



**EASY READING**

# If You Have Lymphoma of the Skin

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## What is lymphoma of the skin?

Lymphoma is a [cancer](#)<sup>1</sup> that starts in white blood cells called lymphocytes (LIM-fo-sites). Lymphomas can start almost any place in the body. When a lymphoma starts in the skin, it is called a **skin lymphoma** (or **cutaneous lymphoma**).

Lymphocytes are part of the body's immune system, and normally they help the body fight infections. There are 2 main types of lymphocytes:

- B lymphocytes (B cells)
- T lymphocytes (T cells)

Most skin lymphomas start in T cells.

## Different kinds of lymphoma of the skin

There are many [types of skin lymphomas](#)<sup>2</sup>. Many of these are very rare. Your doctor can tell you more about the type you have.

Here are the medical names for the most common types of skin lymphoma in the US.

- Mycosis fungoides
- Sezary syndrome

### Questions to ask the doctor

- Why do you think I have a skin lymphoma?
- Is there a chance I don't have a skin lymphoma?
- Would you please write down the kind of skin lymphoma you think I might have?
- What will happen next?

### How does the doctor know I have lymphoma of the skin?

Lymphomas of the skin can be seen and felt. They often start out as a very itchy, red or purple rash, which can look like any of these:

- Small pimples
- Flat areas, which might be raised or lowered
- Lumps or bumps under the skin

The lymphoma might affect only a small area of skin, or it might affect large areas of the body. Sometimes people with skin lymphoma have other symptoms, such as fever, weight loss, and sweating.

The doctor will ask you questions about your [symptoms](#)<sup>3</sup> and your health, and will do a physical exam. The doctor will look closely at the skin, and might feel the nearby lymph nodes (bean-sized groups of immune cells) under the skin to see if they are affected. Skin lymphomas can sometimes spread to the lymph nodes, making them swollen or hard.

### Tests that may be done

It can be hard for doctors to tell a skin lymphoma apart from other causes of skin

rashes, so sometimes it takes a while to be sure. If the doctor thinks you might have a skin lymphoma, tests will be done. Here are some of the [tests](#)<sup>4</sup> you might need:

**Biopsy:** In this test, the doctor takes out a piece of the skin to check it for cancer cells. This is often done with local anesthesia. This means you're awake but the area where the biopsy is done is numb.

A biopsy is the only way to tell for sure if you have a skin lymphoma. There are many types of biopsies. Each type has pros and cons. The choice of which one to use depends on your own case. Ask your doctor what type you will need.

Sometimes biopsies might be done on other parts of the body as well, such as nearby lymph nodes or the bone marrow (the soft, inner part of some bones). This is to check if the cancer has spread there.

**Blood tests:** Certain blood tests can tell the doctor more about the types of cells and chemicals in your blood.

**Chest x-ray:** X-rays may be done to look for enlarged lymph nodes in the chest.

**CT scan:** This is a special kind of x-ray test that makes detailed pictures. It can be used to look for swollen lymph nodes or other organs.

**MRI scan:** MRIs use radio waves and strong magnets instead of x-rays to make detailed pictures. This test isn't often done for skin lymphomas, unless a CT scan can't be done for some reason.

**Ultrasound:** For this test, a small wand is moved around on your skin. It gives off sound waves and picks up the echoes as they bounce off tissues. The echoes are made into a picture on a computer screen. Ultrasound can be used to look for swollen lymph nodes in places like your belly.

**PET scan:** In this test, you are injected with a special type of sugar that can be seen inside your body with a special camera. If there is cancer, this sugar shows up as "hot spots" where the cancer is found. This test can help show if the lymphoma has spread. Sometimes it is done at the same time as a CT scan (known as a **PET/CT scan**).

### Questions to ask the doctor

- What tests will I need?
- Who will do these tests?

- Where will they be done?
- How and when will I get the results?
- Who will explain the results to me?
- What do I need to do next?

