Just Diagnosed With Melanoma... Now What?
Introduction

If you are reading this, you have undergone a biopsy (either of a skin lesion or a lymph node) or have had other tests in which the diagnosis of melanoma is confirmed.

Melanoma is a type of skin cancer that occurs in the cells that color the skin and make moles (melanocytes). Melanoma is the most serious type of skin cancer because it can spread to lymph nodes or a distant site.

Of all the various skin cancers, melanoma is known to be the most deadly if not caught in its earliest phases. Approximately 59,940 people will be diagnosed with invasive melanoma and 8,100 will die this year from melanoma.

So what do you do if you have just been diagnosed with melanoma? First — take a breath… and read the following…

Understanding Melanoma as a Disease

1. You have been given a diagnosis — not a death sentence.
2. Melanoma survival statistics describe a group of similar patients… but they may have nothing to do with your chance of survival.
3. Often for melanoma treatment, there is no single answer.
4. It is important to be an active participant in your treatment (not a passive recipient).

The “phases” that most melanoma patients seem to go through are Discovery, Diagnosis and finally Treatment. These phases are very closely linked to physician visits when the information about melanoma diagnosis and treatment is shared with the patient. While melanoma treatment is fairly straightforward, more advanced stages of melanoma require more physician and patient interaction, especially in the Diagnosis and Treatment phases.

Important Questions to Ask Your Physician

• Why do you think I have melanoma?
• Has my stage of melanoma been determined?
• Do I need more tests to determine my stage?
• If I need more tests, what tests are they?
Once diagnosed with melanoma, your dermatologist will need to find out more about your disease. He/She may order additional tests or refer you to a medical or surgical oncologist for further evaluation. This process is called Staging. Staging includes more thoroughly evaluating the original tumor as well as other areas of your body for melanoma. Staging the melanoma is a very important step because the choice of treatment is determined by this information.

Additional surgery may be required to remove the entire tumor with normal tissue surrounding it. Additionally, depending on the melanoma’s thickness or its level of invasion, lymph nodes may also be evaluated for involvement through a sentinel lymph node biopsy.

Other tests may also play a role in staging. These include:

- **Blood Work**: Non-specific indicator that melanoma may be involved in several organ systems.
- **Bone Scan**: Uses radioactive material to find if there is any bone involvement with your melanoma.
- **CT Scan**: Looks for melanoma in other organs of the body such as: abdomen (bowel and liver), chest (lungs and lymph nodes), neck, and head.
- **MRI Scan**: Used primarily to determine if the brain has any melanoma involvement.
- **PET Scan**: Looks for “metabolically active” areas in the body which may be melanoma.

**Staging Melanoma**

Staging is the process of figuring out exactly what the cancer is doing. Oncologists (doctors who specialize in cancer) consider three things when staging melanoma:

1. **The thickness of the tumor**, referred to as the Breslow Thickness, which is reported in your pathology report.
2. **Whether the tumor is ulcerated (cracked or bleeding)**
3. **If, and how far, it has spread. In general:**
   - Thicker tumors are more serious than thin tumors
   - Ulcerated tumors are more serious than non-ulcerated ones, even if they are thinner
   - Tumors that have spread to the lymph nodes are more serious than tumors that have not spread

**Important Tip #1**

As it is most likely that you have been in some shock given the discovery of melanoma, it is important to bring another person with you to take notes on what is said or suggested during your physician visits. These can then be reviewed after the visit.

**Important Questions to Ask Your Physician**

- What is my stage of melanoma and what does that mean?
- Given my stage of melanoma, what are you recommending my first treatment or surgery be?
- Will my surgery/medical treatment be done here or at another center?
**Why Do You Need to Know Your Melanoma Stage?**

- It determines if you need a surgical approach to your melanoma.
- It determines if you need further testing during your surgery (sentinel node biopsy).
- It determines if you will need adjuvant therapy after surgery.
- It determines if surgery is not indicated and other therapies (gamma knife, bio-chemotherapy, etc.) are needed in the place of surgery.

### Important Tip #2

Before starting any surgical or treatment plans (and especially in more advanced cases in which treatments may be more controversial), you need to understand your diagnosis and all the various options for your stage of melanoma. In other words, before you undergo any treatment, you need to do your homework and understand your options before deciding with your physician what the plan for your melanoma treatment will be.

