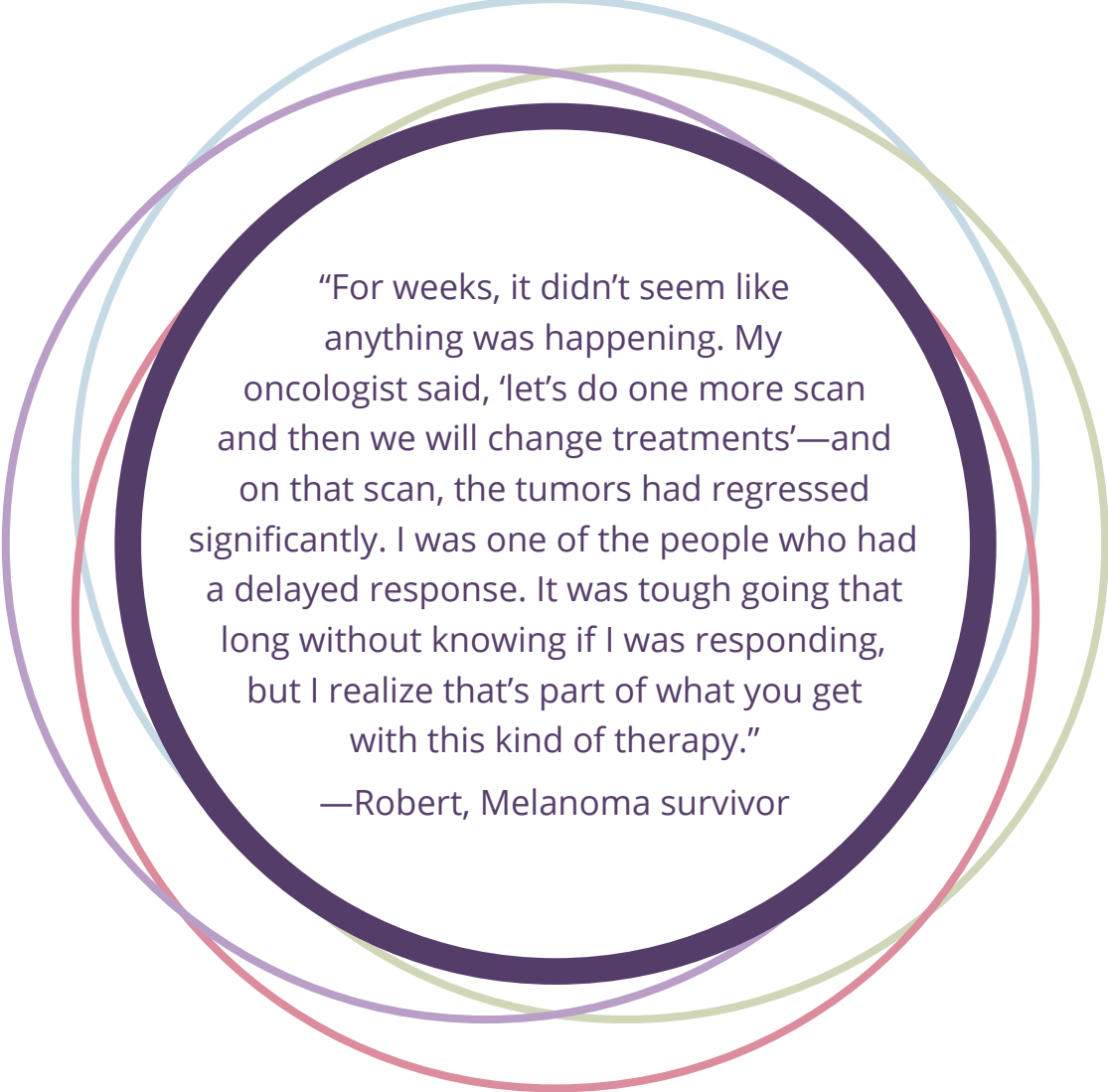


## DELAYED RESPONSE TO TREATMENT

When people with cancer are treated with most standard therapies, it is possible to measure whether it is working or not fairly quickly—usually within 6-8 weeks of starting treatment. It often doesn't work that way with immunotherapy. It can take weeks or even several months to know whether the treatment is working. The tumor may even appear to grow or progress

on a scan. This is the result of an inflammatory reaction—the body attacking the tumor cells and those cells reacting.

