



# Living With **CTCL**

# Taking Care of YOU



If you have been living with cutaneous T-cell lymphoma (CTCL), you know it can affect the way you feel. It also can affect how you live your life.

Symptoms and treatment side effects can make it hard to work or enjoy social time and hobbies. Some days you might feel sad, scared, or lonely. It may be hard to deal with the changes in your appearance. You may feel very tired. Keeping up with your normal daily activities and routines could become difficult. Sometimes you may wonder if you have the strength to overcome the challenges.

But there are things you can do to help take care of yourself — your *whole* self, both your body and your mind. And taking care of your whole self is an important part of coping with a chronic illness like CTCL.

This booklet can help you take care of your whole self. It offers you:

- Information about CTCL
- Helpful everyday ideas for living with CTCL
- Suggestions to help you deal with treatment side effects
- Places to turn for support



CTCL is a type of cancer that affects certain kinds of white blood cells, called *T-lymphocytes*.

CTCL is in the lymphoma family. There are many forms of CTCL. CTCL is not skin cancer, but it shows up on the skin. In a small number of people, the disease may spread to the blood, the lymph nodes, and other internal organs.

The 2 main types are **mycosis fungoides** (my-KOE-sis fung-GOY-deez) and **Sézary** (SAY-zah-ree) **syndrome**.

- **Mycosis fungoides (MF)** is the most common type of CTCL. It primarily affects the skin. It can appear anywhere on the body but tends to affect areas protected from the sun by clothing. There may be flat, red, and scaly patches that look like eczema or dermatitis. Or there can be thicker, raised lesions called *plaques*. There may even be large tumors. People with MF may have pruritus, an intense itching of the skin that scratching does not seem to stop.
- **Sézary syndrome (SS)** is the leukemic form of MF. It affects the skin *and* the blood. Tumor cells are found in the blood (leukemia), and lymph nodes are larger than normal. Skin may be red from head to toe. Skin may severely flake and burn. It may feel hot, sore, itchy, and very sensitive. Some people may develop other symptoms such as skin thickening on the palms of their hands and soles of their feet, brittle fingernails, hair thinning or hair loss, drooping eyelids, and an inability to close their eyes.

## CTCL centers

Treatment for CTCL may be given in different places, such as a doctor's office, a local hospital, or a special CTCL center. There are more than 30 CTCL centers in the United States.

To find a CTCL center near you, visit [www.clfoundation.org](http://www.clfoundation.org) or call the Cutaneous Lymphoma Foundation at 248-644-9014 for names of doctors in your area who may be familiar with the disease.

# Treating CTCL

## The goals of treatment are to help:

- Clear up patches, plaques, or tumors on the skin
- Reduce the number of T-lymphocytes in the blood
- Relieve CTCL symptoms (such as itching, burning, and skin redness)

Treatment is aimed at helping to clear the disease. Treatment may not cure CTCL, but it may help to put the disease into long-term remission (a time when the disease is not active).

CTCL treatment varies from one person to another. Treatment is based on the type of CTCL you have, the extent of your disease, your symptoms, your age, your overall health, and your daily activities. Your doctor may also consider certain treatment options that are available to you locally.

## Treatment side effects you may experience

CTCL treatments work to relieve your physical CTCL symptoms. But treatments may cause uncomfortable side effects that make your daily life more difficult. Let your doctor know if you experience any of these side effects from CTCL treatment:

- Skin irritation and inflammation
- Redness, rash, and itching
- Heat, tenderness, or burning sensation (like sunburn)
- Fatigue or depression

Your doctor and nurse can help manage your side effects. This can help you stay on your treatment and get relief.

