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NCCN Guidelines for Patients®

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NCCN NON-HODGKIN'S LYMPHOMAS SERIES

# Mycosis Fungoides



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# Mycosis Fungoides

Learning that you have cancer can be overwhelming. The goal of this book is to help you get the best cancer treatment. It explains which cancer tests and treatments are recommended by experts of mycosis fungoides.

The National Comprehensive Cancer Network® (NCCN®) is a not-for-profit alliance of 27 of the world's leading cancer centers. Experts from NCCN have written treatment guidelines for doctors who treat mycosis fungoides. These treatment guidelines suggest what the best practice is for cancer care. The information in this patient book is based on the guidelines written for doctors.

This book focuses on the treatment of mycosis fungoides. Key points of the book are summarized in the related **NCCN Quick Guide™**. NCCN also offers patient resources on peripheral T-cell lymphoma, diffuse large B-cell lymphoma, chronic lymphocytic leukemia, and other cancer types. Visit [NCCN.org/patients](http://NCCN.org/patients) for the full library of patient books, summaries, and other resources.

# Credits

NCCN aims to improve the care given to patients with cancer. NCCN staff work with experts to create helpful programs and resources for many stakeholders. Stakeholders include health providers, patients, businesses, and others. One resource is the series of books for patients called the NCCN Guidelines for Patients®. Each book presents the best practice for a type of cancer. The patient books are based on clinical practice guidelines written for cancer doctors. These guidelines are called the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). Clinical practice guidelines list the best health care options for groups of patients. Many doctors use them to help plan cancer treatment for their patients. Panels of experts create the NCCN Guidelines®. Most of the experts are from NCCN Member Institutions. Panelists may include surgeons, radiation oncologists, medical oncologists, and patient advocates. Recommendations in the NCCN Guidelines are based on clinical trials and the experience of the panelists. The NCCN Guidelines are updated at least once a year. When funded, the patient books are updated to reflect the most recent version of the NCCN Guidelines for doctors. For more information about the NCCN Guidelines, visit [NCCN.org/clinical.asp](http://NCCN.org/clinical.asp).

NCCN staff involved in making the guidelines for patients and doctors include:

## **NCCN Guidelines for Patients**

Dorothy A. Shead, MS  
*Director*  
*Patient and Clinical Information Operations*

Laura J. Hanisch, PsyD  
*Medical Writer/Patient Information Specialist*

Lacey Marlow  
*Associate Medical Writer*

## **NCCN Guidelines**

Mary Dwyer, MS  
*Senior Manager, Guidelines*

Hema Sundar, PhD  
*Oncology Scientist/Senior Medical Writer*

Rachael Clarke  
*Guidelines Data and Layout Coordinator*

## **NCCN Marketing**

Susan Kidney  
*Graphic Design Specialist*

## **Endorsed by**

### **THE LEUKEMIA & LYMPHOMA SOCIETY (LLS)**

LLS is dedicated to developing better outcomes for blood cancer patients through research, education and patient services and is happy to have this comprehensive resource available to patients with mycosis fungoides.

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## **Supported by NCCN Foundation®**



The NCCN Foundation supports the mission of the National Comprehensive Cancer Network® (NCCN®) to improve the care of patients with cancer. One of its aims is to raise funds to create a library of books for patients. Learn more about the NCCN Foundation at [NCCN.org/foundation](http://NCCN.org/foundation).

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National Comprehensive Cancer Network (NCCN)  
275 Commerce Drive • Suite 300  
Fort Washington, PA 19034  
215.690.0300

# Mycosis Fungoides

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## Who should read this book?

The focus of this book is mycosis fungoides. Mycosis fungoides is the most common type of lymphoma of the skin. Although related, the book does not address care for Sézary syndrome. People with mycosis fungoides and those who support them—caregivers, family, and friends—may find this book helpful. It may help you discuss and decide with doctors what care is best.

## Where should I start reading?

Starting with Part 1 may be helpful. It explains what mycosis fungoides is and how it is diagnosed. Parts 2 through 5 address issues related to treatment. Part 2 lists what health care is needed before treatment. Part 3 briefly describes all the types of treatments so you can understand your options that are listed in Part 4. Tips for making treatment decisions are presented in Part 5.

## Does the whole book apply to me?

This book includes information for many situations. Your treatment team can help. They can point out what information applies to you. They can also give you more information. As you read through this book, you may find it helpful to make a list of questions to ask your doctors.

The recommendations in this book are based on science and the experience of NCCN experts. However, these recommendations may not be right for you. Your doctors may suggest other tests and treatments based on your health and other factors. If other recommendations are given, feel free to ask your treatment team questions.

## Making sense of medical terms

In this book, many medical words are included. These are words that you will likely hear from your treatment team. Most of these words may be new to you, and it may be a lot to learn.

Don't be discouraged as you read. Keep reading and review the information. Don't be shy to ask your treatment team to explain a word or phrase that you do not understand.

Words that you may not know are defined in the text or in the *Dictionary*. Words in the *Dictionary* are underlined when first used on a page.

Acronyms are also defined when first used and in the *Glossary*. Acronyms are short words formed from the first letters of several words. One example is **DNA** for **deoxyribonucleic acid**.

# Mycosis fungoides basics



# 1 Mycosis fungoides basics

6 What is the lymphatic system?

8 What is mycosis fungoides?

10 Do I have mycosis fungoides?

14 Review



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You've learned that you have or may have mycosis fungoides. It's common to feel shocked and confused. Part 1 reviews some basics that may help you learn about this lymphoma and start to cope. These basics may also help you start planning for treatment.

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## What is the lymphatic system?

The lymphatic system is one of 13 systems of the human body. It transports fluids to the bloodstream and fights germs. As such, it supports your blood-flowing (cardiovascular) and disease-fighting (immune) systems.

Cells are the building blocks of tissue in the body. The spaces between cells are filled with fluid. This fluid is called interstitial or tissue fluid. Most tissue fluid comes from parts of blood plasma that have passed out of blood vessels. Cells also release waste and other products into tissue fluid.

When tissue fluid increases, it drains into vessels. Almost all of tissue fluid drains back into blood vessels. The rest of it drains into lymph vessels. Once inside of lymph vessels, tissue fluid is called lymph. Lymph travels in lymph vessels back to the bloodstream.

The lymphatic system also collects fat and some vitamins from your gut. After you eat, your stomach turns food into a liquid. Then, the liquid drains into



your small intestine. Within your small intestine, fat and some vitamins are absorbed into lymph vessels. This fatty lymph, called chyle, travels in lymph vessels to the bloodstream.

As lymph travels, it will pass through and be filtered by lymph nodes. Lymph nodes are organized masses of lymphoid tissue. There are hundreds of lymph nodes throughout your body. See **Figure 1.1**. High numbers of lymph nodes exist in the middle of your chest, neck, armpit, groin, pelvis, and along your gut.

Lymph nodes and other lymphoid tissue are defined by high numbers of white blood cells called lymphocytes. Lymph also has lymphocytes.

Lymphocytes help fight germs. The three types of lymphocytes are NK (natural killer) cells, B-cells, and T-cells. Lymphocytes are made in bone marrow then are moved by blood to the lymphatic system.

Other parts of your body that have many lymphocytes are included in the lymphatic system. In children, the thymus stores T-cells until they are able to fight germs. Germs in blood are filtered and destroyed by lymphocytes within your spleen. Your tonsils kill germs in lymph that enter through your mouth and nose. There are also small clumps of lymphatic tissue in your gut, thyroid, breasts, lungs, eyes, and skin.

**Figure 1.1**  
**Lymphatic system**

The lymphatic system kills germs in the body and collects and transports lymph to the bloodstream.

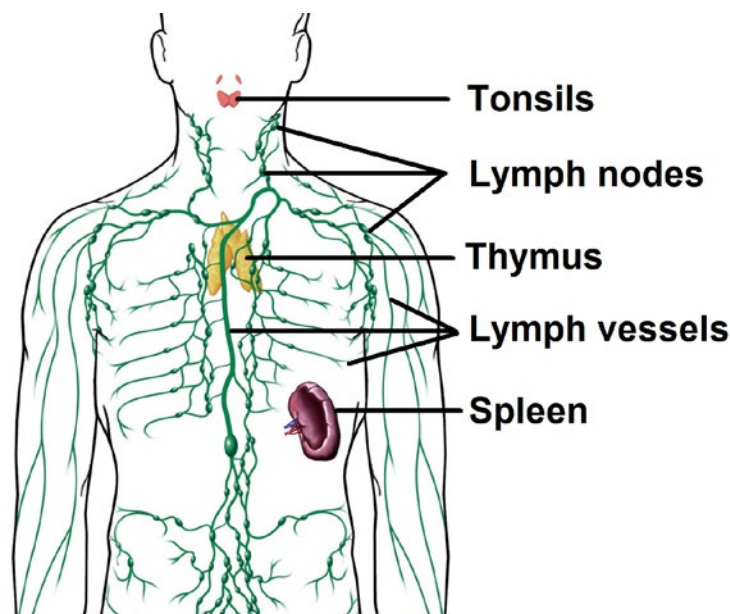


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**Figure 1.2**  
Genetic material in cells

Most human cells contain the “blueprint of life”—the plan by which our bodies are made and work. The plan is found inside of chromosomes, which are long strands of DNA that are tightly wrapped around proteins. Genes are small pieces of DNA that contain instructions for building new cells and controlling how cells behave. Humans have about 24,000 genes.

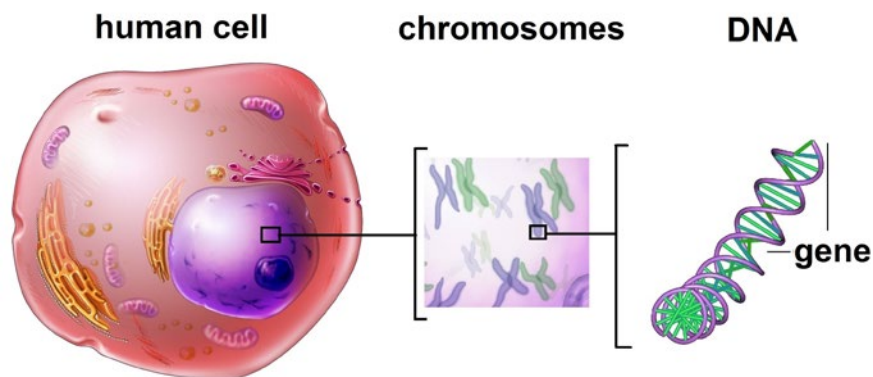


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**Figure 1.3**  
Normal cell growth vs. cancer cell growth

Normal cells increase in number when they are needed and die when old or damaged. In contrast, cancer cells quickly make new cells and live longer because of abnormal changes in genes.

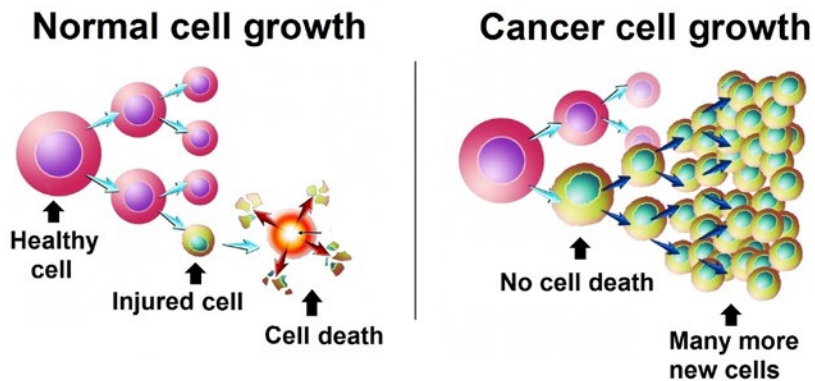


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## Do I have mycosis fungoides?