This can be very challenging and cause anxiety for people going through this therapy. The wait can be very difficult to handle. This is an issue to discuss with your treatment team so that you understand in advance what to expect.



“For weeks, it didn't seem like anything was happening. My oncologist said, ‘let's do one more scan and then we will change treatments’—and on that scan, the tumors had regressed significantly. I was one of the people who had a delayed response. It was tough going that long without knowing if I was responding, but I realize that's part of what you get with this kind of therapy.”

—Robert, Melanoma survivor





## TREATMENTS IN CLINICAL TRIALS

“Clinical trials are essential to advancing any new treatment. Patients are our partners in these efforts.” —Lynn Schuchter, MD, University of Pennsylvania

### Research Drives Progress

The future of melanoma treatment lies in clinical trials. Clinical trials are research studies to test new treatments or learn how to use current treatments better. Research also focuses on the science behind melanoma—what actually happens

when a melanocyte (part of the skin’s epidermis) becomes a cancer cell. These discoveries lead to new drugs and new trials. In some cases, the treatments with the best chance of success may be available only through clinical trials. To learn more about clinical trials or to find a clinical trial see the Resources section on page 51. New drugs and combinations of drugs may be available through a clinical trial. Ask your health care team if a clinical trial is right for you. Also, be sure to ask about the possible side effects of any drugs you consider.

## NEW TREATMENTS MEAN NEW HOPE

In 2011 Steve (pictured right) was diagnosed with metastatic melanoma. He is a husband and a father of four. His initial concern was for his family and would he be around for their important life events. Now, 10 years later, he is cancer-free and living life as he wants to.

The road was not easy, Steve received treatment with an immunotherapy drug by joining a clinical trial. Although his life was threatened when the immunotherapy drug attacked his pituitary gland, he made it through. Steve followed his doctor’s advice and he still does. Steve knew he needed to create life goals to keep him focused while he was undergoing treatment and during those tough times. He keeps his goals with him all the time and reviews periodically.



**Adoptive Cell Therapies for Melanoma**—Cell therapies are new approaches being tested for melanoma. Two different kinds are being tested to help your T cells work better against cancer. T cells are the immune system’s fighters. These new treatments focus on growing more T cells or helping T cells better find and destroy cancer cells. Examples of cell therapy being studied in melanoma are:

**Tumor Infiltrating Lymphocyte (TIL) Cell Therapy**—A Tumor Infiltrating Lymphocyte (TIL) is a type of T cell that has moved from the blood into a tumor. TILs can kill cancer cells. In TIL cell therapy, these cancer fighting cells are taken from a patient’s tumor. They are then grown in large numbers in a lab and returned to the patient through an IV (in your vein).

**CAR T-Cell Therapy**—In CAR T-Cell Therapy, some of a patient’s T cells are removed from their body and are altered in a lab so they can fight cancer better. A “CAR” protein is added to the T cell. It helps the T cells find and destroy cancer cells. These CAR T cells are returned to the patient through an IV.

## **PALLIATIVE CARE**

When you are living with advanced or metastatic melanoma, feeling good on

a day-to-day basis is an important goal of treatment. Palliative care focuses on providing relief. It does not treat the cancer itself. Its goal is to improve how you feel. Palliative care specialists are highly skilled in treating the symptoms of advanced melanoma. Ask if there is one on your health care team. A palliative care team can also offer this extra layer of support. The team may include doctors, nurses, social workers, and other specialists. Palliative care is different from hospice or end-of-life treatment.

