

In October 2015, the Cancer Support Community brought together twenty-four melanoma patients and caregivers for a two-day summit focused on stage III melanoma.

In small and large groups, over coffee and tea, during walks in the woods, participants took part in personal, respectful and heartfelt conversations about what it was like to receive a diagnosis of stage III—and for some, stage IV—melanoma, their cancer care, the caregivers' experience, and what they wish they had known at the time of their diagnosis. They also discussed what helped them, and what might help others become self-advocates as well as advocates for others in our communities.

This Stage III Melanoma Fact Sheet and its accompanying Melanoma Treatment Summary and Care Plan grew out of those discussions.



**CANCER SUPPORT
COMMUNITY**

SUPPORT FOR FINDING INFORMATION ABOUT MELANOMA

AIM at Melanoma 877-246-2635 www.aimatmelanoma.org

Cancer Support Community 888-793-9355 www.cancersupportcommunity.org

Melanoma Research Alliance 202-336-8935 www.curemelanoma.org

Melanoma Research Foundation 800-673-1290 www.melanoma.org

Melanoma International Foundation 866-463-6663 www.melanomainternational.org

Stage III Melanoma and You

Your first thought upon learning you have melanoma may have been: What's that?

Learning you have cancer is never easy. Learning you have melanoma can pose unique challenges. Women and men with stage III melanoma make up about 9 percent of all melanoma diagnoses. This means you are part of a small subset of an already small group of cancer patients.

Women and men who have been diagnosed with melanoma frequently report they had no idea that melanoma was a type of skin cancer, or that a skin cancer could spread into other parts of your body. Many say they not only had to tell their friends, family members or co-workers that they had cancer, but also had to educate them about melanoma and how it was treated.

This is not too surprising. More than 5.4 million cases of skin cancer are diagnosed in the U.S. each year. This means there are more skin cancer diagnoses each year than there are cancers of the breast, prostate, lung and colon combined. But the vast majority of these are non-melanoma skin cancers that can be surgically removed.

Melanoma is a different story. The American Cancer Society estimates there will be 76,380 new cases of melanoma diagnosed in 2016. This represents about 4.5% of all new cancer cases in the U.S. This helps explain why so many people know about skin cancer, but few know about melanoma.

Living with Melanoma

Melanoma is often misunderstood. Some of us had never heard of melanoma before our own diagnosis. Some of us have had to explain to family members and friends that skin cancer can spread to other parts of the body or that having the melanoma removed doesn't mean we are now "cured." Many of us wish we had known more—and now want to do more to raise awareness about the

disease, including the dangers of indoor tanning and sun exposure.

Talking about cancer can be challenging and emotional. But it can also be helpful, for you and for others. Your cancer experience will be unique to you. But that does not mean it is one you have to go through alone. We encourage everyone reading this guide to seek support and build community—online, in person or both.

Living with stage III melanoma means living alongside the knowledge that you are at high risk for recurrence. It's a delicate balance of bravery, fear, vigilance and hope.

WHAT IS STAGE III MELANOMA?

The cancer's "stage" tells us how far the cancer has spread, and thus helps predict the risk of recurrence. The most widely used staging system for melanoma groups melanoma into 4 main stages using the tumor-node-metastasis system (TNM). It takes into account three key aspects of the cancer:

1. How "thick" it is, meaning how far down it has grown within the skin (T stage);
2. if it has spread to nearby lymph nodes or lymph vessels (N stage);
3. if it has spread to distant organs and, if so, which ones (M stage)

In general, stage I and II melanoma are only in the skin, with no spread to lymph nodes or other organs. These melanomas can still come back after surgery, but are at lower risk for recurrence than higher stage melanomas.

Stage III melanoma most commonly includes those that have spread from the skin to nearby lymph vessels or lymph nodes. These melanomas can be removed surgically, and still potentially cured, but are at higher risk for coming back than lower stage melanoma.

Stage IV melanoma refers to disease that has spread beyond the skin or nearby lymph node, often to an organ, like the lung or liver.

THERE ARE THREE SUBCATEGORIES OF STAGE III MELANOMA—IIIA, IIIB AND IIIC.

The subcategories are important because they will further help determine your level of risk for recurrence and treatment options.

