

FRANKLY SPEAKING ABOUT CANCER

Metastatic Melanoma

Metastatic Melanoma – What You Need to Know

If you have metastatic melanoma, you may feel as though your life has been turned upside down.

*“It’s a serious disease,
but patients can do
extremely well.”*

— Dr. Michael Postow, Memorial Sloan-
Kettering Cancer Center

You may be overcome with questions and fears: “How am I going to tell my family?” “What are the odds treatment will work?” “Do I need to get my affairs in order?”

It’s important for you and your loved ones to learn about the disease, possible treatment options and develop a plan for your care. There are more therapies available than ever, and some people are living longer as a result.



Support for Finding Facts about Metastatic Melanoma

Cancer Support Community	888-793-9355	www.cancersupportcommunity.org
AIM at Melanoma	877-246-2635	www.aimatmelanoma.org
Melanoma International Foundation	866-463-6663	www.melanomainternational.org
Melanoma Research Foundation	800-673-1290	www.melanoma.org



Making Treatment Decisions

Your doctor will recommend a treatment based on a variety of factors. These may include:

- Where and how far your cancer has spread
- Your symptoms
- Treatments you've already tried
- The impact on your quality of life, as well as practical costs
- Your preferences and personal goals

If possible, go to a melanoma specialist to:

- Learn about the latest treatments
- Find out if there are clinical trials that might be beneficial
- Get a second opinion, if needed



Consider talking to an Open to Options® Specialist at the Cancer can help you get a clearer idea of your goals and concerns. Support Community who

Goals for Treatment

The main goal of treatment is to help people **live as well as they can** and **for as long as possible**.

That means to help:

- Prolong survival
- Delay disease progression – stop or shrink known metastases and prevent spread of new ones
- Manage symptoms
- Minimize side effects or disfiguring procedures
- Maintain function and quality of life



Treatment Options

Treatments for metastatic melanoma may be used alone or in combination. They may include:

- **local therapies** – for example, surgery or radiation and
- **systemic therapies** – medications that travel through the bloodstream to reach and fight cancer cells throughout the body. These include immunotherapy, targeted therapy and chemotherapy.



Surgery

In some patients with metastatic disease, surgery can be used to remove cancer tumors or lymph nodes, especially if they are causing symptoms.



Radiation Therapy

Radiation therapy uses high-energy X-rays to kill cancer cells. In this case, radiation is used mostly to help alleviate symptoms from the cancer. It is also often used to treat metastases to the brain.

“Treatment has to fit patients’ lives so they can lead as normal a life as possible and stay engaged with things they love.”

— Dr. Postow



Immunotherapy

This treatment triggers the immune system to recognize and fight cancer cells.

These include:

- Ipilimumab (Yervoy®)
- Proleukin (aldesleukin, commonly known as high-dose interleukin-2)

Side effects of these medications can include rash, itching, diarrhea, endocrine disorders, among others.



Targeted Therapy

These therapies are designed to target specific proteins or inhibit genetic mutations that can promote cancer. Roughly half of patients with melanoma have a mutated or abnormally activated BRAF gene, which signals cancer cells to grow.

- Vemurafenib (Zelboraf®) and Dabrafenib (Tafinlar®) shut down (produced when the BRAF gene is abnormally activated) the abnormal BRAF protein
- Trametinib (Mekinist™) blocks a different protein called MEK. This protein is in the same family as the BRAF protein.

Side effects may include fatigue, muscle/joint pain, diarrhea, skin growths, rash/itching, among others.



Chemotherapy

Chemotherapy can be given by mouth or through a vein (intravenously). Chemotherapy drugs most often used for metastatic melanoma include:

- Dacarbazine (DTIC-Dome®) - given through a vein
- Temozolomide (TEMODAR®) - taken as a pill
- Combination chemotherapy

Common side effects are fatigue, nausea, and potential for infection, among others.

“With a complicated cancer like metastatic melanoma, it is always helpful to consider a second opinion and learn about all the options, including clinical trials.”

— Dr. Gangadhar



Palliative Care

Palliative care is a critical part of cancer care, regardless of what type of treatment you are getting. It can help with physical symptoms (for example, pain, fatigue, appetite changes), emotional stress, depression, and anxiety. Palliative care is appropriate at any point.



Clinical Trials

Clinical trials may offer patients access to promising therapies for metastatic disease. These studies may test new ways to use or combine drugs or techniques that are already approved or investigate novel therapies. For example, adoptive cell therapies that select and make immune cells to fight cancer and antibodies against Programmed death-1 receptor axis are currently being investigated.

Ask your doctor if a clinical trial is suitable for you. They are available as a first treatment, and may be a good option for some patients.



Monitoring Your Treatment

Your health care team will want to know how your treatment is working. This means you will have regular appointments and tests to monitor your health and to see what your tumor(s) is doing. If you have a new symptom or side effect in between visits, tell your doctor right away.