### Staging Classifications

<table>
<thead>
<tr>
<th>Stage</th>
<th>What It Means</th>
<th>Treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA</td>
<td>The tumor is less than 1 millimeter thick. The outer layer of skin does not look cracked or scraped (ulcerated). It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Usually no further treatment is necessary.</td>
</tr>
<tr>
<td>IB</td>
<td>The tumor is either less than 1 millimeter thick and ulcerated, or 1–2 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Usually no other treatment is necessary.</td>
</tr>
<tr>
<td>IIA</td>
<td>The tumor is either 1–2 millimeters thick and ulcerated, or 2–4 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Immunotherapy may be given in cases of thicker tumors.</td>
</tr>
<tr>
<td>IIB</td>
<td>The tumor is either 2–4 millimeters thick and ulcerated, or more than 4 millimeters thick and not ulcerated. It has not spread to any lymph nodes or other organs.</td>
<td>The tumor and some surrounding tissue are removed surgically. Immunotherapy may be given.</td>
</tr>
<tr>
<td>IIC</td>
<td>The tumor is more than 4 millimeters thick and is ulcerated. These are aggressive tumors that are very likely to spread.</td>
<td>The tumor and some surrounding tissue are removed surgically. Immunotherapy may be given.</td>
</tr>
<tr>
<td>IIIA</td>
<td>The tumor may be any thickness. It may or may not be ulcerated. The cancer cells have spread either to a few nearby lymph nodes, or to some tissue just outside the tumor but not to the lymph nodes.</td>
<td>The tumor and lymph nodes that have cancer cells are removed surgically. Immunotherapy may be given.</td>
</tr>
<tr>
<td>IIIB</td>
<td>The cancer cells have spread to the lymph nodes, other organs in the body, or areas far from the original site of the tumor. This is called metastatic melanoma.</td>
<td>The tumor and lymph nodes that have cancer cells are removed surgically. Radiation therapy, chemotherapy, or immunotherapy may be given to relieve symptoms.</td>
</tr>
<tr>
<td>IIC</td>
<td></td>
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</tbody>
</table>

*Note: 1 millimeter = 1/25 of an inch
Clinical trials are also a treatment option.*
How to Approach and Organize the Information You Obtain

• Make a list of the various treatment options for your stage of melanoma.
• Compare/contrast how the large melanoma centers treat your stage of disease.
• Look for consensus in their treatment options.
• Determine how the various treatment options could affect your life (i.e., determine side effects of treatment, the effect on family, work, lifestyle you are used to).
• Make a “wish list” based on the information and decisions you have reviewed and made:
  — Your ideal treatment plan (medical/surgical and length)
  — Your ideal place the treatment will take place
  — Your ideal follow up
  — Your ideal outcome

Prepare this and your list of questions for your doctor and take to the appointment with you. As this appointment may require more time than a normal routine visit, be sure the doctor has allowed ample time for the consultation.

Before Treatment Ask Your Doctor

• Do you (or your group) operate on or manage a large number of melanoma patients?
• Will you personally be managing my care or will I be followed by residents/fellows? (Post-graduate doctors in training)
• If you do not have a large experience in melanoma patients, whom do you recommend, or what center will you send me to?
• Are there any alternative surgeries/medical treatments that could be considered besides the one you are offering or suggesting? What is your rationale for the prescribed treatment?
• Should I consider getting a second opinion if the surgery/treatment is complex or controversial?
• Are clinical trials the only option for my stage of melanoma?

Important Questions to Ask Your Physician

• What seems to be the “consensus” for treatment for your stage of melanoma among physicians and patients — excision, sentinel node biopsy, lymph node removal, etc.?
• What seems to be “controversial” for your stage of melanoma — no therapy, adjuvant therapy, radiation, bio-chemotherapy, etc.?
• How do the major melanoma centers approach your stage of disease?
• What is their “rationale” for their suggested therapy?
• Are clinical trials the only options for your stage of melanoma?*

* This may apply primarily to advanced stage patients who have already undergone surgery/therapies and are having a recurrence of melanoma.
Possible Outcomes from Your Doctor Visits

• Agree on treatment and plan for your therapy.
• Disagree on treatment and plan.
• Ask about second opinions.
• Obtain information from your physician about other resources or major melanoma centers.
• If you are concerned or continue to have questions, visit www.mpip.org to post your concerns.

Finally…

This is not an all-inclusive method for determining your stage of melanoma or the “right” treatment. However, this information can be helpful for the newly diagnosed “now what?” patient. The hope is that by giving overwhelmed and frightened melanoma patients an approach to finding information about their disease and treatment options, they will become an empowered and active participant in their diagnosis and treatment.

For More Information

• Melanoma Research Foundation
  www.melanoma.org
• MRF Patient Information Page
  www.mpip.org

MRF has several email addresses set up to handle various specific functions:
education@melanoma.org
To learn about educational programs.
info@melanoma.org
For general information about melanoma and its treatment.
volunteer@melanoma.org
To learn about volunteer activities.
fund@melanoma.org
To learn about how to contribute needed funds, and/or participate in our fundraising campaign.
research@melanoma.org
To learn about how to apply for MRF-sponsored research grants.
mrf@melanoma.org
To communicate with the MRF staff.

Information in the preceding pages has been adapted from a Melanoma Research Foundation (MRF) mini-symposium discussion, “How to Make Good Choices from Bad Options,” by Casey Culbertson, MD, former MRF Chair and Stage III melanoma patient.