The most common sign of mycosis fungoides is skin lesions. A lesion is any type of abnormal skin. Skin lesions of mycosis fungoides may be confined to a small area of the skin or may be widespread. They may wax and wane but persist over time. Types of skin lesions include:

- **Patch** – an area of scaly skin that is flat and may be discolored,
- **Papule** – a red bump that is by a hair follicle,
- **Plaque** – a thickened patch that is raised or hard,
- **Tumor** – a firm, dome-shaped mass at least 1 cm in size, and
- **Erythroderma** – a reddening and scaling of most or all of the skin.

Skin lesions may itch, have no hair, and get infected. It is sometimes hard to tell mycosis fungoides apart from other skin conditions. It can look like psoriasis, eczema, or an allergic reaction. When your doctor suspects mycosis fungoides, testing is needed. The tests that are needed to confirm (diagnose) mycosis fungoides are described next.

### Biopsy

Samples of skin lesions must be removed from your body and be tested to diagnose mycosis fungoides. Testing of more than one lesion is very helpful for diagnosis. A biopsy is a procedure that removes tissue samples. There are multiple types of skin biopsies. Which one you will have depends on how large and where the abnormal skin is. Skin biopsies include:

- **Punch biopsies** – As shown in [Figure 1.4](#), a sharp hollow device—like a cookie cutter—is used to remove a small but deep sample of both skin layers, and
- **Shave biopsies** – A surgical knife or razor blade is used to remove the first layer of skin and part of the second layer.

Except for moisturizers, don't use skin treatments 2 to 4 weeks before the skin biopsy. Right before the biopsy, your skin will be numbed with local anesthesia. You may feel pressure during the biopsy, but no pain. Afterward, your doctor may close the wound and apply a bandage. Often, there are no side effects, but some people do get scars.

Some people may also have a biopsy of enlarged lymph nodes. A lymph node biopsy is often done when the skin biopsy results are unclear. An excisional biopsy is often the best method. This biopsy removes the entire tumor. If an excisional biopsy isn't possible, a core needle biopsy, which removes small samples with a needle, may be done.

Figure 1.4 Skin biopsy

Samples of skin lesions need to be tested to diagnose mucosis fungoides. Testing of more than one lesion is very helpful. A punch biopsy as shown here and a shave biopsy are common methods of removing skin samples.

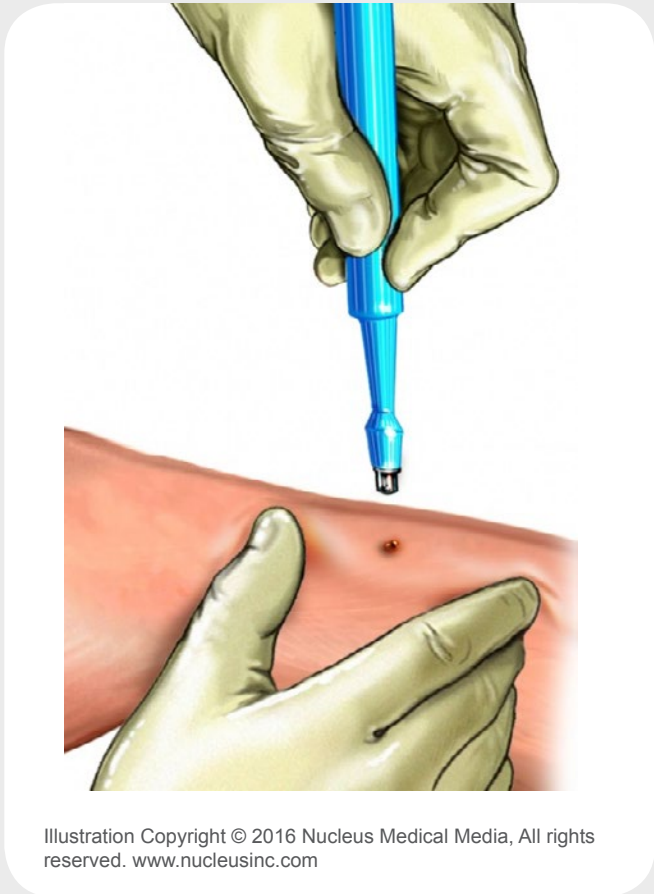


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**Pathology review**

The biopsy samples will be sent to a special type of pathologist. A pathologist is a doctor who’s an expert in testing cells to find disease. For mucosis fungoides, the pathologist should be a specialist in dermatopathology, hematopathology, or both. Dermatopathologists spend all of their time looking at skin samples, so they become very good with diagnosing skin cancers. Hematopathologists can also review the skin samples since they know blood cancers very well.

The dermatopathologist will first examine the samples using a microscope. He or she will study the cells’ shape and size and parts within the cells. A diagnosis can sometimes be made with this information.

If mucosis fungoides is present, the dermatopathologist will determine the subtype. Subtypes include folliculotropic mucosis fungoides. This lymphoma surrounds hair follicles. Another subtype is large-cell transformed mucosis fungoides. These cancer cells are at least 4 times larger than a small lymphocyte.

The results of these tests and those described next will be recorded in a pathology report. It’s a good idea to get a copy of your pathology report. It’s used to plan treatment.

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### Protein tests

At times, it may be useful to study the proteins in the cells' surface (membrane). This is called immunophenotyping. It can support or confirm the diagnosis that was made based on cell structure. An IHC (immunohistochemistry) panel is a test for surface proteins. It involves applying a chemical marker to cells then looking at them with a microscope.

The IHC panel often tests for  $\beta$ F1, CD2, CD3, CD4, CD5, CD7, CD8, CD20, CD25, CD30, CD56, granzyme B, TIA1, and TCR-C $\gamma$ M1. Mycosis fungoides cells typically have  $\beta$ F1, CD2, CD3, CD4, and CD5 but not CD7, granzyme B, and TIA1. Cells rarely have CD8. CD30 is found on at least a few cells in most cases of mycosis fungoides. However, up to half of people with large-cell transformed mycosis fungoides have many cells with CD30.

### Blood tests

If results from the skin biopsy aren't clear, your blood may be tested for Sézary cells. Your blood may also be tested if your doctor suspects Sézary syndrome. Sézary cells have one, round nucleus that is shaped like the outer surface of the brain. Healthy people may have a very small number of cells that look like Sézary cells. People with mycosis fungoides may have more. In Sézary syndrome, there is a very high number of Sézary cells in blood.

Sézary cells have a common pattern of surface proteins. Testing for this pattern is needed for diagnosis since some cells look like Sézary cells. Flow cytometry is a newer method of assessing for surface proteins and should be used to test for Sézary cells. The method first involves adding a marker—a light-sensitive dye—to cells. Then, your blood will be passed through a flow cytometry machine. The machine measures surface proteins on thousands of cells. To test for Sézary cells, flow cytometry often includes CD3, CD4, CD7, CD8, and CD26 proteins.

### Gene tests

A gene rearrangement is the fusion of one gene with another gene to create a new gene. Often, mycosis fungoides has rearrangements in the TCR (T-cell receptor) genes. PCR (polymerase chain reaction) is a test that can assess for TCR rearrangements. PCR may be done on your skin cells, blood cells, or both. This test may be helpful when cell structure and IHC results do not clearly confirm mycosis fungoides.

### HTLV tests

HTLV (human T-cell lymphotropic virus) is important for diagnosing a subtype of T-cell lymphoma. If you have HTLV, the cancer may be adult T-cell leukemia or lymphoma rather than mycosis fungoides. You will need to be tested if your doctor thinks HTLV is important for understanding your diagnosis.

Testing of HTLV is done on a blood sample. Serology is a test that looks for antibodies that target HTLV. If the results from serology are unclear, PCR can be done. PCR is a process in which copies of a part of DNA are made, which helps doctors find viruses.







## Treatment planning



# 2 Treatment planning

16	Medical history
17	Physical exam
18	Blood tests
19	Imaging tests
20	Bone and marrow test
21	Pregnancy test
22	Review



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Doctors plan treatment with many sources of information. One of these sources is tests of your health and the cancer. Part 2 describes who should receive which tests before treatment. Some of these tests are repeated during and after treatment. Besides tests, Part 2 describes other types of care that are important to receive before cancer treatment.

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## Medical history

Your medical history includes any health events and medicines you've taken in your life. You will be asked about illnesses, injuries, health conditions, and more. Some health problems run in families. Thus, your doctor may also ask about the health of your blood relatives.

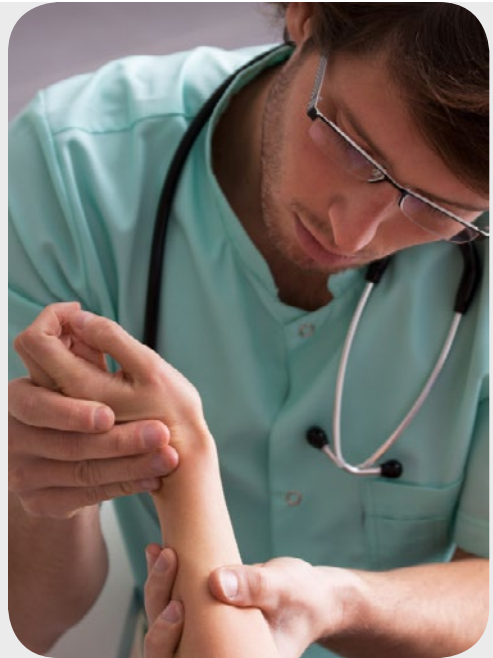
Your history of skin problems is important to obtain. People with mycosis fungoides often have had skin lesions for months to decades before being diagnosed. You may have had biopsies that didn't find any cancer. As such, you may have been told that the scaly skin patches are eczema, psoriasis, or parapsoriasis en plaque. Sometimes doctors are unsure of the type of skin disease (unspecified dermatoses).

A medical history is one of the tests needed for treatment planning. **See Chart 2.1** for a complete list of care that is recommended prior to treatment. Some types of care are for anyone with mycosis fungoides while others may be useful for some people.

## Physical exam

Doctors should perform a physical exam along with taking a medical history. A physical exam is a study of your body for signs of disease. During this exam, your doctor will listen to your lungs, heart, and gut. Parts of your body will likely be felt to see if organs are of normal size, are soft or hard, or cause pain when touched.

For mycosis fungoides, a skin exam of your total body is needed. While mycosis fungoides is often confined to the torso, this exam includes areas like your scalp, between your legs, and toe webs. Your doctor will note the type of skin lesions and assess how much of your skin has lesions. He or she will also assess if any lymph nodes or other organs are enlarged.



**Chart 2.1 Care before treatment**

Must haves	Sometimes useful
• Medical history	• Neck CT
• Physical exam with total body skin exam	• Bone marrow biopsy
• Complete blood count	• Biopsy of lymph nodes or other sites
• Comprehensive metabolic panel	• Repeat skin biopsy
• Lactate dehydrogenase	
• Diagnostic CT or whole body PET/CT based on skin, blood, and lymph node results	
• Pregnancy test if you can have babies	

## Blood tests

In Part 1, blood tests that may be useful for diagnosis are explained. In brief, your blood may be tested for Sézary cells if the skin biopsy is not clear. Also, flow cytometry may be used to assess for surface proteins common to Sézary cells. PCR to test for TCR rearrangements in blood cells may also be done. If these blood tests weren't done for diagnosis, they are advised for treatment planning. Other common blood tests for mycosis fungoides are:

### Complete blood count

A CBC (complete blood count) measures the number of blood cells in a blood sample. It includes numbers of white blood cells, red blood cells, and platelets. Your blood counts may be low or high because of cancer or another health problem. It is an essential test that gives a picture of your overall health.

### Comprehensive metabolic panel

Chemicals in your blood come from your liver, bone, and other organs. A comprehensive metabolic panel often includes tests for up to 14 chemicals. The tests show if the level of chemicals is too low or high. Abnormal levels can be caused by cancer or other health problems.



### Lactate dehydrogenase

Lactate dehydrogenase is a protein that is in most cells. It gets into your blood when a cell is damaged. Thus, a high level of lactate dehydrogenase is a sign of cell damage. High levels can be caused by cancer or other health problems. If related to cancer, high levels may be a sign that the cancer is widespread.