## Treatment choices for CTCL are directed at either the skin or the entire body

### Skin (topical)

- **Topical medicines** — These medicines are placed directly onto the skin to reduce inflammation and help improve the condition of the skin. Topical medicines include corticosteroids, chemotherapies, and retinoids (made from vitamin A).
- **Light therapy** — This therapy exposes the skin to special ultraviolet (UV) light rays that may eliminate the cancerous cells from the skin.
- **Radiation therapy** — This therapy helps to destroy cancer cells using high-dose x-rays directed at just 1 spot on the skin or at the entire body.

### Entire body (systemic)

- **Biologic therapies (or immunotherapies)** — These therapies try to get the body's own immune system to fight the CTCL.
- **Retinoids** — These are vitamin A-related compounds that are active in treating CTCL.
- **Extracorporeal photopheresis** (EK-strah-core-PORE-ee-uhl FOE-toe-fuh-REE-sis) — This therapy involves taking blood from a vein and passing the blood through a machine where it is treated with a drug that makes the white blood cells (particularly T-lymphocytes) more sensitive to UV light. The white blood cells are exposed to UV light, which kills the cancerous cells, and then are returned to the body.
- **Chemotherapy** — Anticancer drugs, used alone or in combination, are put into a person's bloodstream and travel through the body, destroying cancer cells.
- **Bone marrow or stem cell transplantation** — In certain cases, bone marrow (or stem cells) is taken from the patient or a donor and stored. When the patient completes intensive chemotherapy, the bone marrow (or stem cells) is returned to the patient.

For more information about CTCL treatments, visit the Cutaneous Lymphoma Foundation online at [www.clfoundation.org](http://www.clfoundation.org).

# Managing Skin Changes

You and your doctor may have a treatment plan in place to treat your CTCL and help relieve your symptoms. But there are other things you can do to help yourself feel better.



## Oral medicines and topical creams

Talk with your doctor about over-the-counter and prescription medicines that may help relieve skin discomfort, such as heat sensitivity, dryness, cracking, flaking, or severe itching.

These include cooling lotions, creams, and antihistamines.

Symptoms	Treatment
Dryness Flaking Itching	<b>Lotions and creams</b>
Severe itching	<b>Antihistamines and other medicines</b>



## Baths and skin care

Oatmeal baths may feel soothing to your irritated skin. You can buy oatmeal bath products at your local pharmacy. Bathing or showering in lukewarm (not hot) water with mild soap or cleanser also

helps soothe the skin. Bubble-bath products and after-bath powders may cause your skin to itch more, so it is best to avoid using them. Rinse yourself completely and pat (do not rub) your skin lightly to dry. Applying moisturizer after bathing is very important. It can help care for your skin and prevent dryness and itching. Talk with your doctor or nurse about a moisturizer for you.



## Laundry

Try switching to a very mild laundry detergent. Some commercial detergents and fabric softeners may irritate sensitive skin. Try adding vinegar (1 teaspoon per quart of water) to your laundry rinse cycle. This helps remove all the soap from your clothes, which also may help lessen skin irritation.



## Clothing

Wearing loose-fitting, lightweight clothing can help cut down on skin irritation and itching.



## Itch relief

Try applying ice or a cool, damp washcloth to areas of your skin that are especially itchy. Rubbing your skin and applying pressure to the skin are better for your skin than scratching. Talk with your doctor about medicines that may help relieve itching, such as antihistamines or antianxiety medicines.



## Sun protection

Too much sun can be damaging to one's skin. Use sunscreen. Wear a cap or hat with a brim. You also may need to wear long sleeves and long pants year-round. If you receive light therapy as part of your treatment, your doctor may tell you to wear UV-blocking sunglasses. For some people with CTCL, small amounts of sunlight may be good for the skin. Talk with your doctor to learn if this is right for you.



## Facing the challenges

CTCL is a disease that can change the way you look. With CTCL, you can have dry patches, red skin, plaques, skin ulcers, and tumors. You can also have severe itching and discomfort. All of this can affect how you feel about yourself. You may find that you have lost interest in being with others, which can make you feel alone and depressed.

CTCL can also affect your life in other physical, practical, and emotional ways.