STAGE IIIA: A tumor of any thickness that is not ulcerated. It has spread to nearby lymph nodes, but is only detected when the pathologist looks at the node under the microscope (microscopic disease.) This type is most frequently diagnosed when a sentinel lymph node biopsy comes back positive. There is no distant spread.

STAGE IIIB: A tumor of any thickness that is ulcerated. It has spread to nearby lymph nodes, but is only detected when the pathologist looks at the node under the microscope (microscopic disease.) There is no distant spread.

OR A tumor of any thickness that is not ulcerated. It has spread to small areas of nearby skin or into the nearby lymph vessels (satellites or in-transit metastases), but the nodes themselves do not contain melanoma. There is no distant spread.

OR A tumor of any thickness that is not ulcerated, and 1-3 lymph nodes have evidence of larger melanoma deposits, that the doctor can either feel or see on a scan (macroscopic disease). There is no distant spread.

STAGE IIIC: A tumor of any thickness that is ulcerated, and 1-3 lymph nodes have evidence of larger melanoma deposits, that the doctor can either feel or see on a scan (macroscopic disease). There is no distant spread.

OR A tumor of any thickness that may or may not be ulcerated, and it has spread to 4 or more nearby lymph nodes, with any size of tumor deposit (micro- or macroscopic disease).

OR A tumor of any thickness that may or may not be ulcerated, and it has spread to nearby lymph nodes that are clumped together (matted) OR it has spread to nearby skin or lymph vessels (satellites or in-transit metastases) along with spread to nearby lymph nodes (any size of tumor deposit). There is no distant spread.

ADDITIONAL FACTORS THAT DETERMINE TREATMENT OPTIONS

WHAT HAPPENED DURING SURGERY?: Your doctors will tell you whether or not they believe the melanoma was completely removed during surgery. If it could not be surgically removed (the medical term is “unresectable”) you will be treated as if your cancer was stage IV.

ACCESS TO CLINICAL TRIALS: A clinical trial may provide your best treatment option. You may want to talk to your doctor about clinical trials that might be options for you before making a treatment decision.

See page nine titled “Look to Trusted Organizations and Websites” for websites to search for melanoma clinical trials and discuss them with your doctor.

QUESTIONS TO ASK ABOUT SELF-ADVOCACY:

Some of the patients who attended the October 2015 Advocacy Summit were familiar with self-advocacy.

Others were just starting out as self-advocates. They each had tips to share about self-advocacy based on their own experiences. They encouraged all melanoma patients to ask themselves:

- Do I understand my diagnosis?
- Have I investigated all my options?
- Am I comfortable with my doctor?
- Am I seeing a melanoma specialist?
- Did I get a second opinion?
- Do I have someone go with me to my appointments?
- Do I have a strong support system?
- Do I feel like all of my questions have been answered?
- Do I fully understand what my doctor has told me?
- Have I asked about clinical trials?
- Do I have copies of my reports and records?
- Do I have stress or other problems that are going unaddressed?
- Do I know what palliative care is?

The Path to Self Advocacy

self-ad·vo·ca·cy (*noun*)

the action of representing oneself or one's views or interests.

Self-advocacy has its roots in the disability rights movement. It was a transformational time in which people with cognitive, intellectual and physical disabilities fought for the right to be educated about and take control of their health care.

For cancer patients, survivors and caregivers, self-advocacy provides a framework for managing a cancer diagnosis. Most cancer patients don't set out thinking or saying, "I am going to be a self-advocate." Yet many melanoma patients report that at some point during their treatment they found they needed to become more involved to make sure their needs were met or their concerns were heard.

This realization may result from frustration with how little others know about melanoma or how difficult it is to find others near you who have the same diagnosis. It could be because you do not have a melanoma specialist in your area and you have to travel a significant distance to get a second opinion or to take part in a clinical trial. It could be because you experience poor care in a medical setting, feel that your care team is not fully addressing your concerns, or find that your doctor is not aware of all of your treatment options. Or, it could be because you know you and others with stage III melanoma have a high risk for recurrence.

You may feel discouraged by how difficult it is to meet others who understand what you are going through as a melanoma patient. You may even find yourself getting angry about how much research you have to do on your own.