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## Imaging tests

Imaging tests make pictures (images) of the insides of your body. They can show which sites have cancer. This information helps your doctors stage the cancer. More information on cancer staging is in Part 4. Not everyone with mycosis fungoides needs an imaging test. Imaging is advised for people with significant skin lesions, large-cell transformed subtype, folliculotropic subtype, enlarged lymph nodes, or abnormal blood tests.

Your treatment team will tell you how to prepare for the test. You may need to stop taking some medicines and stop eating and drinking for a few hours before the scan. Tell your doctors if you get nervous when in small spaces. You may be given a sedative to help you relax.

Imaging machines are large. You will likely be lying down during testing. At least part of your body will be in the machine. A picture of one type of an imaging machine is shown in **Figure 2.1**.

After the test, you will likely be able to resume your activities right away. If you took a sedative, you will have a waiting period. You may not learn of the results for a few days since a radiologist needs to review the pictures. A radiologist is a doctor who's an expert in reading x-ray images.

### Diagnostic CT

A CT (computed tomography) scan of your body may be needed. CT takes many pictures of a body part from different angles using x-rays. A computer combines the x-rays to make detailed pictures of your internal organs.

A contrast dye is often used for diagnostic CT. It makes the pictures clearer. The dye will be injected into a vein in your hand or arm. You will also be given a liquid contrast to drink to highlight your bowels.

**Figure 2.1** Computed tomography machine

**A CT machine is large and has a tunnel in the middle. During the test, you will lie on a table that moves slowly through the tunnel.**



The contrast may cause you to feel flushed or get hives. Rarely, serious allergic reactions occur. Tell your doctor and the technicians if you have had problems with contrast in the past.

### PET/CT

Another imaging test combines CT with PET (positron emission tomography). PET/CT of your whole body may be given instead of CT. It can show the presence of cancer when other tests do not.

For PET, a sugar radiotracer will be injected into your body. The radiotracer is detected with a special camera. Cancer cells appear brighter than normal cells because they use sugar more quickly. PET/CT may be done with one or two machines depending on the cancer center.

## Bone and marrow test

A bone marrow biopsy removes a sample of bone and soft bone marrow. The samples will be sent to a lab for testing. This test may be helpful if there are unexplained blood results.

Often, this test is done on the back of the hip bone. You will be injected with the same anesthetic used at the dentist office and you may receive a light sedative before the test. You may be asked to lie on your side as shown in **Figure 2.2** or lie on your belly.

Your doctor will clean your skin then give local anesthesia to numb the site. Once numb, a needle will be inserted into your bone and rotated to remove bone and soft marrow. This biopsy may cause some bone pain and can bruise your skin for a few days.

**Figure 2.2 Bone marrow biopsy**

Doctors use a bone marrow biopsy to remove a sample of bone and marrow for testing.

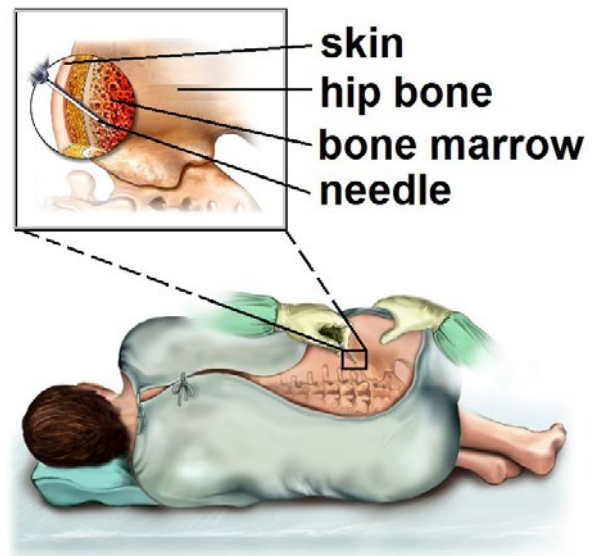


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## Review

- A medical history is a report of all health events in your lifetime.
- Your doctor will examine your body for signs of disease. He or she will check how much of your skin has lesions, the type of lesions present, and the size of your lymph nodes and organs.
- Blood tests can be done to assess for Sézary cells, how widespread the cancer may be, and for other health conditions.
- Imaging tests allow your doctors to see inside your body without cutting into it. Diagnostic CT or whole body PET/CT may be needed for treatment planning.
- A bone marrow biopsy removes a piece of bone and marrow to test for cancer cells. This test may help toward planning treatment for some people.
- If you may be pregnant now, get a pregnancy test since some cancer treatments can harm unborn babies.

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# Overview of cancer treatments





## Steroids

Corticosteroids are called steroids for short. They are a type of drug that is often used to relieve inflammation. They also are toxic to lymphocytes and therefore have anti-cancer effects in lymphoma.

Some steroids are applied directly to skin lesions. They are known as “topical” treatments. Other steroids are pills or liquids that can treat cancer anywhere in the body. Doctors use the term “systemic” when talking about a cancer treatment that is absorbed into and spreads throughout the body. Systemic steroids are a part of some chemotherapy regimens.

Side effects are unhealthy or unpleasant physical or emotional responses to treatment. Most side effects of steroids fade away once the drugs are stopped. Common side effects of systemic steroids include feeling hungry, trouble sleeping, mood changes, slow wound healing, upset stomach, high blood sugar, weight gain, and swelling in the ankles, feet, and hands. Long-term use may cause thinning of the skin, stretch marks, or both. These side effects are more likely with more powerful steroids.

## Retinoids

Retinoids are mostly known as treatments for acne. However, they also stop some types of cancer cells from growing. How they work isn't well known. Retinoids enter cells and bind to retinoic receptors. Retinoic receptors help to manage the life cycle of cells.

Some retinoids are applied directly to skin lesions. Bexarotene gel and tazarotene are topical treatments. Other retinoids are made as pills and treat mycosis fungoides anywhere in the body. Acitretin, bexarotene, isotretinoin, and tretinoin are oral retinoids. Bexarotene is the only one approved by the U.S. FDA (**F**ood and **D**rug **A**dministration) for treating mycosis fungoides.

Most side effects of retinoids fade away once the drugs are stopped. Common side effects include high levels of fatty acids in blood (hyperlipidemia) and low levels of thyroid hormones (hypothyroidism). You may also develop dry skin, muscle and joint pain, headaches, bad night vision, and light sensitivity. Retinoids may cause severe harm to unborn babies and should never be used by pregnant women.

## HDAC inhibitors

DNA is tightly wrapped around proteins called histones to form chromosomes. HDAC (histone **de**acetylase) removes a chemical group from histones so that DNA can wrap more tightly. HDAC inhibitors enter cells and block the action of HDAC. Blocking HDACs can turn on tumor-fighting genes that were shut off by the cancer. This can stop cell growth or lead to cell death.

HDAC inhibitors for mycosis fungoides are briefly described next. Some side effects are listed. Ask your treatment team for a full list of common and rare side effects.

### Romidepsin

Romidepsin is a liquid that will be slowly injected into your vein for about 4 hours. It is given once a week for the first 3 weeks of a 28-day cycle. Your doctor will discuss with you how many cycles are needed.

Common side effects include nausea, tiredness despite sleep (fatigue), changes in taste, and low numbers of platelets. Sometimes numbers of other blood cells drop. You may have an irregular heartbeat while taking romidepsin. Romidepsin can harm unborn babies and may decrease how well estrogen-based birth control works.

### Vorinostat

Vorinostat is a pill that is taken once a day. It should be taken with some food. Try to take this medicine at the same time each day. Common side effects include nausea, diarrhea, fatigue, fever, low numbers of platelets, and changes in taste. Vorinostat can harm unborn babies.

## Monoclonal antibodies

Monoclonal antibodies are human-made antibodies that attach to proteins on cancer cells. The monoclonal antibodies used to treat lymphomas attach to antigens. When antibodies are attached to antigens on a cell, the cell is marked to be destroyed by your immune system. Monoclonal antibodies are also used to deliver chemotherapy to specific cells. Monoclonal antibodies used for mycosis fungoides are:

### Alemtuzumab

Alemtuzumab is a monoclonal antibody that attaches to a molecule called CD52. CD52 is found on mycosis fungoides cells, healthy B-cells and T-cells, as well as other cells. Alemtuzumab is not approved by the FDA for mycosis fungoides, but often works well in treating Sézary syndrome.

Alemtuzumab is a liquid that will be slowly injected into your vein or under your skin. It may take many hours to get the full dose through your vein. Alemtuzumab is often given three times a week for 12 weeks.

Common side effects include an infusion reaction when receiving the medicine into your vein. Also, you may feel nausea, vomit, get diarrhea, and have trouble sleeping. Blood counts are often low when taking this medicine. Taking alemtuzumab will increase your chances of getting a cytomegalovirus or other infection. Lower doses are less likely to cause infections.

### Brentuximab vedotin

Brentuximab vedotin contains a monoclonal antibody that delivers chemotherapy to certain cells. On the surface of large-cell transformed mycosis fungoides cells are molecules called CD30. Brentuximab attaches to CD30 and enters lymphoma cells. Once



inside, it releases the chemotherapy. By targeting only cells with CD30 receptors, fewer normal cells are harmed. Brentuximab vedotin is not yet FDA approved for mycosis fungoides.

Brentuximab vedotin is slowly injected into a vein for about 30 minutes. It is often given every 3 weeks. The most common side effects include low blood counts, tingling in hands and feet, fatigue, nausea, diarrhea, fever, rash, hair loss, and lung infections. Rare but severe side effects include brain infection, serious disorder of skin and mucous membranes, inflammation of the pancreas, and kidney problems.

## Immunotherapy

Immunotherapy uses your immune system to help fight cancer. Immunotherapy is also called biologic therapy. There are three immunotherapies used to treat mycosis fungoides.

### Interferons

Interferon alfa and interferon gamma are molecules called cytokines. Cytokines exist naturally in your body as part of your immune system. They can also be made in the lab and be used as a cancer treatment. When used as a cancer treatment, cytokines can be given in much higher amounts than what the body makes. Cytokines will trigger your immune system to attack cancer cells.

Interferon alfa and gamma can be received as injections under the skin. Interferon alpha can also be received as an injection into a vein. They are systemic treatments that are given several times a week. Common side effects include flu-like symptoms, nausea, vomiting, not feeling hungry, depression, hair thinning, heart damage, and liver damage.

### Imiquimod

Imiquimod is a cream that is applied directly to skin lesions. It triggers the immune system to make interferon and other cytokines. How it treats mycosis fungoides is not fully known and it is not approved by the FDA for mycosis fungoides. Imiquimod can cause skin to flake and itch. It may also cause your limbs to swell.

## Chemotherapy

Chemotherapy, or “chemo,” includes drugs that disrupt the life cycle of cancer cells. Some chemotherapy drugs kill cancer cells by damaging their DNA or by disrupting the making of DNA. Other drugs interfere with cell parts that are needed for making new cells. Thus, no new cells are made to replace dying cells.

Many chemotherapy drugs work when cells are in an active growth phase. During the active growth phase, cells grow and divide to form a new cell. Chemotherapy drugs that disrupt the growth phase work well for cancer cells that are growing and dividing quickly. Other chemotherapy drugs work whether cells are in a growth or resting phase. Chemotherapy can kill both cancer and normal cells.

Some chemotherapy drugs can be applied directly to skin lesions. Mechlorethamine (nitrogen mustard) is a gel that is applied once a day. It may be used for several months.

However, most chemotherapy drugs for mycosis fungoides are not applied to the skin. Most are liquids that are slowly injected into a vein. Some are pills. Injected and oral drugs travel in your bloodstream to treat cancer throughout your body.

Injected chemotherapy is given in cycles of treatment days followed by days of rest. This allows your body to recover before the next cycle. Cycles vary in length depending on which drugs are used. Often, a cycle is 21 days long.

