



Taking an  
**Active Role in Managing  
Your CTCL Care**





## This booklet may help answer questions about CTCL and working with your healthcare team.

Asking questions and learning the answers is the first step to being involved in your healthcare. Taking this step can help you feel a sense of control. And that can help you feel better.

This booklet also offers the support and suggestions of people living with CTCL. It provides tips for talking with your doctors and other members of your healthcare team. And it offers ways to stay involved in your health and in the care of your disease.

Cutaneous T-cell lymphoma (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 involves the skin. It also can involve the blood, the lymph nodes, and other internal organs.

CTCL is rare. Only about 1,500 new cases of CTCL are reported in the United States each year. The cause is not known. CTCL is more common among men than women. People older than 50 years are more likely to develop CTCL than younger people.

## Common kinds of CTCL

**Mycosis fungoides** (my-KOE-sis fung-GOY-deez) and **Sézary** (SAY-zah-ree) **syndrome** are the 2 main types of CTCL.

- **Mycosis fungoides (MF)**, the most common type of CTCL, 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. Or there could be thicker, raised lesions called *plaques*. There may even be large tumors.
- **Sézary syndrome (SS)** is the leukemic form of MF. SS affects the skin *and* the blood. Skin may be red, often from head to toe. Tumor cells are found in the blood (leukemia), and lymph nodes are larger than normal. Skin may be hot, sore, and itchy. It may severely flake and burn.

"I was totally shocked.  
What's going to happen to me now?  
I have too much to live for and  
want to beat this."

— Armen, patient with CTCL

# Your CTCL Healthcare Team








During the course of your treatment, members of your healthcare team may include the following:

The most important member of your healthcare team is **YOU.**

Many people with cancer feel better when they play an active role in their own healthcare. Some ways to stay involved in your care are:

- Gathering information to make treatment decisions with your healthcare team
- Asking questions of your healthcare team
- Telling your healthcare team how you are feeling
- Learning about treatment choices and side effects
- Seeking relief from itching and pain
- Asking others for support

Dermatologist	A doctor who specializes in the diagnosis and treatment of skin diseases. Some dermatologists specialize in treating CTCL.	
Oncologist	A doctor who specializes in diagnosing and treating cancer.	
Radiation oncologist	A doctor who uses radiation to treat cancer.	
Nurse practitioner	A registered nurse with advanced education and training who can help manage disease, symptoms, and side effects of treatments.	
Your care partner	You might want to ask a family member or friend to give you support. This person could help you <ul style="list-style-type: none"> <li>• Learn about your illness and treatment options.</li> <li>• Talk with your healthcare team.</li> <li>• Assign important tasks or chores to others.</li> <li>• Help with insurance matters.</li> <li>• Drive you to and from treatment.</li> <li>• Find resources.</li> </ul>	

## CTCL centers

Treatment 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 treatment 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.

"Learning about my disease, treatments, and side effects gave me a sense of control, and I was able to determine how this would affect my daily life."

— Judy Jones, Executive Director  
Cutaneous Lymphoma Foundation

"Early diagnosis gives us the opportunity to put CTCL in remission with simple therapies."

— Madeleine Duvic, MD

Each person's treatment for CTCL varies.

Treatment is based on your:

- Type of CTCL
- Extent of disease
- Symptoms
- Age and activity level
- Overall health
- Access to treatment options

Treatment choices for CTCL are directed at either the skin (topical) or the entire body (systemic). Be sure to talk about these choices with your doctor.

## Treatments for CTCL

### Skin (topical)

- **Medicines you put onto the skin** include topical corticosteroids, chemotherapies, and retinoids (made from vitamin A).
- **Light therapy (phototherapy)** exposes the affected areas of the skin to special ultraviolet (UV) rays.
- **Radiation therapy** uses high-dose x-rays and can include:
  - Local radiation to single areas of the skin
  - Total skin electron beam radiation to the entire body

### Entire body (systemic)

- **Biologic therapies (or immunotherapies)** use the body's own immune system to fight CTCL.
- **Retinoids** are vitamin A-related compounds that are active in treating CTCL.
- **Extracorporeal photopheresis** (EK-strah-core-PORE-ee-uhl FOE-toe-fuh-REE-sis) involves taking blood from a vein and passing it 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 blood is then exposed to UV light and returned to the body.
- **Chemotherapy** uses a single anticancer drug or a combination of drugs.
- **Bone marrow or stem cell transplantation** is used 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.



Cancer changes your life in many ways. It can create physical, practical, and emotional challenges. Talking with your healthcare team, family, or close friends can help you understand more, plan more, and take more control.

Here are some of the challenges you may face and some ways you can deal with them.