### **Palliative care can:**

- Provide relief from pain and other illness-related symptoms at the same time as treatment.
- Be a part of your treatment plan at ANY stage of your cancer, including right after you learn you have advanced melanoma.
- Offer support to you and your family to help you all cope with your cancer.
- Help you feel better and may even help you live longer.
- Help you focus on activities that are important to you.

If possible, try to see a palliative care specialist early in your care. Be open about your worries, goals, and hopes to your entire health care team.



## The Difference Between Palliative Care and Hospice

Some people confuse palliative care with hospice. While both focus on helping patients and their families feel as good as possible for as long as possible, they are not the same. Hospice focuses on end-of-life care.

It is used when active treatment has ended. Hospice provides comfort to the patient and the patient's family. Even though hospice focuses on the end of life, it is a good idea to ask about it at the beginning of treatment. Palliative care focuses on improving how you feel at any point in your disease.

### COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) OR INTEGRATIVE MEDICINE

People who have cancer sometimes consider treatments that are outside of traditional western medicine. You may hear of special diets, herbs, or other treatments from a friend or family member, on the internet, in a magazine, or on the radio or television.

Complementary and alternative medicine (CAM) is a broad area. These words have different meanings. Yet, they are often confused. Some CAM therapies may be harmless or even helpful. Others can have serious consequences. Talk with your health care team about anything you are doing or considering doing to help with melanoma or the side effects of treatment. The following definitions may be helpful. They describe how

these medicines relate to conventional medicine. Conventional means the treatment you get from your regular doctor.

- **Complementary medicine** is used together with conventional medicine. It may include, for example, meditation for stress reduction, peppermint tea for nausea, acupuncture for back pain, or massage. These approaches add to conventional treatments.
- **Alternative medicine** refers to treatments that are used instead of conventional medicine. They are not scientifically proven and may be dangerous.
- **Integrative medicine** combines conventional medicine with complementary treatments that have been proven safe and effective after being studied in people.



# Managing Side Effects

“The cancer diagnosis is such a roller coaster. Talking to the team—the oncologist, the nurse practitioners, the nurse, the physician assistant to get information can really help the process.”— Suzanne McGettigan, Nurse Practitioner, Penn Medicine

## YOUR VALUES AND SIDE EFFECTS

When you make decisions about treatment, it’s important to think about potential benefits of that therapy and balance those with the things in your life that are important. That means having an open, honest, two-way conversation with your health care team. You need to have a good understanding of the goals of your treatment, just as your doctors and nurses need to understand your goals. Your willingness to deal with side effects may be influenced by what can be realistically achieved with the approach being offered, or by your situation. You may decide a treatment that offers a potential cure or a significant extension of your life is worth tolerating more serious side effects, or side effects that last for months or years.

If you have already been through a number of treatments, the treatment offers only a short response time, or you have other serious health

conditions, those same side effects may not be justified for you. These are very individual decisions. One person may focus solely on living as long as possible. Another’s focus may be to see their child graduate from college, while someone else will choose to stop or reduce treatment. Your values matter. Talk to your doctor and treatment team about what is important in your life.



## Things to Keep in Mind

As you prepare to start treatment, take the time to learn about the side effects of the treatment you are considering. There may be steps you can take or choices you can make to help make treatment a little easier.

### Keep in mind:

- **You probably won't have all the side effects or symptoms listed here.** These lists can seem endless. They are long because they include every possible side effect for many different drugs. You are unlikely to get all or even most of the items on these lists. Every treatment has different side effects, and every person has a unique response to treatment.
- **Your health care team can help manage your symptoms and side effects.** Discuss possible side effects with them before you begin treatment. Know what may happen and how side effects will be managed. Ask if there is anything you can do or take in advance to prevent or lessen side effects. Work with your team to develop a plan for controlling any problems that interfere with daily life.
- **Your health care team only knows what you tell them.** Report any change you notice as soon as you notice it. Often, side effects can be successfully managed, but your team needs to know about them. Tell them about anything you intend to use to manage side effects. This includes over-the-counter drugs, herbs, vitamins, or visits to complementary or alternative health care providers.
- **You can benefit from new ways to prevent or treat side effects.** In the last few years, new treatments have been found for common side effects. Even if you experienced these side effects in the past and did not have effective treatments, you might find that better treatments are available now.