Chemotherapy for mycosis fungoides often consists of just one drug. When only one drug is used, it is called a single agent. Two or more drugs may be used for advanced mycosis fungoides.



### Side effects of chemotherapy

The reactions to chemotherapy differ between people. Some people have many side effects. Others have few. Some side effects can be very serious while others can be unpleasant but not serious. Most side effects appear shortly after treatment starts and will stop after treatment. However, other side effects are long-term or may appear years later.

Side effects of chemotherapy depend on many factors. These factors include the drug type, amount taken, length of treatment, and the person. In general, most side effects are caused by the death of fast-growing normal cells. These cells are found in the blood, gut, hair follicles, and mouth. Thus, common side effects of chemotherapy include low blood cell counts, not feeling hungry, nausea, vomiting, diarrhea, hair loss, and mouth sores. Lung damage may also occur at the time of treatment. Late side effects include another type of cancer, heart disease, low levels of thyroid hormones (hypothyroidism), and problems having babies (infertility).

Not all side effects of chemotherapy are listed here. Please ask your treatment team for a complete list of common and rare side effects. If a side effect bothers you, tell your treatment team. There may be ways to help you feel better. There are also ways to prevent some side effects.

## Radiation therapy

Radiation therapy consists of high-energy rays that damage DNA. This either kills the cancer cells or stops new cancer cells from being made. Radiation can also harm normal cells. As a result, treatment methods are always being improved to target the tumor more precisely.

Radiation may be used to treat skin lesions of mycosis fungoides. Either x-ray (photon) or electron forms of radiation may be used. X-rays work very well but may cause severe side effects. Most often, electron beam therapy is used to treat skin lesions. Electrons do not travel far and are less likely to harm the tissue beneath the skin. Local electron beam therapy can be used to treat up to a few lesions. Total skin electron beam therapy (TSEBT, for short) can treat widespread lesions.

### Local electron beam therapy

For local electron beam therapy, a simulation session to plan treatment is needed. During simulation, pictures of the lesions will be taken after your body is moved into the position needed for treatment. Your skin will also be marked with a felt marker. Using the pictures, your treatment team will plan the best radiation dose and best way to target the lesions.

During treatment, you will lie on a table in the same position as done for simulation. You will be wearing a hospital gown. Devices may be used to keep you from moving. These may include a mesh mask and body mold.

You will be alone while the therapists operate the machine from the nearby control room. The therapists will be able to see, hear, and speak with you. As treatment is given, you may hear noises.

Local electron beam therapy is completed in one to three weeks. Treatment is given a few times each



week. Receiving the radiation takes just minutes but your entire visit may be over an hour.

### Total skin electron beam therapy

A simulation session is not needed for total skin electron beam therapy. During treatment, you will be standing. You will stand on a platform that moves or you will have to change positions during treatment.

Skin areas that might be blocked from receiving enough radiation may be treated again. Such sites include your scalp, soles, groin area, and between skin folds. Skin folds may be spread apart with styrofoam. On some treatment days, sensitive areas may be shielded from radiation.

You will be alone while the therapists operate the machine from the nearby control room. The therapists will be able to see, hear, and speak with you. As treatment is given, you may hear noises.

Total skin electron beam therapy is completed in about 10 weeks. Treatment is often given twice a week. Receiving the radiation takes just minutes but your entire visit may be over an hour.

### Side effects of radiation

Electron beam therapy will likely affect your skin. How

much so partly depends on how often and how much radiation you receive. For local treatment, side effects depend on the treatment site. Ask your doctor if you will receive low- or high-dose treatment and what side effects you should expect.

Depending on the dose, your treated skin may look and feel as if it is sunburned. It may also become dry, sore, and feel painful when touched. Open sores may occur and may become infected. Short-term loss or thinning of your hair at the treatment site is common. Your nails may come off or stop growing for a while. You may also sweat less.

Not all side effects of radiation are listed here. Please ask your treatment team for a complete list of common and rare side effects. If a side effect bothers you, tell your treatment team. There may be ways to help you feel better. There are also ways to prevent some side effects.

## Phototherapy

Phototherapy is a treatment that uses UV (ultraviolet) radiation. UV radiation is light energy that can't be seen. Think of sunlight that can be seen versus unseen UV light from the sun that can cause sunburns. UV radiation does not travel as far as electrons and x-rays that are used in radiation therapy. UVA is long-wave light and UVB is short-wave light that is used in phototherapy.

### UVB phototherapy

UVB phototherapy is a skin treatment of mycosis fungoides. It is used to treat patches and thin plaques. Either narrowband or broadband UVB can be used, but narrowband is advised by most doctors. Narrowband consists of a 311 to 312 nm wavelength of UV radiation. Broadband consists of 290 to 320 nm wavelength.

Treatment often occurs at a dermatology office. You will stand undressed in a cabinet with fluorescent light tubes for about 30 minutes. Some parts of your body, such as your eyes, will be shielded. The dose of UVB is increased at each visit. Visits occur 3 to 5 times a week.

Skin lesions often start to fade in 20 to 40 visits. Once the lesions are gone, the number of visits will be reduced slowly then will be stopped. UVB will cause your skin to turn red. Sometimes, skin feels painful as if it got sunburned. High exposure to UVB increases the chance of getting skin cancer.

### PUVA

PUVA is a skin treatment that consists of psoralen and UVA. UVA travels deeper into the skin than UVB. Thus, PUVA damages skin more so than UVB phototherapy. PUVA is used to treat thick plaques. It is also called photochemotherapy.

About two hours before UVA exposure, you will receive psoralen. Psoralen sensitizes your skin to UVA. You may take psoralen in pill form (methoxsalen) or soak in it during a bath. To treat most of your skin, you may stand in a cabinet that has many UVA bulbs. Otherwise, there may be devices to treat smaller skin areas. Some parts of your body, such as your eyes, will be shielded. Exposure to UVA is about 30 minutes.

PUVA is given three times a week until the lesions are gone. This can take between 2 and 6 months. Once the lesions are gone, PUVA is reduced very slowly down to once every two weeks.

Shortly after treatment, your skin may look red, feel itchy and dry, and may be blistered. You may also feel nauseated. Protect your skin from the sun for at least 24 hours after treatment. Long-term side effects include cataracts. PUVA increases the chance of getting another skin cancer, especially if you received PUVA over a long period of time.



## Extracorporeal photopheresis

Extracorporeal photopheresis is a method of treating your white blood cells with PUVA outside of your body. A machine will remove some of your blood and extract from the blood some of your white blood cells. The rest of your blood will be returned to you. While in the machine, your white blood cells will be mixed with methoxypsoralen and exposed to UVA radiation. The treated white blood cells will then be returned to your body.

Extracorporeal photopheresis treats mycosis fungoides throughout the body. How it works isn't fully known. It may trigger your immune system to attack cancer cells.

Extracorporeal photopheresis is given 2 days in a row every 2 to 4 weeks for up to 6 months. The treatment process takes about 4 hours for each day of treatment. Extracorporeal photopheresis may be done with one or multiple machines depending on the cancer center.

Side effects include short-term hypotension, fast heart rate, and low numbers of red blood cells and platelets. Many people have no problems with this treatment. Drawbacks of this treatment may include long-distance travel to a treatment center and the amount of time needed to complete treatment.

## Supportive care

Supportive care doesn't aim to treat cancer but aims to improve quality of life. It is also called palliative care. It can address many needs. One example is treatment for physical and emotional symptoms. Supportive care can also help with treatment decisions as you may have more than one option. It can also help with coordination of care between health providers. Talk with your treatment team to plan the best supportive care for you.



## Stem cell transplant

Hematopoietic stem cells are cells that develop into mature blood cells. Hematopoietic stem cells and mature blood cells are made in bone marrow. Cancer or its treatment can damage or destroy the cells in bone marrow. A stem cell transplant replaces damaged or destroyed stem cells with healthy stem cells, which form new marrow and blood cells.

There are two types of stem cell transplants. Autologous stem cell transplant uses your healthy stem cells to repair bone marrow after high-dose chemotherapy. This type of transplant does not work well for mycosis fungoides and is not used.

Allogeneic stem cell transplant uses healthy blood stem cells that come from a donor. The goal of an allogeneic transplant is to create a new immune system in your body. This is done by suppressing your bone marrow and killing the cancer then transplanting healthy blood stem cells. The healthy stem cells will form new bone marrow and attack remaining cancer cells. This attack is known as the GVT (**graft-versus-tumor**) effect. On the other hand, there is a serious risk of GVHD (**graft-versus-host disease**). GVHD is when the donated cells see the cells in your body as foreign and attack them.

An allogeneic transplant may be an option after other treatments have not worked. There is no overall agreement on its role in treating mycosis fungoides. It is a complex treatment and can cause severe side effects, including death. Thus, it may not be a good treatment choice for most people with mycosis fungoides. More details on this transplant are given next.

### HLA typing

Special testing must be done to find the right donor for you. The donor and your tissue type must be a near-perfect match for this treatment to work. The

test used to check tissue type is called HLA (human leukocyte antigens) typing. A blood sample is needed to perform the test.

### Conditioning treatment

Before the transplant, you will receive treatment that will suppress your immune system allowing the donor cells to grow. This is called conditioning treatment. High-dose chemotherapy has typically been used for conditioning. Not every person can tolerate the high-dose chemotherapy before the transplant. As such, nonmyeloablative transplants have been tested. These transplants use lower doses of chemotherapy or newer methods to reduce the severity of side effects. Newer methods include total skin electron beam therapy, total lymphoid irradiation, and anti-thymocyte globulin.

### Transplanting stem cells

After chemotherapy, you will receive the healthy stem cells through a transfusion. A transfusion is a slow injection of blood products through a central line into a large vein. A central line (or central venous catheter) is a thin tube. The tube will be inserted into your skin through one cut and into your vein through a second cut. Local anesthesia is used. This process can take several hours to complete.

The transplanted stem cells will travel to your bone marrow and grow. New, healthy blood cells will form. This is called engraftment. It usually takes about 2 to 4 weeks.

Until then, you will have little or no immune defense. You may need to stay in a very clean room at the hospital. You may be given an antibiotic to prevent or treat infection. You may also be given a blood transfusion to prevent bleeding and to treat anemia. While waiting for the cells to engraft, you will likely feel tired and weak.

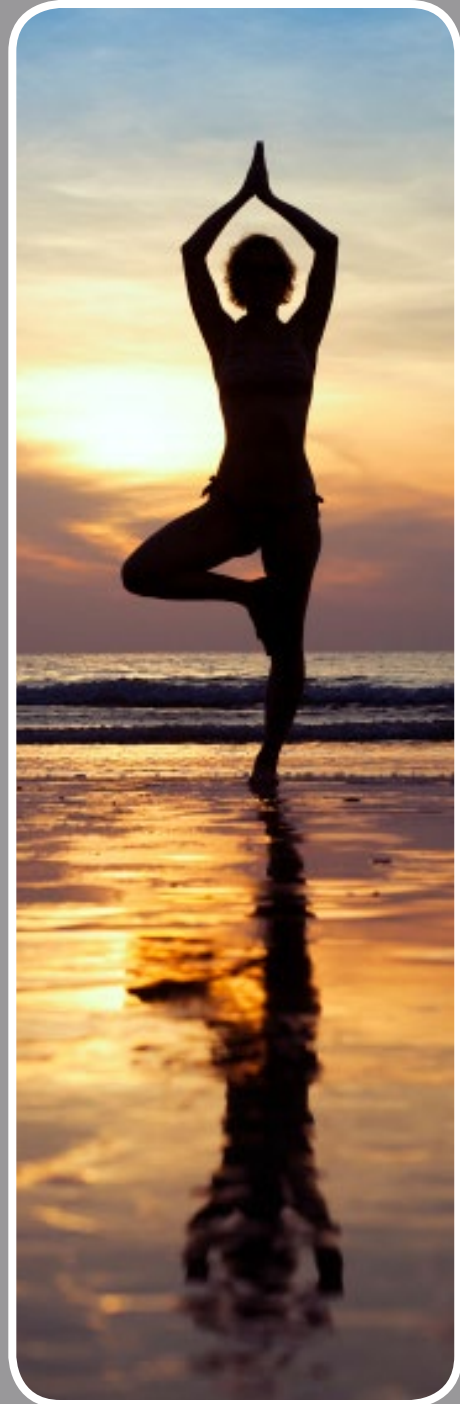
## Complementary and alternative medicine

*CAM* (complementary and alternative *medicine*) is a group of treatments that aren't often given by doctors. There is much interest today in CAM for cancer. Many CAMs are being studied to see if they are truly helpful.