## Physical effects

You may have difficulty:

- Sleeping because of itching and discomfort
- Finding comfortable clothes to wear
- Following your normal routine because skin care may take extra time
- Using your hands because of scaling and cracking
- Working or exercising because of fatigue or the condition of your skin
- Being intimate because you may feel self-conscious about your physical appearance or because of fatigue or restrictions resulting from specific topical treatments

## Practical effects

Physical discomfort and fatigue may cause you to have difficulty with certain activities, such as:

- Working
- Enjoying your hobbies
- Cooking or cleaning house
- Doing errands

## Emotional effects

You may feel:

- Embarrassed by the way you look
- Lonely because you are spending less time with other people
- Scared about the disease and what your future may hold
- Depressed because of the changes the disease has caused
- Angry at the diagnosis and the limits the disease has put on you

## Talking with others can help

You may wonder how you can live — and enjoy life — with CTCL. You are not alone. Others have felt the same way. And they have found ways to manage the challenges and start enjoying life again. Talking about these concerns and feelings with a family member, friend, or someone on your healthcare team can help you find solutions and support.



CTCL will present you with challenges. But try to remember that you do not have to cope with your illness alone. By reaching out to others for information and the support you need, you are taking care of your whole self — a key to coping with your CTCL.

### Your CTCL support team might include:

- Your doctor and healthcare team
- Family and friends
- A counselor or therapist
- A CTCL support group
- Others with CTCL
- The Cutaneous Lymphoma Foundation and related organizations (see the list of resources on page 12)
- People in your spiritual community

It may not be easy for you to ask for help or to even know what kind of help you need. You may need different types of support at various times during your illness. Luckily, help and support come in many different forms. Today you may need someone to listen to your concerns or offer you guidance. Another day you might need practical help — someone to drive you to treatment or run an errand. Family members or friends often want to help. When you reach out to them for support, everyone may benefit.

Talking with other people who have CTCL also can be helpful. They have walked in your shoes and really understand what you are going through. That is one reason why support groups can be so useful. In a CTCL support group, people share experiences and information and offer each other tips on coping. The Cutaneous Lymphoma Foundation can provide you with information on how to find a CTCL group.

You may find it helpful to talk about your most difficult thoughts and feelings with someone who has experience counseling people with cancer, such as a psychologist or an oncology social worker. You also may want to reach out to a member of your faith or spiritual community.

Remember, you do not have to face this disease alone.

## Resources

The Cutaneous Lymphoma Foundation and the other organizations listed here are dedicated to helping you find the information and support you need.

- **Cutaneous Lymphoma Foundation**  
248-644-9014  
[www.clfoundation.org](http://www.clfoundation.org)
- **American Academy of Dermatology**  
1-866-503-7546  
[www.aad.org](http://www.aad.org)
- **American Cancer Society**  
1-800-227-2345  
[www.cancer.org](http://www.cancer.org)
- **Association of Cancer Online Resources**  
(Patient and caregiver exchange)  
<http://listserv.acor.org/archives/ctcl-mf.html>
- **CancerCare**  
1-800-813-4673  
[www.cancer.org](http://www.cancer.org)
- **Lymphoma Research Foundation**  
1-800-500-9976  
[www.lymphoma.org](http://www.lymphoma.org)
- **National Cancer Institute**  
1-800-422-6237  
[www.cancer.gov](http://www.cancer.gov)
- **National Coalition for Cancer Survivorship**  
1-877-622-7937  
[www.canceradvocacy.org](http://www.canceradvocacy.org)
- **The Leukemia & Lymphoma Society**  
1-800-955-4572  
[www.lls.org](http://www.lls.org)

Other booklets available from the Cutaneous Lymphoma Foundation or your doctor include:

- *Taking an Active Role in Managing Your CTCL Care*
- *Your CTCL Treatment Guide*

Now that you have read about CTCL and its treatment, be sure to talk with your doctor about what is right for you.



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