At the same time, you may also feel inspired to find ways to increase awareness about melanoma, help other patients get a second opinion or advocate for more research on melanoma. In short, you may find yourself making a transition from patient to self-advocate.



Amy's aunt was diagnosed with malignant melanoma in November 2013. Amy is living with multiple myeloma.

“It’s been extremely important that I’ve been able to advocate for myself and for other people who don’t feel they can advocate for themselves.”

— Amy, caregiver for aunt with melanoma



Frank was diagnosed with melanoma. His wife, Colleen, has been his caregiver.

“When we went to a support group, we met people who didn’t know they could get a second opinion. Most people in the support group were shocked we had done that. People think doctors are the end all, be all. We tell everyone to get a second opinion.”

— Frank and Colleen

Your Cancer Journey

A stage III melanoma diagnosis means you will need to find a way to both live your life to the fullest extent possible while also being aware that you are at higher risk for recurrence. This requires learning how to live with and alongside worry, rather than having worry rule your day-to-day experiences.

Because of your high risk for recurrence, you will need to receive ongoing follow-up care that includes a skin examination, physical examination, imaging tests

and, possibly, a brain MRI, though it is important to note there is no one standard schedule or plan for all to follow. This means it also is important that you have a care plan. We worked with advocates who attended the Summit to develop a care plan specifically for those with stage III melanoma. You can find the care plan on page eleven of this guide. It can also be downloaded from the Cancer Support Community website.

FOLLOW-UP CARE

Part of living with stage III melanoma includes routine follow-up care. After treatment, all patients should regularly receive a physical examination, including a skin examination. Your doctor may also recommend regular chest x-rays, CT scans of the trunk and pelvis, and brain MRI. These types of imaging tests are generally not recommended after five years if there has been no recurrence and no symptoms. Having an established relationship with a dermatologist who sees melanoma patients can be beneficial, as it typically will allow you to be seen within a week of spotting a worrisome lesion.

The National Comprehensive Cancer Network's patient guidelines recommend these follow-up tests:

- Complete skin exam every year for life
- Regular self-exam of skin and lymph nodes
- Medical history and physical exam with focus on skin and lymph nodes
 - Every three to six months for two years, then
 - Every three to twelve months for three years, then
 - Every year as needed.
- Possible regional lymph node ultrasound
- Imaging tests for specific symptoms
- Possible chest x-ray, CT, PET/CT scans every four to twelve months to screen for recurrence or metastases, and
- Possible brain MRI each year

For more information: www.nccn.org

Credit: National Comprehensive Cancer Network Guidelines for Patients



“Don’t Google. Don’t focus on numbers. Ask questions. Learn about melanoma. That knowledge is power, and it will give you power over your cancer.”

—Kim, living with melanoma

Self-Advocacy: Helping and Educating Others

Many people living with melanoma say their self-advocacy began when they realized how little they—and their friends and family—knew about melanoma prior to their diagnosis. This experience often made them want to get involved in efforts that would help others with melanoma prepare for their own cancer journey.

There are many different ways you can be involved in this type of advocacy.

What might you do? Pete Daly, a 13-year melanoma survivor who works at the Center for Patient Partnerships at the University of Wisconsin, Madison, shares this advice, “Choose something that will feed you in a certain way. This is not about being altruistic. It’s about what will put you on a healing path. Do what feeds your heart.”

Some of the work melanoma advocates can do includes:

- Blog about your experience or communicate with other people living with melanoma on Facebook groups or message boards.
- Increase awareness about the dangers of tanning beds and sun exposure and advocate for sun shelters at schools and parks.
- Ensure support programs are available for caregivers.
- Increase melanoma awareness among African-American, Latino and Asian communities.
- Stress the importance of self-advocacy to other patients and caregivers.

LOOK TO TRUSTED ORGANIZATIONS & WEBSITES

You—as well as your family members and friends—are probably going to want to learn as much about melanoma as possible. You will probably ask your doctors a lot of questions. You are also likely to look to the Internet for additional information. However, many melanoma patients and survivors advise against doing “too much Googling”—and for good reason. It can send you down a path that leads to outdated or incorrect information (often anything written before 2011). It can also cause you to go into a “tailspin” of too much information. So use the Internet, but use it wisely.