## How serious is my cancer?

If you have a skin lymphoma, the doctor will want to find out how far it has spread. This is called the [stage](#)<sup>5</sup> of the cancer. Your doctor will want to find out the stage of your lymphoma to help decide what type of treatment is best for you.

The stage is based on the spread of the lymphoma on the skin, as well as if it has reached other parts of your body.

Some types of skin lymphoma are given as stage such as 1, 2, 3, or 4. The lower the number, the less the cancer has spread. A higher number, like stage 4, means a more serious cancer that has spread farther. Be sure to ask the doctor about the cancer stage and what it means for you.

## Questions to ask the doctor

- Do you know the stage of the lymphoma?
- If not, how and when will you find out the stage?
- Would you explain to me what the stage means in my case?
- How does the stage affect my treatment options?
- What will happen next?

## What kind of treatment will I need?

There are many ways to treat skin lymphomas. The main types of treatment are divided into 2 groups:

- [Treatments aimed only at the skin](#)<sup>6</sup>
- [Treatments that affect the whole body](#)<sup>7</sup>

Doctors might use one or both types of treatment for a skin lymphoma. The treatment plan that's best for you will depend on:

- The type of skin lymphoma you have
- The stage of the lymphoma
- The chance that a type of treatment will cure your lymphoma or help in some other way
- Your age
- Other health problems you have
- Your feelings about the treatment and the side effects that come with it

### Treatments aimed just at the skin

For many skin lymphomas (especially if they are small and have not spread), the first treatment is aimed just at the skin lymphoma, to try to avoid side effects in the rest of the body. There are many ways to do this.

**Surgery:** This is rarely the only treatment for skin lymphoma, but it might be used to treat some types of skin lymphomas that can be removed completely. Even then, other types of treatment may be used as well.

**Radiation:** This treatment uses high-energy rays (like x-rays or parts of atoms) to kill cancer cells. It may be used as the main treatment for some skin lymphomas. The treatment is a lot like getting an x-ray. The radiation is stronger, but it is still painless.

The most common side effects are skin changes (most often like a sunburn) in the area being treated. If a large part of the body is treated, it might cause loss of all hair on the body, and even the loss of fingernails and toenails.

**Phototherapy**, also known as **UV light therapy**: UV light can be used to treat some skin lymphomas. Treatment is given a few times a week with a special lamp, which is like those used in tanning salons. Sometimes a drug is taken as a pill before each treatment to help it work better. This type of treatment is called **PUVA**.

Just like when you are exposed to sunlight outside, treatment with UV light can cause sunburn. If pills are taken as part of PUVA, they can make the skin very sensitive to sunlight, so you will need to protect yourself from sunlight in the days after treatment.

**Topical medicines:** These are drugs that are put right on (or into) the skin. They treat the lymphoma while limiting side effects in other parts of the body.

- **Topical steroids:** These drugs affect immune cells (like lymphoma cells), and they can be very helpful in treating some skin lymphomas. They can be put on the skin

as ointments, gels, foams, and creams, or they can be injected into skin.

- **Topical chemotherapy:** Chemotherapy (chemo) drugs are strong medicines used to treat cancer. Some chemo drugs can be put right on the skin (usually in a cream, ointment, or gel) to treat skin lymphomas that have not spread. Side effects can include redness and swelling in places where the drug is used.
- **Topical retinoids:** Retinoids are drugs related to vitamin A. They can affect certain genes in lymphoma cells that cause them to grow or mature. Some retinoids come in a gel that can be put right on the skin. Side effects can include redness, itching, swelling, and sensitivity to sunlight in places where the drug is used.
- **Topical immune treatment:** Imiquimod is a cream that causes an immune reaction when applied to skin lymphomas, which may help destroy them. This drug is used mainly to treat some other types of skin cancers, but some doctors might also use it to treat early forms of skin lymphoma. It can cause redness, swelling, and itching in the place where it is used.

### Treatments that affect the whole body

These treatments are most useful for skin lymphomas that are widespread or are growing quickly.

**Photopheresis**, also known as **ECP**: This treatment can kill lymphoma cells, as well as help the body's immune system attack them.