Complementary medicines are treatments given along with usual medical treatments. While CAMs aren't known to kill cancer cells, they may improve your comfort and well-being. Two examples are acupuncture for pain management and yoga for relaxation.

Alternative medicine is used in place of usual medicine. Some alternative medicines are sold as cures even though they haven't been proven to work in clinical trials. If there was good proof that CAMs or other treatments cured cancer, they would be included in this book.

It is important to tell your treatment team if you are using any CAMs. They can tell you which CAMs may be helpful and which CAMs may limit how well medical treatments work.



## Clinical trials

New tests and treatments aren't offered to the public as soon as they're made. They first need to be studied. A **clinical trial** is a type of research that studies a test or treatment.

Clinical trials study how safe and helpful tests and treatments are. When found to be safe and helpful, they may become tomorrow's standard of care. Because of clinical trials, the tests and treatments in this book are now widely used to help people with mycosis fungoides. Future tests and treatments that may have better results than today's treatments will depend on clinical trials.

New tests and treatments go through a series of clinical trials to make sure they're safe and work. Without clinical trials, there is no way to know if a test or treatment is safe or helpful. Clinical trials have four phases. Some examples of the four phases to test a treatment are:

- **Phase I trials** – aim to find the best dose of a new drug with the fewest side effects.
- **Phase II trials** – assess if a drug works to treat a specific type of cancer.
- **Phase III trials** – compare a new drug to the standard treatment.
- **Phase IV trials** – test new drugs approved by the U.S. FDA (**F**ood and **D**rug **A**dministration) in many patients with different types of cancer.

Joining a clinical trial has benefits. First, you'll have access to the most current cancer care. Second, you will receive the best management of care. Third, the results of your treatment—both good and bad—will be carefully tracked. Fourth, you may help other people who will have cancer in the future.



Clinical trials have risks, too. Like any test or treatment, there may be side effects. Also, new tests or treatments may not help. Another downside may be that paperwork or more trips to the hospital may be needed.

To join a clinical trial, you must meet the conditions of the study. Patients in a clinical trial are often alike in terms of their cancer and general health. This is to know that any progress is because of the treatment and not because of differences between patients.

To join, you'll need to review and sign a paper called an informed consent form. This form describes the study in detail. The study's risks and benefits should be described and may include others than those described above.

Ask your treatment team if there is an open clinical trial that you can join. There may be clinical trials where you're getting treatment or at other treatment centers nearby. You can also find clinical trials through the websites listed in Part 5.



## Review

- Steroids have anti-cancer effects and are often applied directly to skin lesions.
- Retinoids stop some types of cancer cells from growing. Some retinoids are applied directly to the skin while others are pills that can treat cancer anywhere in the body.
- HDAC inhibitors enter cancer cells and turn genes back on to cause cell death.
- Monoclonal antibodies for mycosis fungoides attach to the lymphoma cells to 1) trigger an attack from your immune system, or 2) deliver chemotherapy.
- Immunotherapy for mycosis fungoides includes medicines that are human-made copies of molecules from your immune system. Another medicine triggers your body to make these molecules.
- Chemotherapy stops the life cycle of cancer cells.
- Electron radiation therapy treats skin lesions without much, if any, damage to underlying tissue. There are two approaches—local and total skin electron beam therapy.
- Phototherapy uses ultraviolet radiation to treat local skin lesions.
- Extracorporeal photopheresis uses ultraviolet radiation to treat cancer throughout the body.
- An allogeneic transplant suppresses your immune system then transfuses donor stem cells that will attack cancer cells.
- Clinical trials give people access to new tests and treatments that otherwise can't usually be received. These new tests and treatments may be approved, in time, by the FDA.

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## Treatment guide



# 4 Treatment guide

## 40 4.1 Stage IA treatment

Stage IA consists of lesions on less than 10% of your skin. Lesions may include patches, papules, and plaques but no skin tumors. There are no proven signs of mycosis fungoides in your lymph nodes, blood, or internal organs.

## 42 4.2 Stages IB and IIA treatment

Stage IB consists of lesions on 10% or more of your skin. Lesions may include patches, papules, and plaques but no skin tumors. There are no proven signs of mycosis fungoides in your lymph nodes, blood, or internal organs.

Stage IIA consists of lesions without tumors on 10% or more of your skin. Your lymph nodes feel enlarged, but a biopsy found no lymphoma or wasn't done. There are no proven signs of mycosis fungoides in your lymph nodes, blood, or internal organs.

## 44 4.3 Stage IIB treatment

Stage IIB consists of skin lesions with tumors. There are no proven signs of mycosis fungoides in your lymph nodes, blood, or internal organs.

## 48 4.4 Stage III treatment

Stage III consists of skin lesions involving more than 80% of the skin (erythroderma). There are no proven signs of mycosis fungoides in your lymph nodes, blood, or internal organs.

## 52 4.5 Stage IV treatment

Stage IV consists of mycosis fungoides affecting one or more of the following: your lymph nodes, blood, or internal organs.

## 54 Review





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Part 4 is a guide to the treatment options for people with mycosis fungoides. Options are listed by cancer stage. This information is taken from the treatment guidelines written by NCCN experts of mycosis fungoides. These treatment guidelines list options for people with mycosis fungoides in general. Thus, your doctors may suggest other treatment for you based on your health and personal wishes. Fully discuss your treatment options with your doctor.

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### Treatment process

Mycosis fungoides often is a slow-growing cancer that often can be controlled for long periods of time. Even advanced mycosis fungoides (stage IIB–IV) is often a long-term disease. However, mycosis fungoides can grow fast.

Your treatment will likely consist of repeated periods of treatment over many years. First-line treatment is the first treatment given. It is also called primary treatment. You may receive more than one first-line treatment. Second-line treatment is given once first-treatments have been fully used.

After treatment, your doctor may advise you to receive more. This “extra” treatment is called maintenance treatment. The goal of maintenance treatment is to prevent the cancer from coming back.

Along with cancer treatment, you may also be treated to prevent or control other health conditions. Such actions are a part of supportive care. Health conditions that are a concern for some people include severe itching (pruritus) and infections. Talk to your doctor about which health conditions you may develop as a result of cancer treatment.

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## 4.1 Stage IA treatment

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### Start with first-line treatments:

**Chart 4.1.1 First-line treatments**

#### Options for local skin treatments

- Topical steroids
- Topical chemotherapy (ie, mechlorethamine)
- Local radiation therapy
- Topical retinoids (ie, bexarotene, tazarotene)
- Phototherapy
- Topical imiquimod

Try another course of first-line treatments if:

- Treatment worked at first but the cancer came back as stage IA, or
- 1 or 2 treatment options didn't work

2

### Switch to second-line treatments if:

- Multiple courses of first-line treatment didn't work, or
- The cancer is worse and is a higher cancer stage

**Chart 4.1.2 Second-line treatments**

#### Options for widespread treatment

- Systemic treatment ± generalized skin treatment:

##### Systemic treatment

- Oral retinoids
- Interferons
- HDAC-inhibitors (ie, belinostat, vorinostat, romidepsin)
- Extracorporeal photopheresis
- Methotrexate

##### Generalized skin treatment

- Topical steroids
- Topical chemotherapy (ie, mechlorethamine)
- Phototherapy
- Total skin electron beam therapy

- Total skin electron beam therapy

- Clinical trial

**Chart 4.1.1** lists treatment options for stage IA cancers. Treatments that are directly given to skin lesions work very well. However, such treatments may work less well for folliculotropic and large-cell transformed subtypes. Some research suggests that treatment for stage III cancer works better for stage IA cancers with blood involvement, but more research is needed.

One or more treatments may be used to treat stage IA cancers. Options for topical treatment include steroids, mechlorethamine, bexarotene, tazarotene, and imiquimod. Radiation therapy and phototherapy are options, too. Radiation treats a single lesion of mycosis fungoides very well. If treatment works, you may stay on your treatment for a while or slowly stop treatment to prolong the good results.

Start skin treatment again if the cancer was fully treated but came back as stage IA. In this case, you

may receive the same treatment as before or a new treatment. People often have good results with the same treatment. If one or two courses of local skin treatment didn't work well, try another treatment listed in the chart.

You may have already tried multiple courses of local skin treatment without much change. Despite treatment, the cancer may be worse. In either case, options are listed in Chart 4.1.2.

**Chart 4.1.2** lists second-line options for cancers that were stage IA at diagnosis. There are three options. One or more systemic treatments with or without generalized skin treatment is one option. Another option is total skin electron beam therapy. A third option is to join a clinical trial.

## 4.2 Stages IB and IIA treatment

1

### Start with first-line treatments:

**Chart 4.2.1 First-line treatments**

#### Options for local skin treatments

- Generalized skin treatment ± local skin treatment:
  - Generalized skin treatments
    - Topical steroids
    - Topical chemotherapy (ie, mechlorethamine)
    - Phototherapy
    - Total skin electron beam therapy
  - Local skin treatments used after generalized
    - Local radiation therapy
    - Topical retinoids (ie, bexarotene, tazarotene)
    - Topical imiquimod

Try another course of first-line treatments if:

- Treatment worked at first but the cancer came back as stage I or IIA, or
- Only 1 or 2 treatments were tried and didn't work

2

### Switch to second-line treatments if:

- Multiple courses of first-line treatment didn't work, or
- The cancer is worse and is a higher cancer stage

**Chart 4.2.2 Second-line treatments**

#### Options for widespread treatment

- Clinical trial
- Systemic treatment
  - Oral retinoids
  - Interferons
  - HDAC-inhibitors (ie, belinostat, vorinostat, romidepsin)
  - Extracorporeal photopheresis
  - Methotrexate
- Combination treatment ± skin treatment

**Chart 4.2.1** lists treatment options for stages IB and IIA cancer. However, some people with folliculotropic or large-cell transformed subtype of mycosis fungoides may receive stage IIB treatments. Also, some research suggests that treatment for stage III cancer works better for stage IB and IIA cancers with blood involvement. However, more research is needed.

Treatment for stage IB and IIA cancers starts with generalized skin treatment. Topical steroids and mechlorethamine can be used to treat larger lesions. Phototherapy and total skin electron beam therapy are options, too.

After generalized skin treatment, local skin treatment may be used to treat any small lesions that remain. Local treatment options include radiation therapy, topical retinoids, and topical imiquimod. If skin treatment works, you may stay on your treatment for a while or slowly stop treatment to prolong the good results.

Start skin treatment again if the cancer was fully treated but came back as stage I or IIA. People often have good results with the same treatment as before. If a new treatment will be received, the choice of which treatment will be partly based on how much of your skin has lesions. If one or two courses of skin

treatment didn't work, try another treatment listed in the chart.

You may have already tried multiple courses of skin treatment without much change. Despite treatment, the cancer may be worse. In either case, options are listed in Chart 4.2.2.

**Chart 4.2.2** lists second-line options for cancers that were stage IB or IIA at diagnosis. There are three options. You could join a clinical trial. Another option is one or more systemic treatments. A third option is combination treatment with or without skin treatment. Examples of combination treatments include phototherapy with a retinoid, extracorporeal photopheresis with an interferon, and total skin electron beam therapy with photopheresis.