The Cancer Support Community (CSC) offers a number of online, print and in-person resources that can help you and your loved ones understand your treatment options, manage side effects, deal with emotions and connect with others affected by melanoma. Turn to the back page of this publication to see a listing of these services, as well as other trusted organizations that focus specifically on melanoma. CSC and many of these organizations also have forums or message boards, where you can seek support online from others who have a similar diagnosis or have had similar treatments. You can learn from their experiences and, in turn, others will learn from you.

OTHER TRUSTED ONLINE RESOURCES

List of Cancer Centers that Specialize in Melanoma Treatment

AIM at Melanoma’s List of Melanoma Specialists

www.aimatmelanoma.org/living-with-melanoma/find-a-melanoma-specialist/

Compiled by the Melanoma International Foundation:

www.melanomainternational.org/web-resources/cancer-centers/#.VmHkBmSrScY/

INFORMATION ABOUT MELANOMA CLINICAL TRIALS

Melanoma Research Foundation’s Clinical Trials Finder:

www.melanoma.org/understand-melanoma/melanoma-treatment/clinicaltrials

Centerwatch’s Melanoma Clinical Trials Listing:

www.centerwatch.com/clinical-trials/listings/condition/723/metastatic-melanoma

National Cancer Institute:

www.cancer.gov/about-cancer/treatment/clinical-trials

National Institute of Health’s Clinical Research Studies Search:

www.clinicalstudies.info.nih.gov



“I think your purpose evolves as your experience changes. This is a chronic illness. It doesn’t go away, and there is no end. My story comes up in daily life and there are people close to me who don’t want to hear my story anymore. Others want to move on. I’m not on treatment anymore, but they don’t understand that physically and emotionally I am not the same person I was before.”

—Lilly, melanoma survivor

Stage III Melanoma Care Plan

What's a care plan? It's a roadmap to guide your cancer care following your diagnosis of stage III melanoma. Your care plan should:

- Summarize your diagnosis
- Provide information about the treatments you have had or are currently taking
- Tell you the best person on your medical team to contact with questions or concerns
- Provide information about symptoms or side effects you might experience and who you should call if you need help managing them
- Explain what type of follow-up care you should receive and who will be providing it

Some people ask their doctor to complete their care plan. Some fill it out with their doctor. And some choose to fill it out on their own and then ask their doctor to review it. You should do what feels most comfortable for you.

When you discuss your care plan with your doctor, you may want to think of yourself as both a patient and a self-advocate. This can include asking questions such as:

- Do I understand everything on my treatment summary and care plan?
- Is there anything I want to add to my care plan?
- Was I told all my treatment options?
- Have I asked about clinical trials?
- Have I talked to my doctor about my treatment goals?
- Have I talked to my doctor about my concerns?
- Do I know what my treatment will cost and how I will pay for it?
- Do I need to get information on pharmaceutical assistance programs?
- Do I want to get a second opinion before starting treatment?
- Do I know who I will call if I develop symptoms and side effects?
- Is there anything else I need?

Additional Information and Support:

[CANCER SUPPORT COMMUNITY](http://www.cancersupportcommunity.org) www.cancersupportcommunity.org

[AIM AT MELANOMA](http://www.aimatmelanoma.org) www.aimatmelanoma.org

[AMERICAN MELANOMA FOUNDATION](http://www.melanomafoundation.org) www.melanomafoundation.org

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

[MELANOMA RESEARCH FOUNDATION](http://www.melanoma.org) www.melanoma.org

[MELANOMA INTERNATIONAL FOUNDATION](http://www.melanomainternational.org) www.melanomainternational.org

Support for My Caregiver:

[CANCER SUPPORT COMMUNITY](http://www.cancersupportcommunity.org) www.cancersupportcommunity.org

[CAREGIVER ACTION NETWORK](http://www.caregiveraction.org) www.caregiveraction.org

[NATIONAL ALLIANCE FOR CAREGIVING](http://www.caregiving.org) www.caregiving.org

[FAMILY CAREGIVER ALLIANCE](http://www.caregiver.org) www.caregiver.org

Stage III Melanoma Treatment Summary and Care Plan

GENERAL INFORMATION

Patient Name: _____ Patient DOB: _____

Patient Phone: _____ Email: _____

HEALTH CARE PROVIDERS (INCLUDING NAMES, INSTITUTION)