## MANAGING SIDE EFFECTS

This list includes common side effects people experience from many different cancer treatments. Know that everyone reacts to their treatments differently. Use this list as a reference as your doctor explains your treatments and as you have side effects.

### Lymphedema

Lymphedema is a side effect of some melanoma treatments. It is caused by damage to the pathways in the lymph system. Instead of draining fluid, the pathways get blocked and fluid builds up. This can cause swelling, pain, or loss of feeling in the affected area. Your risk of lymphedema is higher if you had:

- Surgery or radiation to the lymph nodes in the arms or legs
- A lymph node dissection

Lymphedema can be a very serious, disabling condition. It is important to let your doctor know right away if you notice swelling, numbness, or pain. Early treatment can prevent it from getting worse. Treatment is provided by doctors trained in rehabilitation medicine or physical therapists with special training in lymphedema.

### Fatigue

Fatigue is one of the most common and toughest side effects of cancer treatment. Fatigue is much more than

being tired. Fatigue is feeling physically, mentally, and emotionally exhausted.

Fatigue can be caused by multiple things. Fatigue can be a symptom of your cancer. Fatigue can also be a side effect of your cancer treatment. It can also be caused by a lack of sleep or a symptom of depression.

Your health care team can help determine what is causing your fatigue. You can make some lifestyle changes to help manage your fatigue regardless of the cause:

- **Take breaks.** Rest and allow yourself more time to accomplish your tasks. Don't feel guilty if you need more time or have slower days.
- **Commit to your sleep.** Try to get at least 8 hours of sleep every night. Wake up and go to bed at the same time each day.
- **Ask for help.** Ask family and friends to assist with your tasks. Set realistic goals for yourself and ask others for help.
- **Take advantage of good days.** Some days you may feel more energetic than others. Use those days for things that are more important to you like spending time with your loved ones, being more active, or getting work done.



“The issues that people bring up vary over time. The questions someone has at diagnosis are different from those that come up after a person has been on treatment for a while. People want to know how their treatment is going to affect their lives.”

—Ryan Nipp, MD, Dana-Farber Cancer Institute

## **Pain**

Cancer treatment may cause pain. Pain can be distressing, so it is important to communicate with your health care team about your pain. Some important characteristics of your pain to talk about are:

- **Severity:** How bad is the pain? Your care team may ask you to describe it on a scale of 0 to 10, with 0 being “no pain” and 10 being “the worst pain you’ve ever experienced”
- **Location:** Where is the pain?
- **Frequency and Duration:** How often do you have pain? For how long?
- **Quality:** Describe the pain. Is it stabbing or burning? Sharp or dull?
- **Change:** What makes the pain better or worse?
- **Onset:** When did the pain begin? Was it sudden or gradual?

These questions will help you and your care team figure out the best way to manage your pain. Your care team may prescribe medications

or complementary therapy like massage or acupuncture. If your pain is not well controlled, you can ask your provider to refer you to a pain specialist.

## **Diarrhea**

Some medications may irritate the lining of your stomach and small intestines. This can cause diarrhea or watery stools. You can cope with diarrhea by:

- **Staying hydrated.** Drink 8–12 glasses of fluids a day to prevent dehydration.
- **Avoid caffeine.** Caffeine may irritate your stomach and intestines further or cause you to become more dehydrated.
- **Avoid spicy or fatty foods and milk products.**
- **Eat low fiber foods.**

A Registered Oncology Dietician may also be able to help you plan a healthy diet to manage this side effect.

If you are experiencing more than three episodes of diarrhea in a day, contact your health care team.



## Things to Keep in Mind

It is important to realize every treatment has some side effects. The exact nature of those side effects and their severity depend on the specific treatments you receive, and your responses.