## Physical needs

At times, CTCL may be uncomfortable or painful. There may be discomfort from the illness or from the treatment. For example:

- You may have severe itching. Itching may be so severe you might lose sleep.
- Your skin may feel hot and sore. This may be a sign of infection.
- Your skin may severely flake or burn.
- Skin tumors may become inflamed. This can be uncomfortable.

## What you can do about uncomfortable symptoms or side effects of treatment:

- **Talk with your doctor.** There are ways to control symptoms or side effects and treat infections. Your doctor can give you medicine that can help.
- **Soothe your skin.** Taking oatmeal baths and using mild soaps can be soothing. Applying a moisturizer after bathing can also help with dry skin.
- **Use distraction.** Try listening to music or taking a walk.
- **Keep a diary to describe your symptoms.** You can write down what you think causes your discomfort and what helps you feel better. Share this information with your doctor.
- **Use the treatment tracker in *Your CTCL Treatment Guide*** to keep track of your response to treatment and any side effects you may have.

# Knowing Your Needs

## Practical needs

Going for treatments over a long period of time may require you to adjust your work or personal responsibilities. You also may need to change your daily routines. For instance, you may need to change your work schedule if you are going to treatment more than once a week. Or you may need someone to drive you to treatment if you feel tired.

## Help for meeting your everyday needs

- **Think about asking others for help**, such as family members, friends, other people with cancer, people from your support group, or people from your spiritual community.
- **Consider hiring someone or finding a volunteer** to help with household or yard chores.
- **Ask your doctor or insurance company about skilled care** to help with special needs, such as skin care, dressing changes, or checking your skin condition.

*"I try to make sure I know what my energy level is before I take on an activity."  
— Beverlee, patient with CTCL*

## Emotional needs

People with CTCL have many different feelings. At times, you may:

- Be angry, afraid, or worried
- Not really believe you have cancer
- Feel out of control and unable to care for yourself
- Feel sad, guilty, or lonely
- Wonder if you will live or die
- Feel helpless

## Help for meeting your emotional needs

Learn as much as you can about your cancer and its treatment.	This can help you feel more in control. A good source of information is the Cutaneous Lymphoma Foundation at <a href="http://www.clfoundation.org">www.clfoundation.org</a> . Other important resources are listed on the inside back cover of this booklet.
Ask questions.	Tell your healthcare team if you do not understand what they are saying or if you need more information.
Find a support group.	Other people also have cutaneous lymphoma. These groups allow people to share their feelings, offer coping tips, and learn what is new in cancer treatment. For help finding a group, visit the Cutaneous Lymphoma Foundation at <a href="http://www.clfoundation.org">www.clfoundation.org</a> .
Find someone to talk with.	Some people prefer to talk with someone one-on-one. Ask your doctor or nurse to refer you to a counselor. Or talk with someone from your spiritual community, a close friend, or a family member.
Have hope.	Some doctors think that hope may actually help the body deal with cancer. It can help to remember that: <ul style="list-style-type: none"><li>• More people are surviving cancer today than in the past.</li><li>• Many people with CTCL lead active, normal lives even during treatment.</li></ul>

*"The online support group helped me realize that my husband and I were not alone in dealing with his CTCL."*

*— Cathy, caregiver*



Here are some ways to help you talk with the people involved in your care and in your life.

## Your healthcare team

Talking openly and honestly with your doctor and the rest of your healthcare team is important. You may want to:

- Write down your questions about your illness, treatment, or side effects and take them with you when you visit your doctor.
- Take a family member or close friend along to doctor appointments. This person can help you ask questions and write down or remember answers.
- Tape-record your healthcare visits with your doctor so you can listen to the information later (first get permission from the doctor).

## Your family or close friends

You may not feel like talking, especially at first. It is OK to tell family or close friends if you do not want to talk or if you are not ready to talk. When you *are* ready to talk, remember that sharing your feelings with others can be a great support. Although some family or close friends may be very supportive, others may not be ready to accept that you have cancer. Think about the people who may be able to listen to and support you. Try to talk openly with them about your fears as well as your hopes and dreams.

Family or friends may ask how they can help. Offer *specific ways* that they can. For instance, you might ask them to pick up some groceries, take a walk with you, bring a movie you can watch together, or just listen to you.

## Resources

- **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)
- **Association of Cancer Online Resources**  
(Patient and caregiver exchange)  
<http://listserv.acor.org/archives/ctcl-mf.html>
- **CancerCare**  
1-800-813-4673  
[www.cancercare.org](http://www.cancercare.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)
- **The Leukemia & Lymphoma Society**  
1-800-955-4572  
[www.lls.org](http://www.lls.org)

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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