If second-line treatment works, you may stay on your treatment for a while or slowly stop treatment to prolong the good results. Start treatment again if the cancer was fully treated but came back as stage I or IIA. If one or two courses of second-line treatment didn't work, try another treatment listed in the chart.

If multiple second-line treatments didn't work or the cancer got worse, your next options are a clinical trial, total skin electron beam therapy, or chemotherapy used for stage III or IV.

## 4.3 Stage IIB treatment

Limited skin lesions — Less than 10% of the skin

1

Start with first-line treatments:

**Chart 4.3.1 First-line treatments**

### Treatment options

- Local radiation therapy for tumors ± skin treatment
  - Skin treatment for patches, papules, and plaques
    - Steroids
    - Mechlorethamine
    - Retinoids
    - Phototherapy
    - Imiquimod
- Systemic treatment ± radiation therapy ± skin treatment
  - Systemic treatment
    - Oral retinoids
    - Interferons
    - HDAC-inhibitors (ie, belinostat, vorinostat, romidepsin)
    - Extracorporeal photopheresis
    - Methotrexate

Try another course of first-line treatments if:

- Treatment worked at first but the cancer came back as stage I, IIA, or limited IIB, or
- Only 1 or 2 treatments were tried and didn't work

2

Switch to second-line treatments if:

- Multiple courses of first-line treatment didn't work, or
- The cancer is worse and is a higher cancer stage

**Chart 4.3.2 Second-line treatments**

### Treatment options

- Total skin electron beam therapy
- Systemic treatment ± skin treatment
- Combination treatment

Part 4.3 has two sections based on the extent of the cancer. The first section, *Limited skin lesions*, typically includes stage IIB cancers that cover less than 10% of the skin. The second section, *Widespread skin lesions*, addresses treatment for stage IIB that covers 10% or more of the skin.

### Limited skin lesions

**Chart 4.3.1** lists two treatment options for limited stage IIB cancers. One option is to treat skin tumors with local radiation therapy. In addition, patches and plaques may be treated with skin treatments. If treatment works, you may receive immunotherapy for a while to prolong the good results. The second option is to treat the cancer with systemic treatment. In addition, skin tumors may be treated with radiation therapy and patches and plaques with skin treatments. If treatment works, you may stay on your treatment for a while or slowly stop treatment to prolong the good results.

Start treatment again if the cancer was fully treated but came back as stage I, IIA, or limited IIB. People often have good results with the same treatment. If a new treatment will be received, the choice of which treatment will be partly based on how much of your skin has lesions. If one or two courses of first-line treatment didn't work, try another treatment listed in the chart.

You may have already tried multiple courses of first-line treatment without much change. Despite treatment, the cancer may be worse. In either case, options are listed in Chart 4.3.2.

**Chart 4.3.2** lists options for widespread treatment of stage IIB cancers that were limited in extent at diagnosis. There are three options. One option is total skin electron beam therapy. The last two options include systemic or combination treatments that are listed in Chart 4.3.3.

## Widespread lesions — 10% or more of the skin

1

## Start with first-line treatments:

Chart 4.3.3 First-line treatments

## Treatment options

- Total skin electron beam therapy

- Systemic treatment ± skin treatment

## Group A systemic agents

- Oral retinoids
- Interferons
- HDAC inhibitors (ie, belinostat, vorinostat, romidepsin)
- Extracorporeal photopheresis
- Methotrexate

## Group B systemic agents

- Brentuximab vedotin
- Liposomal doxorubicin
- Gemcitabine
- Low-dose pralatrexate
- Chlorambucil
- Pentostatin
- Etoposide
- Cyclophosphamide
- Temozolomide
- Low-dose methotrexate
- Bortezomib

## Group C systemic agents

- Bortezomib
- Brentuximab vedotin
- Gemcitabine
- Liposomal doxorubicin
- Low- or standard-dose pralatrexate
- Romidepsin

## Skin treatments

- Topical steroids
- Mechlorethamine
- Local radiation
- Topical retinoids
- Phototherapy
- Topical imiquimod
- Total skin electron beam therapy

- Combination treatment

## Skin-directed + systemic

- Phototherapy + retinoid
- Phototherapy + interferon
- Phototherapy + photopheresis
- Total skin electron beam + photopheresis

## Systemic + systemic

- Retinoid + interferon
- Photopheresis + retinoid
- Photopheresis + interferon
- Photopheresis + retinoid + interferon

## Try another course of first-line treatments if:

- Treatment worked at first but the cancer came back as stage I or II, or
- Only 1 or 2 treatments were tried and didn't work



2

### Switch to second-line treatments if:

- Multiple courses of first-line treatment didn't work, or
- The cancer is worse and is a higher cancer stage

**Chart 4.3.4 Second-line treatments**

#### Treatment options

- Multi-agent chemotherapy
- Consider allogeneic stem cell transplant
- Clinical trial

### Widespread skin lesions

**Chart 4.3.3** lists three treatment options for widespread stage IIB cancers. One option is to treat all skin lesions with total skin electron beam therapy. If treatment works, you may receive immunotherapy for a while to prolong the good results.

The second option is to treat the cancer with systemic treatment. In addition, skin lesions may be treated with skin treatment. Treatments in Group A won't suppress your immune system while treatments in Group B and Group C will. Slower-growing cancers may be treated with Group A and Group B treatments. Group C treatments are preferred for cancers that are growing fast. The large-cell transformed subtype often, but not always, grows fast.

The third option for widespread stage IIB cancers is combination treatment. Combination treatment may consist of skin and systemic treatment. It may also consist of two systemic treatments. Specific regimens of combination treatment are listed in the chart.

If first-line treatment works, you may stay on your treatment for a while or slowly stop treatment to prolong the good results. Start treatment again if the cancer was fully treated but came back as stage I or II. People often have good results with the same treatment. If a new treatment will be received, the choice of which treatment will be partly based on how much of your skin has lesions. If one or two courses of first-line treatment didn't work, try another treatment listed in the chart.

You may have already tried multiple courses of first-line treatment without much change. Sometimes, despite treatment, the cancer may get worse. In either case, second-line options are listed in Chart 4.3.4.

**Chart 4.3.4** lists options for second-line treatment of stage IIB cancers that were widespread at diagnosis. There are three options. One option is multi-agent chemotherapy. Another option is allogeneic stem cell transplant. The third option is a clinical trial.

## 4.4 Stage III treatment

1

### Start with first-line treatments:

**Chart 4.4.1 First-line treatments**

#### No blood involvement

- Topical steroids
- Topical chemotherapy (ie, mechlorethamine)
- Phototherapy
- Total skin electron beam therapy

#### Blood involvement

- Systemic treatment ± skin treatment
  - Systemic treatment
    - Oral retinoids
    - Interferons
    - HDAC inhibitors (ie, belinostat, vorinostat, romidepsin)
    - Extracorporeal photopheresis
    - Methotrexate
  - Skin treatment
    - Topical steroids
    - Mechlorethamine
    - Local radiation
    - Topical retinoids
    - Phototherapy
    - Topical imiquimod
    - Total skin electron beam therapy

Try another course of first-line treatments if:

- Treatment worked at first but the cancer came back as stage I, II, or III, or
- Only 1 or 2 treatments were tried and didn't work



See second- and third-line treatments, page 50.

**Chart 4.4.1** lists first-line treatment options for stage III cancers with and without blood involvement. When no blood is involved, generalized skin treatment is advised. If treatment works, you may stay on some treatments for a while or slowly stop some treatments to prolong the good results.

Start treatment again if the cancer was fully treated but came back as stage I, II, or III. People often have good results with the same treatment. If a new treatment will be received, the choice of which treatment will be partly based on how much of your skin has lesions. If one or two courses of first-line treatment didn't work, try another treatment listed in the chart.

You may have already tried multiple courses of treatment without much change. Despite treatment, the cancer may be worse. In either case, options are listed in Chart 4.4.2.

For stage III cancers with some blood involvement, systemic treatment is advised. Skin treatment may also be used to treat skin lesions. If treatment works, you may stay on some treatments for a while or slowly stop some treatments to prolong the good results.

Start treatment again if the cancer was fully treated but came back as stage I, II, or III. People often have good results with the same treatment. If a new treatment will be received, the choice of which treatment will be partly based on how much of your skin has lesions. If one or two courses of first-line treatment didn't work, try another treatment listed in the chart.

You may have already tried multiple courses of first-line treatment without much change. Despite treatment, the cancer may be worse. In either case, options are listed in Chart 4.4.2.

2

**Switch to second-line treatments if:**

- Multiple courses of first-line treatment didn't work, or
- The cancer is worse and is a higher cancer stage

**Chart 4.4.2 Second-line treatments****Treatment options**

- Combination treatment
 

<ul style="list-style-type: none"> <li>◦ Skin-directed + Systemic</li> <li>◦ Phototherapy + retinoid</li> <li>◦ Phototherapy + interferon</li> <li>◦ Phototherapy + photopheresis</li> <li>◦ Total skin electron beam + photopheresis</li> </ul>	<ul style="list-style-type: none"> <li>◦ Systemic + Systemic</li> <li>◦ Retinoid + interferon</li> <li>◦ Photopheresis + retinoid</li> <li>◦ Photopheresis + interferon</li> <li>◦ Photopheresis + retinoid + interferon</li> </ul>
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- Clinical trial

Try another course of second-line treatments if:

- Treatment worked at first but the cancer came back as stage III, or
- Only 1 or 2 treatments were tried and didn't work

3

**Switch to third-line treatments if:**

- Multiple courses of second-line treatment didn't work, or
- The cancer is worse and is a higher cancer stage

**Chart 4.4.3 Third-line treatments****Treatment options**

- Clinical trial
- Systemic treatment
 

<ul style="list-style-type: none"> <li>◦ Brentuximab vedotin</li> <li>◦ Gemcitabine</li> <li>◦ Liposomal doxorubicin</li> </ul>	<ul style="list-style-type: none"> <li>◦ Low-dose pralatrexate</li> <li>◦ Chlorambucil</li> <li>◦ Pentostatin</li> <li>◦ Etoposide</li> </ul>	<ul style="list-style-type: none"> <li>◦ Cyclophosphamide</li> <li>◦ Temozolomide</li> <li>◦ Low-dose methotrexate</li> <li>◦ Bortezomib</li> </ul>
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- Alemtuzumab
- Nonmyeloblastic allogeneic transplant



## 4.5 Stage IV treatment

1

## Start with first-line treatments:

Chart 4.5.1 First-line treatments

## Treatment options

- Single-agent systemic treatment ± radiation therapy

## Cancer growth is not fast

- Brentuximab vedotin
- Liposomal doxorubicin
- Gemcitabine
- Low-dose pralatrexate
- Chlorambucil
- Pentostatin
- Etoposide
- Cyclophosphamide
- Temozolomide
- Low-dose methotrexate
- Bortezomib

## Cancer growth is fast

- Bortezomib
- Brentuximab vedotin
- Gemcitabine
- Liposomal doxorubicin
- Low- or standard-dose pralatrexate
- Romidepsin

- Multi-agent chemotherapy ± radiation therapy

## Try another course of first-line treatments if:

- Treatment worked at first but the cancer came back, or
- Only 1 or 2 treatments were tried and didn't work



## Join a clinical trial if:

- Multiple courses of treatment didn't work, or
- The cancer is worse

**Chart 4.5.1** lists treatment options for stage IV cancers. These cancers are often treated with one or more systemic treatments. Radiation therapy may follow to treat cancer in the skin.

Systemic options include targeted therapy and chemotherapy. Which systemic treatment you will receive partly depends on how fast the cancer is growing. If systemic treatment works, you may receive immunotherapy or targeted therapy for a while to prolong the good results.

If treatment worked but the cancer came back, you may receive the same systemic treatment as before. People often have good results with the same treatment. Allogeneic stem cell transplant may be an option when receiving a second or third course of systemic treatment. If one or two courses of systemic treatment didn't work, try another systemic treatment listed in the chart.