### Remember:

- ❑ **Many treatments decrease the symptoms** of the disease so people feel better and their quality of life improves.
- ❑ **Talk to your doctor and treatment team before you start therapy.** Let them know what is important to you, what scares you, and what you want to be able to do during therapy.
- ❑ **Know that there are many ways to ease or eliminate side effects.** Let your team know immediately if you develop side effects or they become worse. This is true for all treatments, but especially for immunotherapy. More information on the side effects of immunotherapy can be found in CSC's *Frankly Speaking About Cancer: Immunotherapy for Melanoma* booklet.
- ❑ **Not all side effects are physical.** Don't forget the emotional side.
- ❑ **Take care of yourself.** You are the expert in what you can handle, what kind of activities you can engage in, and how much you can and want to do on any day.
- ❑ **Let family and friends help you.** Give people specific suggestions for what will be helpful: a meal, childcare, a ride, an afternoon to yourself, or a walk together in the park.
- ❑ **Most of all communicate—** with your health care team and your family.







Robin Barnes, Melanoma survivor

# Taking Control of Your Care

“I’m thankful I have a great support system with my family and friends. But, I feel like I have more support with the community that I’m connected with online. Their experience with melanoma may not be exactly the same, but they understand.” —Donna, Melanoma survivor

As you live with melanoma, you will find your path and develop your strategies to manage your treatment, and your life, but here are some tips that can help:

- Don’t try to do everything at once. Stay in the moment, as much as possible, and focus on what is happening now, and what you need to do to address that situation.
- Ask for support from your caregivers. Many of your family and friends will want to be there for you. Be open about what they can do to support you. It is useful to be specific. Ask someone for a meal, to watch your children, give you a ride, or just be there on a tough day. For some people, religion and spirituality are a very important source of strength and support while going through cancer. That support may come from a person’s faith or relationship with a god, as well as from the wonderful bonds that

often exist among those in the same faith community.

- Take someone with you to medical appointments and procedures. This is important because an extra set of eyes and ears often helps to remember and interpret the information you are given.
- Acknowledge and express your feelings. There are many ways to do this. Talk to a friend or family member, spiritual leader, or counselor. Write, paint, or play music. Many people benefit from joining a support group and sharing their experiences with other members of the community.

“It is so important to find your support for yourself and your family. We joined a support group for our three kids who at the time were in grade school, high school, and starting college.”

—Frank, Melanoma survivor



**Make time for yourself and the things you enjoy.** Being a cancer patient can be very time-consuming and mentally exhausting. It is important to continue to do what you love as much as possible. For some people, that is as simple as taking a walk or planting some flowers. For others, it may mean continuing to work. You may have to adjust your activities to fit your energy level and physical condition, but don't lose sight of the importance of continuing to do what you like to do in your life.

- ❑ **Learn to relax.** For most people, living with cancer involves at least some level of anxiety and emotional distress. It can be very helpful to learn how to give yourself moments in which you feel calm and controlled. Many people benefit from mindfulness or meditation classes, or from practicing yoga. For others, those moments might come from a walk in the woods or from playing the piano. Learning to relax is a skill you have to learn but it can help with many aspects of life.
- ❑ **Develop a plan.** Having a treatment plan—one that is developed and shared with your team—is very important. You can coordinate your care and make sure that your emotional needs are met, as well as your physical needs. You can also identify resources to help with the various aspects of your care. Your plan will likely change as you progress through treatment. For people whose treatment ends, the emphasis will be on moving forward and receiving the proper follow-up care. For those who are continuing with their treatment, it is important to talk about your specific goals to ensure your voice is heard in the decision-making process.
- ❑ **Hold onto hope.** There are many ways to hope. You can hope for the big things—that the cancer is successfully treated and you can return to your life, or, depending on your circumstances, you can focus on smaller goals. You might hope for a good result on a scan or a positive report from your doctor. Or, you might hope that tomorrow will be a sunny day and you can get out in your garden, or that you will spend time with your friends and family doing something you all enjoy. The main thing is not to let go of hope, to keep setting goals, and to keep finding things in your life that matter and bring you happiness.





