

CTCL and the changes it can bring

Welcome to the second issue of *CTCL Links*. In this newsletter, you'll learn ways to manage the unseen changes of CTCL so that you can live better with the disease.

Although physical changes are the most visible in cutaneous T-cell lymphoma (CTCL), these are not the only changes you may experience.

Redness, scaling, rashes, and tumors on the skin are some of the *visible* changes of CTCL. But there are other changes that may happen, too. Though not visible, these changes and the effect they can have on your daily life are every bit as real.

People with CTCL also may feel fatigue, isolation, pain, and depression, all of which can make living with CTCL difficult. You may not be able to keep these changes from happening. But learning what you can do about them may help you live with CTCL.

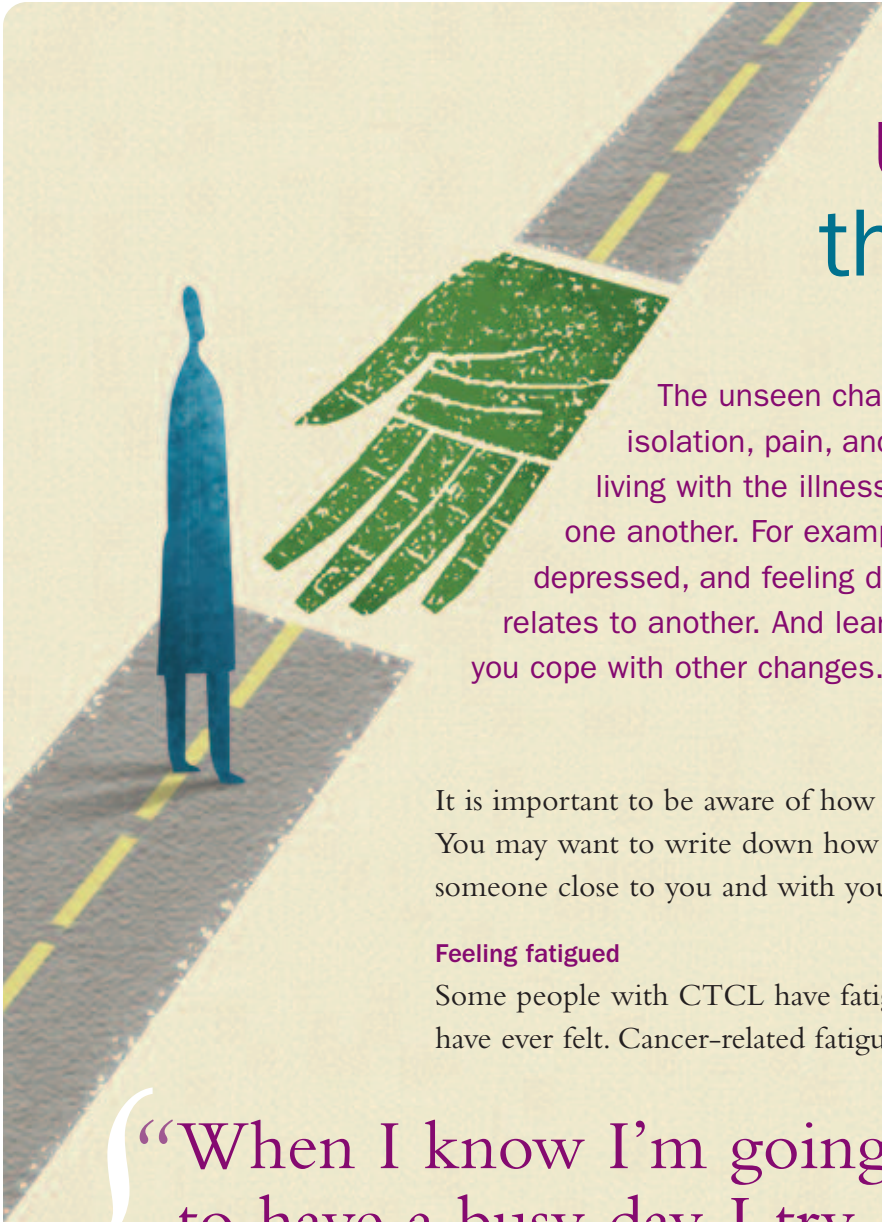
“You don't have any control over the fact that you have the disease. But you *do* have control over how you react to it.”

—Judy Jones
Executive Director, Cutaneous Lymphoma Foundation

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An illustration on the left side of the page shows a blue silhouette of a person standing on a grey road with yellow dashed lines. A large, green, textured hand is reaching down from the top of the road towards the person. The background is a light beige color.

Understanding and managing the unseen changes

The unseen changes that can happen with CTCL—fatigue, isolation, pain, and depression—add to the challenges of living with the illness. Often, these changes are connected to one another. For example, feeling fatigued can make you feel depressed, and feeling depressed can be very tiring. One feeling relates to another. And learning how to handle one change can help you cope with other changes.