You may have already tried multiple courses of systemic treatment. Sometimes the cancer gets worse despite systemic treatment. In either case, joining a clinical trial may be an option. Ask your treatment team about a clinical trial that is right for you.

## Review

- Treatment for mycosis fungoides partly depends on the stage of cancer.
- You will likely receive multiple courses of first-line treatments before moving on to second-line treatments, if needed.
- Local skin treatments are often first used to treat stage IA cancers. Second-line treatments include systemic treatments and total skin electron beam therapy.
- Generalized skin treatments are often first used to treat stage IB and IIA cancers. Second-line treatments include systemic treatments and combination treatments.
- Local radiation therapy for skin tumors and skin treatments for other lesions are first used to treat limited stage IIB cancers. Second-line treatments include total skin electron beam therapy, systemic treatments, and combination treatments.
- Total skin electron beam therapy, systemic treatment with or without skin treatment, and combination treatment are first used to treat generalized stage IIB cancers. Second-line treatments include multi-agent chemotherapy and allogeneic stem cell transplant.
- Stage III first-line treatment depends on whether there is blood involvement. If not, skin treatments may be received. Systemic treatment with or without skin treatment is used if there is blood involvement. Second-line treatments are combinations of systemic treatments or systemic with skin treatments. Third-line treatments include systemic treatments, alemtuzumab, and nonmyeloablative allogeneic transplant.
- Single-agent or multi-agent systemic treatments are used to treat stage IV cancers.

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# Making treatment decisions







## Questions to ask your doctors

You will likely meet with experts from different fields of medicine. Strive to have helpful talks with each person. Prepare questions before your visit and ask questions if the person isn't clear. You can also record your talks and get copies of your medical records. It may be helpful to have your spouse, partner, or a friend with you at these visits. A patient advocate or navigator might also be able to come. They can help to ask questions and remember what was said. Suggested questions to ask include:

### What's my diagnosis and prognosis?

It's important to know that there are different types of cancer. Cancer can greatly differ even when people have a tumor in the same organ. Based on your test results, your doctors can tell you which type of cancer you have. He or she can also give a prognosis. A prognosis is a prediction of the pattern and outcome of a disease. Knowing the prognosis may affect what you decide about treatment.

1. Where did the cancer start? In what type of cell?
2. Is this cancer common?
3. What is the cancer stage? Does this stage mean the cancer has spread far?
4. Is this a fast- or slow-growing lymphoma?
5. What other test results are important to know?
6. How often are these tests wrong?
7. Would you give me a copy of the pathology report and other test results?
8. Can the cancer be cured? If not, how well can treatment stop the cancer from growing?

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## What are my options?

There is no single treatment practice that is best for all patients. There is often more than one treatment option along with clinical trial options. Your doctor will review your test results and recommend treatment options.

1. What will happen if I do nothing?
2. Can I just carefully monitor the cancer?
3. Do you consult NCCN recommendations when considering options?
4. Are you suggesting options other than what NCCN recommends? If yes, why?
5. Do your suggested options include clinical trials? Please explain why.
6. How do my age, health, and other factors affect my options?
7. Which option is proven to work best?
8. Which options lack scientific proof?
9. What are the benefits of each option? Does any option offer a cure? Are my chances any better for one option than another? Less time-consuming? Less expensive?
10. What are the risks of each option? What are possible complications? What are the rare and common side effects? Short-lived and long-lasting side effects? Serious or mild side effects? Other risks?
11. What can be done to prevent or relieve the side effects of treatment?

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## Weighing your options

Deciding which option is best can be hard. Doctors from different fields of medicine may have different opinions on which option is best for you. This can be very confusing. Your spouse or partner may disagree with which option you want. This can be stressful. In some cases, one option hasn't been shown to work better than another, so science isn't helpful. Some ways to decide on treatment are discussed next.

### 2<sup>nd</sup> opinion

The time around a cancer diagnosis is very stressful. People with cancer often want to get treated as soon as possible. They want to make their cancer go away before it spreads farther. While cancer can't be ignored, there is time to think about and choose which option is best for you.

You may wish to have another doctor review your test results and suggest a treatment plan. This is called getting a 2<sup>nd</sup> opinion. You may completely trust your doctor, but a 2<sup>nd</sup> opinion on which option is best can help.

Copies of the pathology report, a DVD of the [imaging tests](#), and other test results need to be sent to the doctor giving the 2<sup>nd</sup> opinion. Some people feel uneasy asking for copies from their doctors. However, a 2<sup>nd</sup> opinion is a normal part of cancer care.

When doctors have cancer, most will talk with more than one doctor before choosing their treatment. What's more, some health plans require a 2<sup>nd</sup> opinion. If your health plan doesn't cover the cost of a 2<sup>nd</sup> opinion, you have the choice of paying for it yourself.

If the two opinions are the same, you may feel more at peace about the treatment you accept to have. If the two opinions differ, think about getting a 3<sup>rd</sup> opinion. A 3<sup>rd</sup> opinion may help you decide between your options. Choosing your cancer treatment is a



very important decision. It can affect your length and quality of life.

### Support groups

Besides talking to health experts, it may help to talk to patients who have walked in your shoes. Support groups often consist of people at different stages of treatment. Some may be in the process of deciding while others may be finished with treatment. At support groups, you can ask questions and hear about the experiences of other people with mycosis fungoides.

### Compare benefits and downsides

Every option has benefits and downsides. Consider these when deciding which option is best for you. Talking to others can help identify benefits and downsides you haven't thought of. Scoring each factor from 0 to 10 can also help since some factors may be more important to you than others.





## Websites

### American Cancer Society

[cancer.org/cancer/non-hodgkinlymphoma/detailedguide/index](http://cancer.org/cancer/non-hodgkinlymphoma/detailedguide/index)

### National Coalition for Cancer Survivorship

[www.canceradvocacy.org/toolbox](http://www.canceradvocacy.org/toolbox)

### National Cancer Institute

[cancer.gov/types/lymphoma](http://cancer.gov/types/lymphoma)

### NCCN

[nccn.org/patients](http://nccn.org/patients)

### The Leukemia & Lymphoma Society (LLS)

[LLS.org/information specialists](http://LLS.org/information specialists)

## Review

- Shared decision-making is a process in which you and your doctors plan treatment together.
- Asking your doctors questions is vital to getting the information you need to make informed decisions.
- Getting a 2<sup>nd</sup> opinion, attending support groups, and comparing benefits and downsides may help you decide which treatment is best for you.

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# Glossary

## Dictionary Acronyms

# Dictionary

## **allogeneic stem cell transplant**

A cancer treatment that replaces blood stem cells with donor stem cells, which in turn make a new immune system and attack the lymphoma.

## **autologous stem cell transplant**

A cancer treatment that destroys cancer cells with high doses of chemotherapy then rebuilds destroyed bone marrow with your own healthy blood stem cells. Also called an HDT/ASCR (high-dose therapy with autologous stem cell rescue).

## **B-cell**

One of three types of a white blood cell called a lymphocyte.

## **biopsy**

Removal of small amounts of tissue or fluid to be tested for disease.

## **bone marrow**

Soft, sponge-like tissue in the center of most bones where blood cells are made.

## **bone marrow biopsy**

Removal of a small amount of solid bone and bone marrow to test for disease.

## **cancer stage**

Ratings of tumors that suggest the outlook of the disease.

## **chemotherapy**

Drugs that stop the life cycle of cells so new cells aren't made.

## **chromosome**

Strands of genetic material inside of cells.

## **chyle**

A fatty liquid absorbed from the gut into the lymphatic system.

## **clinical trial**

Research on a test or treatment to assess its safety or how well it works.

## **complete blood count (CBC)**

A test of the number of blood cells in a sample.

## **comprehensive metabolic panel**

Tests of up to 14 chemicals in your blood.

## **computed tomography (CT)**

A test that uses x-rays to view body parts.

## **contrast**

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

## **core needle biopsy**

Removal of small samples of solid tissue with a needle.

## **deoxyribonucleic acid (DNA)**

A chain of chemicals inside cells that contains coded instructions for making and controlling cells.

## **diagnose**

To identify a disease.

## **erythroderma**

A reddening of most or all of the skin.

## **excisional biopsy**

Removal of an entire tumor and some surrounding tissue with a surgical knife.

## **extracorporeal photopheresis**

Treatment that consists of removing white blood cells from the body, exposing them to psoralen then UVB rays, and returning the treated cell back into the body.

## **fatigue**

Severe tiredness despite getting enough sleep that limits one's ability to function.

## **flow cytometry**

A test that looks at certain substances on the surface of cells to identify the type of cells present.

## **folliculotropic mycosis fungoides**

A fast-growing subtype that grows around hair follicles.

## **gene**

Instructions in cells for making and controlling cells.

## **gene rearrangement**

The fusion of parts from two genes that creates a new gene.

**histone deacetylase (HDAC) inhibitor**

A drug that blocks the action of proteins called histone deacetylase, which leads to cell death.

**human leukocyte antigen (HLA) typing**

A blood test that finds a person's unique set of proteins on cells.

**imaging test**

A test that makes pictures (images) of the inside of the body .

**immune system**

The body's natural defense against infection.

**immunohistochemistry (IHC)**

A test of cancer cells to find specific cell traits involved in abnormal cell growth.

**interferon**

A drug used to activate the body's disease-fighting ability (immune system).

**lactate dehydrogenase**

A protein that helps to make energy in cells.

**large-cell transformed mycosis fungoides**

A fast-growing subtype consisting of large cells.

**lesion**

Any type of abnormal skin.

**local anesthesia**

A controlled loss of feeling in a small area of the body caused by drugs.

**local electron beam therapy**

Treatment with high-energy rays (radiation) given to limited areas of cancer close to the skin's surface.

**lymph**

A clear fluid containing white blood cells.

**lymph node**

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

**lymph vessel**

Tube-shaped ducts that carry lymph throughout the body.

**lymphatic system**

A network in the body that collects and transports a fluid (lymph) and fights germs.

**lymphocyte**

A type of white blood cell that helps protect the body from illness.

**lymphoma**

Cancer that begins in white blood cells called lymphocytes that are within the lymphatic system.

**maintenance treatment**

Extra treatment given to prolong the good effects of prior treatment.

**medical history**

All health events and medications taken to date.

**monoclonal antibody**

Man-made antibodies that attach proteins on cancer cells.

**natural killer (NK) cell**

One of three types of a white blood cell called a lymphocyte.

**nonmyeloablative allogeneic stem cell transplant**

A cancer treatment consisting of low doses of chemotherapy to reduce side effects followed by transfusion of donor stem cells.

**papule**

A red bump that is by a hair follicle.

**patch**

An area of scaly skin that is flat and may be discolored.

**pathologist**

A doctor who's an expert in testing cells to find disease.

**phototherapy**

A treatment with UV rays.

**physical exam**

A review of the body by a health expert for signs of disease.

**plaque**

A thickened patch of skin that is raised or hard.

**positron emission tomography (PET)**

A test that uses radioactive material to see the shape and function of body parts.

**positron emission tomography/computed tomography (PET/CT)**

A test that uses radioactive material and x-rays to view the shape and function of organs and tissues.

**psoralen and UVA (PUVA)**

Treatment with UVA rays to psoralen-exposed skin.

**punch biopsy**

Removal of a skin sample using a sharp hollow device.

**radiation therapy**

The use of radiation to treat cancer.

**retinoid**

A drug that enters cells and attaches to a specific type of protein, which in turn causes cell death.

**sedative**

A drug that helps a person to relax or go to sleep.

**Sézary cell**

A cell with one, round nucleus that is shaped like the first layer of the brain.

**Sézary syndrome**

A lymphoma that presents with reddening of most of the skin and very high numbers of Sézary cells in the blood.

**shave biopsy**

Removal of a skin sample from the first and part of the second skin layers.

**side effect**

An unplanned physical or emotional response to treatment.

**spleen**

An organ to the left of the stomach that helps protect the body from disease.