## Emotional Support

Donna was diagnosed with stage III B melanoma. Even though her family and friends were very supportive, a cancer diagnosis can be hard on everyone. Family and friends do not always know what to say or how or when to help.

Donna says, "I went to counseling for some time to talk to someone who wasn't related to my family just so I could really let my hair down so to speak and tell him exactly how I was feeling." One-on-one counseling may not be for everyone. Donna also found online communities to be very helpful. She says, "There are closed groups out there that you can get into. One woman I met encouraged me when I was going through a really difficult time during my treatment and I had the chance to meet her in person recently at a melanoma walk in Houston, which was incredible."

## WHAT ABOUT WORK?

For many people, a cancer diagnosis involves serious concerns about the impact of illness and treatment on work. These concerns may include lost time, earnings, and opportunities; the possibility of losing health insurance; or the fear of not being able to support yourself or your family.

Your ability to continue to work throughout your cancer experience will depend on the stage of your disease, the treatment and your response to it, and, in many instances, on your priorities and needs.

Employers also differ greatly in their willingness and ability to provide support and accommodate your needs during treatment.

“A cancer diagnosis often raises huge issues surrounding work and career. People want to know if they can continue to work, or how it will affect their relationships. It is a very real and often overlooked area of concern.”

—Hester Hill Schnipper, LICSW,  
OCW-C, Beth Israel Deaconess  
Medical Center

There is no single approach to dealing with your work situation and cancer. There are steps you can take to help assess your situation and make decisions about how to manage your work-life during this time.

- Think about what you need to do, and what you want to do. Can you take time off? Do you want to do that?
- Find out what your employer offers and what you are entitled to in terms of insurance coverage, disability insurance, sick leave, and reduced hours.
- Let your colleagues and friends support you as much as possible.
- Explore the possibility of working part-time or cutting back during the most difficult times.
- Reach out to organizations like Cancer and Careers ([www.cancerandcareers.org](http://www.cancerandcareers.org)) or try contacting the Cancer Legal Resource Center ([www.disabilityrightslegalcenter.org](http://www.disabilityrightslegalcenter.org)) to learn more about your rights and the resources available to you.



## WHAT IS QUALITY OF LIFE?

Quality of life is an expression that comes up frequently when people are talking about cancer treatment. In medical terms, it is usually defined as maximizing the ability to function normally, while minimizing the negative effects of the disease or its treatment. But there is no single definition.

Each person can define what quality means, and that definition will depend on who you are, what is happening in your life, and how your cancer impacts

the things that are important to you—whether that is your job, your ability to care for your children, taking care of your home, or going on the trip you planned.

“People with serious illnesses have stress in different ways. We need to understand what individuals are going through and focus on the physical, emotional, and spiritual quality of life our patients want.” —Hunter Groninger, MD, MedStar Georgetown Washington Hospital Center

## Tools to Help Communicate Your Wishes

Advance directives are legal documents, such as a living will and durable power of attorney for health care, which you put in place to inform your doctors and family what you want to do in terms of end-of-life treatment.

Most of these documents can be prepared without the use of a lawyer and without any cost to you or your family.

While it can be difficult to have this discussion, most people find that they and those who love them benefit from talking about the issues and making decisions beforehand so wishes are clearly understood. Anyone can have an advance directive, but it becomes more important when you are facing a cancer diagnosis, especially when the prognosis is uncertain and unfavorable. Your health care team can help you think about your wishes and refer you to someone experienced to help prepare these documents.



## Be Careful About the Internet

Just about everyone searches for health-related information on the internet. But, when you research melanoma, be careful about what you read and how you interpret it. Any information you get about the treatment of advanced melanoma that was written before 2011 is completely out of date, and even materials from the last year may no longer be current. If you choose to search for melanoma information on the internet:

- check the date
- stay with credible organizations that update their sites frequently
- and most importantly, discuss what you find with your doctor



No matter how you define it, quality of life is very important in treating cancer, at all stages of the journey. Talk to your treatment team about what matters to you. Let them know if you are having problems. Share your goals and values with them, so that they can help you achieve the best possible quality for your life.