For each treatment, the person's blood is collected from a vein. It goes into a special machine that separates out the lymphocytes (including lymphoma cells). The cells are mixed with a drug that makes them sensitive to light, and then they're exposed to UV light. They are then mixed back in with the rest of the blood and put back into the patient through a vein. The treatment usually takes a few hours.

This treatment can make the skin very sensitive to sunlight, so you will need to protect yourself from the sun in the days after treatment.

**Chemotherapy (chemo):** Chemo drugs that are taken as a pill or injected in the blood can reach all parts of the body. Chemo may be used if the lymphoma in the skin is more advanced and no longer getting better with other treatments, or if it has spread to other parts of the body.

Many different chemo drugs can be used. Often a single drug is tried first, but sometimes more than one drug is used. Chemo is given in cycles or rounds, which last

a few weeks. Each round of treatment is followed by a break.

Chemo can make you feel very tired, sick to your stomach, and cause your hair to fall out. These problems tend to go away after treatment ends. Some chemo drugs can have other side effects. There are ways to treat most chemo side effects. If you have side effects, talk to your cancer care team so they can help.

**Targeted drugs:** Targeted drugs work by aiming at parts of cancer cells that make them different from normal cells. These drugs don't work the same way as chemo drugs. They can sometimes help when chemo drugs don't, and they often have different side effects. Some are given into a vein, while others are taken as pills.

The side effects depend on which drug you are taking. Talk to your cancer care team to learn more about which side effects you might have.

**Immune treatments:** Some drugs work by helping the body's immune system attack the cancer cells. These drugs are given into a vein.

The side effects depend on which drug you are taking. Talk to your cancer care team to learn more about which side effects you might have.

**Retinoids:** These are drugs related to vitamin A. They can be taken in pill form for skin lymphomas that are widespread.

Side effects can include headaches, feeling sick to your stomach, fever, thyroid problems, and eye problems. Some retinoids can cause more serious side effects, like fluid buildup in the body.

**Stem cell transplant:** This treatment (also known as a bone marrow transplant) might be an option if other treatments are no longer working. It lets doctors give higher doses of chemo than they normally could (because of the severe side effects it would cause).

First, a person gets high doses of chemo. This can destroy the bone marrow, where new cells are made. To help with this, the person then gets an injection of stem cells (which most often come from another person). The stem cells go to the bone marrow, where they start to make new blood cells.

A stem cell transplant is a complex treatment that can cause major side effects, and you might need to stay in the hospital for a long time. It should only be done at a center that has a team of doctors who are experts in this treatment.

## Clinical trials

Clinical trials are research studies that test new drugs or other treatments in people. They compare standard treatments with others that may be better.

If you would like to learn more about clinical trials that might be right for you, start by asking your doctor if your clinic or hospital conducts clinical trials. See [Clinical Trials](#)<sup>8</sup> to learn more.

Clinical trials are one way to get the newest cancer treatment. They are one of the best ways for doctors to find better ways to treat cancer. But they might not be for everyone. If your doctor can find one that's studying the kind of cancer you have, it's up to you whether to take part. And if you do sign up for a clinical trial, you can always stop at any time.

### **What about other treatments I hear about?**

When you have a skin lymphoma you might hear about other ways to treat the cancer or treat your symptoms. These may not always be standard medical treatments. These treatments may be [vitamins, herbs, special diets, and other things](#)<sup>9</sup>. You may wonder about these treatments.

Some of these might help, but many have not been tested. Some have been shown not to help. A few have even been found to be harmful. Talk to your doctor about anything you're thinking about using, whether it's a vitamin, a diet, or anything else.

### **Questions to ask the doctor**

- Will I need to see any other types of doctors?
- What [treatment](#)<sup>10</sup> do you think is best for me?
- What's the goal of this treatment? Do you think it could cure the lymphoma?
- Will I need other types of treatment, too?
- What's the goal of these treatments?
- What side effects could I have from these treatments?
- What can I do about side effects that I might have?
- Is there a clinical trial that might be right for me?
- What about special vitamins or diets that friends tell me about? How will I know if they are safe?
- Do I need to start treatment right away?
- What should I do to be ready for treatment?
- Is there anything I can do to help the treatment work better?
- What's the next step?