Primary Care Provider: _____

Surgeon: _____

Medical Oncologist: _____

Oncology Nurse: _____

Dermatologist: _____

Palliative Care Team: _____

Hospital Social Worker: _____

Pathologist: _____ Additional Care Providers: _____

Stage: IIIA IIIB IIIC

Diagnosis Date: _____

Resected (all known tumor removed) Unresectable (not all tumor removed) being treated as stage IV

TREATMENT

Surgery Yes No Surgery Date(s) (year): _____

Surgical procedure/location/findings, including sentinel lymph node biopsy results: _____

Radiation: Yes No Body area treated: _____ End Date (year): _____

Additional Notes About Surgery and Radiation: _____

SYSTEMIC TREATMENTS: TARGETED THERAPY AND IMMUNOTHERAPY

Names of Treatments Used and, if applicable, Clinical Trial Number	Start and End Dates

FAMILIAL CANCER RISK ASSESSMENT

Genetic/hereditary risk factor(s) or predisposing conditions: _____

Plan for patient's family members: _____

ONGOING CARE PLAN

Please continue to see your primary care provider for all general health care recommended for a person your age, including screening tests for other cancers such as breast, colorectal, prostate, and lung cancers.

SCHEDULE OF CLINICAL VISITS

Coordinating Provider	How often

CANCER SURVEILLANCE OR OTHER RECOMMENDED RELATED TESTS

Coordinating Provider	How often

Cancer and its treatments can cause symptoms and side effects. If you experience any symptoms or side effects, the first doctor you should contact is: _____

All cancer treatments may have associated late- and long-term side effects. The side effects that are most commonly associated with the drugs you are on include:

Name of Drug: _____

Common Side Effects: _____

Name of Drug: _____

Common Side Effects: _____

Additional Information: _____

Symptoms and Side Effects You Are Currently Experiencing: _____

Have you discussed these symptoms and side effects with a palliative care specialist? Yes No

Cancer can affect many aspects of your life. If you have any concerns in these or other areas, please speak with your doctors or nurses to find out how you can get help with them. Emotional and mental health Fatigue Weight changes Stopping smoking Physical Functioning Insurance School/Work Fertility Financial advice or assistance Memory or concentration loss Parenting Sexual functioning Body Image

A number of lifestyle/behaviors can affect your ongoing health. Some topics you may want to discuss with your doctor or nurse include: Tobacco use/cessation Diet Alcohol use Stress management Sun exposure and sunscreen use Weight management (loss/gain) Physical activity

Prepared by: _____ Delivered on: _____

My Notes: _____

Your Cancer Journey: A stage III melanoma diagnosis means you will need to find a way to both live your life to the fullest possible while also being aware that you are at high risk for recurrence. This requires learning how to live with and alongside worry, rather than having worry rule your day-to-day experiences.



“When I was diagnosed I thought you would get skin cancer and then cut it out. I didn’t know what melanoma was. I didn’t know it could spread or go to your organs. And my friends didn’t know that either. My goal is to spread awareness.”

—Carla, melanoma survivor

Melanoma Information, Survivorship & Support

AIM at Melanoma 877-246-2635 www.aimatmelanoma.org

American Melanoma Foundation 619-448-0991 www.melanomafoundation.org

Cancer Support Community 888-793-9355 www.cancersupportcommunity.org

Melanoma Research Alliance 202-336-8935 www.curemelanoma.org

Melanoma Research Foundation 800-673-1290 www.melanoma.org

Melanoma International Foundation 866-463-6663 www.melanomainternational.org

National Institutes of Health 301-496-4000 www.cancer.gov

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

CANCER SUPPORT HELPLINE ®

Whether you are newly diagnosed with cancer, a longtime cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you Mon-Fri 9 am- 9 pm ET.

OPEN TO OPTIONS ®

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor.

FRANKLY SPEAKING ABOUT CANCER ®

CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

AFFILIATE NETWORK SERVICES

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

CANCER EXPERIENCE REGISTRY®

The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

THE LIVING ROOM, ONLINE

Here you will find support and connection with others on discussion boards, a special space for teens, and personal web pages to keep your family and friends up-to-date.

The Cancer Support Community 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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