It is important to be aware of how CTCL affects your feelings and your daily life. You may want to write down how you are feeling. Share the information with someone close to you and with your healthcare provider. They can help.

Feeling fatigued

Some people with CTCL have fatigue. Some say it is unlike any tiredness they have ever felt. Cancer-related fatigue can have a number of causes. Fatigue can be

a side effect of some medicines used to treat CTCL. Sometimes, fatigue can lead to depression. If you are tired and depressed, it may be difficult to take your medicine as prescribed. Be sure to let your healthcare provider know if fatigue prevents you from following your treatment plan.

“When I know I’m going to have a busy day, I try to pace myself.”

—Patient

Managing fatigue

There are many things you can do to manage fatigue. Here are some that cancer specialists recommend:

- Eat nutritious foods and drink plenty of liquids throughout the day.
- To save your energy, do the activities that are most important to you first. Rest between activities, and only do what you can manage.
- Let others help you with meals, errands, or chores.
- Talk with your healthcare provider about exercise.

Managing Changes caused by CTCL

Feeling isolated

People with various kinds of cancer may feel lonely and disconnected from others. With CTCL, you may not feel well enough to be with family or friends, and that may make you feel lonely. Friends and family members may sometimes stay away because they don't know what to say. Because so few people have CTCL, you may feel lonely because you think no one understands what you are going through.

Managing isolation

If you feel lonely, it may help if you try to keep in touch with others. You might feel better just by talking to a close friend, a family member, or a counselor. But many people say that what helps the most is talking with someone who understands what you are going through. Support groups are a great resource for this. You may want to talk with your healthcare provider about support groups you could join. Joining an online support group is another good way to be in touch with others with CTCL.

Experiencing pain

Some people with CTCL experience pain. CTCL pain may come from intense itchiness or open skin wounds. And, when people are in pain, they may feel fatigued, depressed, and isolated.

Managing pain

You do not have to just learn to live with pain, no matter what its source. Most pain can be managed.

Medicines can help. So can other treatments, like relaxation and imagery. When you talk with your healthcare providers, describe your pain in detail.

Let them know where your pain is, how it feels, how often it happens, and what makes it better or worse. That information will help them find the best treatment.

Feeling depressed

Depression is common in people living with cancer. Sadness and grief are perfectly normal responses to the changes that cancer brings. But if you are so down that you cannot carry out your usual activities and the feeling lasts for 2 weeks or more, it might be depression. Depression can make it difficult for you to stick with your treatment. Managing depression can help you feel better able to cope with your disease.

Managing depression

Recognizing that you have symptoms of depression is the first step to getting help. Cancer-related depression can be managed. Together, you and your healthcare provider can talk about what may help your depression. Your healthcare provider may recommend that you talk with a counselor and may also prescribe medicine to treat your depression.



Managing the changes of CTCL—Giving treatment a chance to work

Some of the unseen CTCL changes can make it difficult for you to stay with your treatment. Talking with your healthcare team can help you manage your feelings so they do not keep you from staying on your CTCL treatment.





Care-partner's corner

As a care partner, you play an important role in the life of the person with CTCL. But being a care partner can be challenging. Often, your own feelings and needs get put aside. Over time, it can be difficult to keep up with caregiving demands.

Have you felt some of these common care-partner emotions?

Anger

You may feel angry with yourself, family members, or the patient. Sometimes, anger comes from fear or worry.

Grief

You may be mourning the loss of your loved one's health or the life you had before illness.

Guilt

You may feel guilty that your own life and responsibilities keep you from helping enough. You may feel guilty for being healthy, or for not always being in a good mood.

Anxiety & depression

You may worry, have trouble relaxing, or feel sadness that won't go away.

Taking care of *you*

Taking care of yourself matters not only to you but to the person with CTCL. It matters to both of you that you feel supported and well.

Trying these steps may be helpful:

- ▶ **Make time for yourself to recharge your mind, body, and spirit.** It can help you be a better care partner. Try to do some nice things for yourself.
- ▶ **Comfort yourself** by exercising, napping, keeping up with a hobby, taking a drive, or visiting a friend.
- ▶ **Ask for help** from family and friends.
- ▶ **Join a support group** for caregivers. Or join the online CTCL listserv support group and link to other CTCL care partners.
- ▶ **Talk with a counselor.**

CTCL support is just a couple of clicks away

You may not be able to find a CTCL support group in your neighborhood, but you can find one online.

The CTCL Online Support Group was started by Judy Jones, executive director of the Cutaneous Lymphoma Foundation. Judy felt very much alone after she received a diagnosis of CTCL in 1990, and she knew she needed to connect with others who understood. Today, the listserv is a primary source of support and information for people with CTCL and their care partners.

Joining the listserv is easy.

Just go to **clfoundation.org**. Click on **On-line support** under the **SUPPORT** section on the left side of the screen. Click on the link provided just below the first paragraph on the next screen. Or e-mail: listserv@listserv.acor.org. Leave the subject area blank. In the message area, type: subscribe CTCL-MF *your name*.

Photos are for illustrative purposes only.