## What will happen after treatment?

Some people might keep getting treatment, while others might be finished at some point. You'll be glad when treatment is over. But it's hard not to worry about cancer coming back. Even when cancer never comes back, people still worry about it. For years after treatment ends, you will see your cancer doctor. Be sure to go to all of these [follow-up visits](#)<sup>11</sup>. You might have exams, blood tests, and scans to see if the cancer has come back. At first, your visits may be every few months. Then, the longer you're cancer-free, the less often the visits are needed.

Having cancer and dealing with treatment can be hard, but it can also be a time to look at your life in new ways. You might be thinking about how to improve your health. Call us at 1-800-227-2345 or talk to your cancer care team to find out what you can do to feel better.

You can't change the fact that you have cancer. What you can change is how you live the rest of your life – making healthy choices and feeling as good as you can.

## Hyperlinks

1. [www.cancer.org/cancer/cancer-basics/what-is-cancer.html](http://www.cancer.org/cancer/cancer-basics/what-is-cancer.html)
2. [www.cancer.org/cancer/skin-lymphoma/about/types-of-skin-lymphoma.html](http://www.cancer.org/cancer/skin-lymphoma/about/types-of-skin-lymphoma.html)
3. [www.cancer.org/cancer/skin-lymphoma/detection-diagnosis-staging/signs-and-symptoms.html](http://www.cancer.org/cancer/skin-lymphoma/detection-diagnosis-staging/signs-and-symptoms.html)
4. [www.cancer.org/cancer/skin-lymphoma/detection-diagnosis-staging/how-diagnosed.html](http://www.cancer.org/cancer/skin-lymphoma/detection-diagnosis-staging/how-diagnosed.html)
5. [www.cancer.org/cancer/skin-lymphoma/detection-diagnosis-staging/staging.html](http://www.cancer.org/cancer/skin-lymphoma/detection-diagnosis-staging/staging.html)
6. [www.cancer.org/cancer/skin-lymphoma/treating/skin-directed-treatments.html](http://www.cancer.org/cancer/skin-lymphoma/treating/skin-directed-treatments.html)
7. [www.cancer.org/cancer/skin-lymphoma/treating/whole-body-treatments.html](http://www.cancer.org/cancer/skin-lymphoma/treating/whole-body-treatments.html)
8. [www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html](http://www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html)
9. [www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html](http://www.cancer.org/treatment/treatments-and-side-effects/complementary-and-alternative-medicine.html)
10. [www.cancer.org/cancer/skin-lymphoma/treating/specific-types.html](http://www.cancer.org/cancer/skin-lymphoma/treating/specific-types.html)
11. [www.cancer.org/cancer/skin-lymphoma/after-treatment/follow-up.html](http://www.cancer.org/cancer/skin-lymphoma/after-treatment/follow-up.html)
12. <http://www.cancer.org>

## Words to know

**Biopsy** (BY-op-see): taking out a small piece of tissue to see if there are cancer cells in it

**Cutaneous** (cue-TAY-nee-us): related to the skin

**Dermatologist** (der-muh-TAH-luh-jist): a doctor who treats diseases of the skin

**Hematologist** (hee-muh-TAH-luh-jist): a doctor who treats disease of the blood, including some lymphomas

**Immune system**: the body system that fights infection

**Lymph nodes**: small, bean-shaped collections of immune system tissue found all over the body

**Lymphocyte** (LIM-fo-site): a type of white blood cell that helps fight infection; this is the cell in which skin lymphoma starts

**Topical medicine**: a medicine put right on the skin

**Ulceration** (ull-ser-AY-shun): the breaking open of the top layer of the skin

## How can I learn more?

We have a lot more information for you. You can find it online at [www.cancer.org](http://www.cancer.org) (<http://www.cancer.org>)<sup>12</sup>. Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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