**stem cell transplant**

A cancer treatment that destroys bone marrow then replaces it by adding healthy blood stem cells.

**steroid**

A drug used to reduce redness, swelling, and pain, but also to kill cancer cells.

**supportive care**

Treatment for the symptoms or health conditions caused by cancer or cancer treatment.

**systemic treatment**

Treatment that is absorbed into the body to treat cancer anywhere.

**targeted therapy**

Drugs that stop the growth process that is specific to cancer cells.

**T-cell**

One of three types of a white blood cell called a lymphocyte.

**thymus**

A gland located behind the breastbone.

**tonsil**

A group of tissue within the throat that contains many white blood cells called lymphocytes and fights germs that enter the mouth and nose.

**total skin electron beam therapy (TSEBT)**

Treatment with high-energy rays (radiation) given to widespread cancer close to the skin's surface.

**UVB phototherapy**

Treatment with UVB rays to limited areas of skin cancer.

# Acronyms

**CAM**

complementary and alternative medicine

**CBC**

complete blood count

**CT**

computed tomography

**DNA**

deoxyribonucleic acid

**FDA**

Food and Drug Administration

**GVHD**

graft-versus-host disease

**GVT**

graft-versus-tumor

**HDAC**

histone deacetylase

**HLA**

human leukocyte antigens

**HTLV**

human T-cell lymphotropic virus

**IHC**

immunohistochemistry

**NK cells**

natural killer cells

**PCR**

polymerase chain reaction

**PET**

positron emission tomography

**TCR**

T-cell receptor

**TSEBT**

total skin electron beam therapy

**UV**

ultraviolet

## NCCN Abbreviations and Acronyms

**NCCN®**

National Comprehensive Cancer Network®

**NCCN Patient Guidelines**

NCCN Guidelines for Patients®

**NCCN Guidelines®**

NCCN Clinical Practice Guidelines in Oncology®

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Kidney Cancer  
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Melanoma  
Multiple Myeloma  
Myelodysplastic Syndromes  
Non-Hodgkin's Lymphomas  
Diffuse Large B-cell Lymphoma  
Follicular Lymphoma  
Mantle Cell Lymphoma  
Mycosis Fungoides  
Peripheral T-cell Lymphoma

Non-Small Cell Lung Cancer  
Ovarian Cancer  
Pancreatic Cancer  
Prostate Cancer  
Soft Tissue Sarcoma  
Stage 0 Breast Cancer  
Stages I and II Breast Cancer  
Stage III Breast Cancer  
Stage IV Breast Cancer

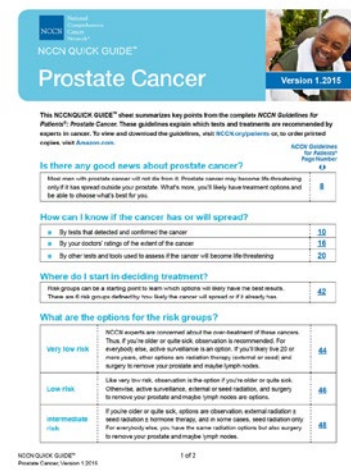
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Andrew D. Zelenetz, MD, PhD/Chair  
*Memorial Sloan Kettering Cancer Center*

Leo I. Gordon, MD/Co-Vice Chair  
*Robert H. Lurie Comprehensive Cancer  
Center of Northwestern University*

William G. Wierda, MD, PhD/Co-  
Vice Chair  
*The University of Texas  
MD Anderson Cancer Center*

Jeremy S. Abramson, MD  
*Massachusetts General Hospital  
Cancer Center*

Ranjana H. Advani, MD  
*Stanford Cancer Institute*

C. Babis Andreadis, MD, MSCE  
*UCSF Helen Diller Family  
Comprehensive Cancer Center*

Nancy Bartlett, MD  
*Siteman Cancer Center at Barnes-  
Jewish Hospital and Washington  
University School of Medicine*

John C. Byrd, MD  
*The Ohio State University Comprehensive  
Cancer Center - James Cancer Hospital  
and Solove Research Institute*

Luis E. Fayad, MD  
*The University of Texas  
MD Anderson Cancer Center*

Richard I. Fisher, MD  
*Fox Chase Cancer Center*

Martha J. Glenn, MD  
*Huntsman Cancer Institute  
at the University of Utah*

Thomas M. Habermann, MD  
*Mayo Clinic Cancer Center*

Nancy Lee Harris, MD  
*Massachusetts General Hospital  
Cancer Center*

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*Roswell Park Cancer Institute*

Richard T. Hoppe, MD  
*Stanford Cancer Institute*

Steven M. Horwitz, MD  
*Memorial Sloan Kettering Cancer Center*

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*University of Michigan  
Comprehensive Cancer Center*

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*Duke Cancer Institute*

Youn H. Kim, MD  
*Stanford Cancer Institute*

Susan Krivacic, MPAff  
*Patient Advocate*

Ann S. LaCasce, MD  
*Dana-Farber/Brigham and  
Women's Cancer Center*

Matthew Lunning, DO  
*Fred & Pamela Buffett Cancer Center*

Auayporn Nademanee, MD  
*City of Hope Comprehensive Cancer Center*

Pierluigi Porcu, MD  
*The Ohio State University Comprehensive  
Cancer Center - James Cancer Hospital  
and Solove Research Institute*

Oliver Press, MD, PhD  
*Fred Hutchinson Cancer Research Center/  
Seattle Cancer Care Alliance*

Rachel Rabinovitch, MD  
*University of Colorado Cancer Center*

Nishitha Reddy, MD  
*Vanderbilt-Ingram Cancer Center*

Erin Reid, MD  
*UC San Diego Moores Cancer Center*

Kenneth Roberts, MD  
*Yale Cancer Center/Smilow Cancer Hospital*

Ayman A. Saad, MD  
*University of Alabama at Birmingham  
Comprehensive Cancer Center*

Lubomir Sokol, MD, PhD  
*Moffitt Cancer Center*

Lode J. Swinnen, MB, ChB  
*The Sidney Kimmel Comprehensive  
Cancer Center at Johns Hopkins*

Julie M. Vose, MD, MBA  
*Fred & Pamela Buffett Cancer Center*

Lynn Wilson, MD, MPH  
*Yale Cancer Center/Smilow Cancer Hospital*

Joachim Yahalom, MD  
*Memorial Sloan Kettering Cancer Center*

Nadeem Zafar, MD  
*St. Jude Children's Research Hospital/  
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# NCCN Member Institutions

Fred & Pamela Buffett Cancer Center  
Omaha, Nebraska  
800.999.5465  
[nebraskamed.com/cancer](http://nebraskamed.com/cancer)

Case Comprehensive Cancer Center/  
University Hospitals Seidman  
Cancer Center and Cleveland Clinic  
Taussig Cancer Institute  
Cleveland, Ohio  
800.641.2422 • UH Seidman Cancer Center  
[uhhospitals.org/seidman](http://uhhospitals.org/seidman)  
866.223.8100 • CC Taussig Cancer Institute  
[my.clevelandclinic.org/services/cancer](http://my.clevelandclinic.org/services/cancer)  
216.844.8797 • Case CCC  
[case.edu/cancer](http://case.edu/cancer)

City of Hope Comprehensive  
Cancer Center  
Los Angeles, California  
800.826.4673  
[cityofhope.org](http://cityofhope.org)

Dana-Farber/Brigham and  
Women's Cancer Center  
Massachusetts General Hospital  
Cancer Center  
Boston, Massachusetts  
877.332.4294  
[dfbwc.org](http://dfbwc.org)  
[massgeneral.org/cancer](http://massgeneral.org/cancer)

Duke Cancer Institute  
Durham, North Carolina  
888.275.3853  
[dukecancerinstitute.org](http://dukecancerinstitute.org)

Fox Chase Cancer Center  
Philadelphia, Pennsylvania  
888.369.2427  
[foxchase.org](http://foxchase.org)

Huntsman Cancer Institute  
at the University of Utah  
Salt Lake City, Utah  
877.585.0303  
[huntsmancancer.org](http://huntsmancancer.org)

Fred Hutchinson Cancer  
Research Center/  
Seattle Cancer Care Alliance  
Seattle, Washington  
206.288.7222 • [seattlecca.org](http://seattlecca.org)  
206.667.5000 • [fredhutch.org](http://fredhutch.org)

The Sidney Kimmel Comprehensive  
Cancer Center at Johns Hopkins  
Baltimore, Maryland  
410.955.8964  
[hopkinskimmelcancercenter.org](http://hopkinskimmelcancercenter.org)

Robert H. Lurie Comprehensive Cancer  
Center of Northwestern University  
Chicago, Illinois  
866.587.4322  
[cancer.northwestern.edu](http://cancer.northwestern.edu)

Mayo Clinic Cancer Center  
Phoenix/Scottsdale, Arizona  
Jacksonville, Florida  
Rochester, Minnesota  
800.446.2279 • Arizona  
904.953.0853 • Florida  
507.538.3270 • Minnesota  
[mayoclinic.org/departments-centers/mayo-clinic-cancer-center](http://mayoclinic.org/departments-centers/mayo-clinic-cancer-center)

Memorial Sloan Kettering  
Cancer Center  
New York, New York  
800.525.2225  
[mskcc.org](http://mskcc.org)

Moffitt Cancer Center  
Tampa, Florida  
800.456.3434  
[moffitt.org](http://moffitt.org)

The Ohio State University  
Comprehensive Cancer Center -  
James Cancer Hospital and  
Solove Research Institute  
Columbus, Ohio  
800.293.5066  
[cancer.osu.edu](http://cancer.osu.edu)

Roswell Park Cancer Institute  
Buffalo, New York  
877.275.7724  
[roswellpark.org](http://roswellpark.org)

Siteman Cancer Center at Barnes-  
Jewish Hospital and Washington  
University School of Medicine  
St. Louis, Missouri  
800.600.3606  
[siteman.wustl.edu](http://siteman.wustl.edu)

St. Jude Children's Research Hospital/  
The University of Tennessee  
Health Science Center  
Memphis, Tennessee  
888.226.4343 • [stjude.org](http://stjude.org)  
901.683.0055 • [westclinic.com](http://westclinic.com)

Stanford Cancer Institute  
Stanford, California  
877.668.7535  
[cancer.stanford.edu](http://cancer.stanford.edu)

University of Alabama at Birmingham  
Comprehensive Cancer Center  
Birmingham, Alabama  
800.822.0933  
[www3.ccc.uab.edu](http://www3.ccc.uab.edu)

UC San Diego Moores Cancer Center  
La Jolla, California  
858.657.7000  
[cancer.ucsd.edu](http://cancer.ucsd.edu)

UCSF Helen Diller Family  
Comprehensive Cancer Center  
San Francisco, California  
800.689.8273  
[cancer.ucsf.edu](http://cancer.ucsf.edu)

University of Colorado Cancer Center  
Aurora, Colorado  
720.848.0300  
[coloradocancercenter.org](http://coloradocancercenter.org)

University of Michigan  
Comprehensive Cancer Center  
Ann Arbor, Michigan  
800.865.1125  
[mcancer.org](http://mcancer.org)

The University of Texas  
MD Anderson Cancer Center  
Houston, Texas  
800.392.1611  
[mdanderson.org](http://mdanderson.org)

Vanderbilt-Ingram Cancer Center  
Nashville, Tennessee  
800.811.8480  
[vicc.org](http://vicc.org)

University of Wisconsin  
Carbone Cancer Center  
Madison, Wisconsin  
608.265.1700  
[uwhealth.org/cancer](http://uwhealth.org/cancer)

Yale Cancer Center/  
Smilow Cancer Hospital  
New Haven, Connecticut  
855.4.SMILOW  
[yalecancercenter.org](http://yalecancercenter.org)

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# Mycosis Fungoides

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National  
Comprehensive  
Cancer  
Network®

275 Commerce Drive  
Suite 300  
Fort Washington, PA 19034  
215.690.0300

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