Even though treatment can be very effective in some patients, cancer cells usually find a way to outsmart and resist therapy at some point. This means your treatment may need to be revisited.

Questions to Ask

- What does my diagnosis mean?
- Which treatment(s) do you recommend and why?
- What kind of side effects might I experience, for how long, and how can I manage them?
- How and when will we know if the treatment is working?
- How can I talk to my children/family about my diagnosis?
- Is there a clinical trial here or elsewhere that I might benefit from?
- Has my tumor been tested for the BRAF gene?
- Should my melanoma be tested for other abnormal genes?
- How do I get a copy of my pathology report?
- What else can I do to stay as healthy as possible?
- Are there other resources available to me both in and outside the hospital?



Who is on Your Treatment Team

- Medical oncologist (ideally someone who focuses on melanoma)
- Surgeon – surgical oncologist, plastic and/or general surgeon
- Dermatologist
- Nurse
- Social worker or counselor
- Nutritionist
- Patient advocate or navigator
- YOU!



You're Not Alone

Many people living with metastatic melanoma share similar concerns. For example:

- Worries about how treatment will affect you or your life
- Need for greater emotional and spiritual support
- Fear of dying or the cancer taking over
- Financial and medical insurance issues

Get help to better cope with the disease. Visit **www.cancersupportcommunity.org** for helpful tips and more resources.



Other Considerations

There may come a time when cancer treatments are no longer working. Or you may decide you want to spend the time you have left in other ways. Hospice care provides comfort for people with metastatic cancer who are no longer receiving medical treatment for the cancer. Hospice care is most commonly given by trained nurses in the comfort of your home. It is also available in inpatient settings.



What is Metastatic Melanoma?

Melanoma is a type of cancer that begins in the cells that make our skin color (called melanocytes). If the initial cancer spreads to another area(s) of the body, it is called metastatic or Stage IV. It can develop without warning, or from or near a mole on the skin.

Metastatic melanoma can't be cured, but it can be treated. How someone will fare depends on a number of factors. For example:

- the location and extent of their disease
- how fast it is growing

Melanoma can be especially troubling because patients can see cancer on their skin and often wonder where else it might be. The good news is that some people with metastatic melanoma are living longer and better than ever. Several new drugs have recently been approved – the first new treatments in over a decade.

"We are in a sense rewriting history and changing the way advanced melanoma is treated because of improved survival and outcomes in some patients on newer treatments," says Dr. Tara Gangadhar, Abramson Cancer Center of the University of Pennsylvania. Although new treatments are advancing quickly, nothing is a home run yet.

Where Does Melanoma Usually Spread?

- Skin
- Brain
- Distant Lymph Nodes
- Lung
- Liver
- Abdomen
- Bone



Getting Organized

Taking an active role in your care can help you along your journey. Here are some tips to consider:

- Learn as much as you can about metastatic melanoma
- Make a list of possible treatments and the pros and cons of each
- Map out your goals for treatment
- Ask your health care provider about what the treatment will mean for your everyday life
- Get a notebook or binder to keep copies of medical reports, track symptoms and side effects, and to write down questions and concerns
- Talk to other people living with the disease
- Work with your health care team to anticipate the next step if one treatment doesn't work
- Appoint someone to make health decisions for you if you are unable to do so (called a health care proxy)
- Have a living will in place (this is a good idea regardless of your health)

"If you look at the statistics, I should be gone already. It's not an easy road, but every day is truly a gift."

— Donna, 51

VALUABLE RESOURCES

Help is available to you and your loved ones. These resources can help you understand your treatment options, manage side effects, deal with emotions and connect with others impacted by metastatic melanoma.

CSC Resources for Support

Cancer Support Helpline® 888-793-9355

Our free helpline is open Monday – Friday 9:00 am – 8:00 pm ET. Anyone impacted by cancer can call to talk to a call center counselor. We will connect you with local and national resources, and help you find the right support.

NOW AVAILABLE!

CSC's website now houses up-to-date information for people living with metastatic melanoma. Here you will find more information, tips and resources.

OPEN TO OPTIONS®

Do you have questions about your cancer treatment? Open to Options® is a research-proven program that can help you prepare a list of questions to share with your health care team. In less than an hour, our Open to Options specialists can help you create a written list of specific questions about your concerns for your doctor.

Frankly Speaking About Cancer®

CSC's cancer education series, providing sound educational and psychological information for cancer patients and their loved ones.

Affiliate Network

Over 50 locations plus more than 100 satellites around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost.

The Living Room, online

Through CSC's "The Living Room" you will find online support groups, discussion boards and social networking for patients and caregivers.

To access these services, or for more information and resources for coping with metastatic melanoma, visit www.cancersupportcommunity.org or call 1-888-793-9355.

Other Resources and Support



www.aimatmelanoma.org



www.melanomainternational.org



www.melanoma.org



This fact sheet is part of *Frankly Speaking About Cancer: Advanced Skin Cancers*. CSC and its partners provide this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professionals to answer questions and learn more.

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