“I was very involved in coaching lacrosse for my kids. I never stopped during my treatment. For me, that was my escape mechanism, my support.”  
—Steve, Metastatic Melanoma survivor



## LIVING LIFE

Shelley has faced cancer twice. The first time, she was diagnosed with breast cancer. The second time, it was melanoma. In both instances, she used the energy and determination she demonstrated in her years as a high school physical education teacher to make sure her experience had meaning, for herself and others.

For Shelley, one way of sharing her experience is to organize a dragon boat program for cancer survivors in her area. Dragon boating is the essence of team activity. It takes 20 people to paddle the boat, along with a drummer to set the pace and a steersperson. The more in sync the paddlers are, the faster the boat moves. Dragon boating has become a popular sport for people who face cancer because of its strong sense of community, shared experience, and purpose.

“We go out once a week,” says Shelley. “There’s nothing like getting a group out there on a beautiful morning. People will come to me, especially the ones who are there for the first time and are so excited about the fact they can do this, and they

can do it with other individuals who have all faced cancer. We celebrate each other, support each other, and sometimes, we grieve together for the ones who aren’t with us anymore. It’s very empowering. They thank me, but really, they are giving me and each other so much. I just think it is so important for all of us who have been through the cancer experience to find each other and to do things that make us feel good about life.”





## CANCER SUPPORT COMMUNITY RESOURCES

The Cancer Support Community's (CSC) resources and programs are available free of charge.

To access any of these resources below call 1-888-793-9355 or visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)

**Cancer Support Helpline®** — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET and Sat-Sun 9am - 5pm ET.

**Open to Options®** — Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

**Frankly Speaking about Cancer®** — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

**Services at Local CSCs and Gilda's Clubs** — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you.

[www.CancerSupportCommunity.org/FindLocation](http://www.CancerSupportCommunity.org/FindLocation).

**Cancer Experience Registry®** — Help others by sharing your cancer patient or cancer caregiver experience via survey at

[www.CancerExperienceRegistry.org](http://www.CancerExperienceRegistry.org)

**MyLifeLine** — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at [www.MyLifeLine.org](http://www.MyLifeLine.org)

**Grassroots Network** — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at [www.CancerSupportCommunity.org/become-advocate](http://www.CancerSupportCommunity.org/become-advocate)



## Acknowledgments

A special thanks to our contributors and reviewers: AIM at Melanoma, Melanoma Research Alliance, Melanoma Research Foundation, Erin Mcallister, MSW, LSW, OSW-C, Gilda's Club South Jersey; April K.S. Salama, MD, Duke University.

The Cancer Support Community provides this information as a service. This publication does not take the place of medical care or the advice of your doctor. Talk to your doctor or other health care professional to answer your questions and learn more.

## Melanoma Information and Support

AIM AT MELANOMA  
1-877-246-2635  
[www.aimatmelanoma.org](http://www.aimatmelanoma.org)

CANCERCARE  
1-800-813-4673  
[www.cancercare.org](http://www.cancercare.org)

CANCER SUPPORT COMMUNITY  
1-888-793-9355  
[www.CancerSupportCommunity.org/Melanoma](http://www.CancerSupportCommunity.org/Melanoma)

MELANOMA INTERNATIONAL FOUNDATION  
1-866-463-6663  
[www.melanomainternational.org](http://www.melanomainternational.org)

MELANOMA RESEARCH ALLIANCE  
[www.curemelanoma.org](http://www.curemelanoma.org)

MELANOMA RESEARCH FOUNDATION  
1-800-673-1290  
[www.melanoma.org](http://www.melanoma.org)

NATIONAL CANCER INSTITUTE  
1-800-422-6237  
[www.cancer.gov](http://www.cancer.gov)

## Financial, Insurance and Legal Help

CANCER AND CAREERS  
646-929-8023  
[www.cancerandcareers.org/en](http://www.cancerandcareers.org/en)

CANCERCARE  
1-800-813-4673  
[www.cancercare.org](http://www.cancercare.org)

CORPORATE ANGELS NETWORK  
1-866-328-1313  
[www.corpangelnetwork.org](http://www.corpangelnetwork.org)

CANCER LEGAL RESOURCE CENTER  
1-866-843-2572  
[www.disabilityrightslegalcenter.org](http://www.disabilityrightslegalcenter.org)

HEALTH INSURANCE MARKETPLACE  
1-800-318-2596  
[www.healthcare.gov](http://www.healthcare.gov)



NEEDYMEDS  
1-800-503-6897  
[www.needymeds.org](http://www.needymeds.org)

PARTNERSHIP FOR PRESCRIPTION  
ASSISTANCE  
1-888-477-2669  
[www.pparx.org](http://www.pparx.org)

PATIENT ACCESS NETWORK  
FOUNDATION  
1-866-316-7263  
[www.panfoundation.org](http://www.panfoundation.org)

PATIENT ADVOCATE FOUNDATION  
1-800-532-5274  
[www.patientadvocate.org](http://www.patientadvocate.org)

PATIENT ADVOCATE FOUNDATION  
CO-PAY RELIEF  
1-866-512-3861  
[www.copays.org](http://www.copays.org)

UNITED WAY  
211  
[www.unitedway.org](http://www.unitedway.org)

## Clinical Trials

AIM AT MELANOMA  
1-877-246-2635  
[www.aimatmelanoma.org](http://www.aimatmelanoma.org)

CANCER SUPPORT COMMUNITY  
888-793-9355  
[www.CancerSupportCommunity.org/  
ClinicalTrials](http://www.CancerSupportCommunity.org/ClinicalTrials)

MELANOMA INTERNATIONAL  
FOUNDATION  
1-866-463-6663  
[www.melanomainternational.org](http://www.melanomainternational.org)

MELANOMA RESEARCH ALLIANCE  
[www.curemelanoma.org](http://www.curemelanoma.org)

MELANOMA RESEARCH FOUNDATION  
1-800-673-1290  
[www.melanoma.org](http://www.melanoma.org)

NATIONAL CANCER INSTITUTE  
1-800-422-6237  
[www.cancer.gov](http://www.cancer.gov)

## Caregivers

CANCER SUPPORT COMMUNITY  
1-888-793-9355  
[www.CancerSupportCommunity.org/  
Caregivers](http://www.CancerSupportCommunity.org/Caregivers)

CAREGIVER ACTION NETWORK  
202-454-3970  
[www.caregiveraction.org](http://www.caregiveraction.org)

CARING FROM A DISTANCE  
[www.cfad.org](http://www.cfad.org)

FAMILY CAREGIVER ALLIANCE  
1-800-445-8106  
[www.caregiver.org](http://www.caregiver.org)





# A Bold New Era: A Bright Future

“This is the first time I have seen responses this durable, and most of these people had no side effects. These were patients who had weeks to live. Their immune systems were primed to attack the tumor but were turned off by the tumor.” —Antoni Ribas, MD, University of California at Los Angeles

Ten years ago, even the most seasoned and optimistic melanoma doctors and researchers would not have predicted the progress that has been made in understanding and treating this disease. There has truly been an explosion of knowledge, new drugs, approaches, and wisdom about how to use these new tools. For the first time, a percentage of people with advanced melanoma are achieving remissions so complete and long lasting that they are now considered cured.

That’s very exciting but there is still a great deal of work to be done. The goal now is to continue to deepen and broaden the understanding of what causes melanoma and allows

it to spread and grow, and to apply that knowledge to treatment that will benefit every individual affected by this disease.

**That goal is in sight.**



## SO THAT NO ONE FACES CANCER ALONE®

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC), including its Gilda's Club affiliates, is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community. CSC achieves its mission through three areas: direct service delivery, research, and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral, and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C., and across the nation.

**For more information, visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org)  
or call the toll-free Cancer Support Helpline at 888-793-9355**



Frankly Speaking About Cancer: Melanoma  
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This publication was made possible  
through an educational grant from:

