

## CTCL and your quality of life

Welcome to the third issue of *CTCL Links*, a newsletter series to help you live each day with cutaneous T-cell lymphoma (CTCL).

When you have CTCL, how you feel *physically* matters. Yet there is much more to you and to your life than a list of physical symptoms. You, after all, are much more than your disease.

How CTCL makes you feel *emotionally* and how it affects your life also matter. While you may be focused mainly on the physical impact of the disease, it is important to consider *all* the ways CTCL can

affect you. This can make you better able to cope with those changes.

This issue of *CTCL Links* explores how CTCL can affect your quality of life, including your emotional well-being, your relationships with others, and how you function day to day. While CTCL can change your life, you can find sources of comfort and strength to help you.

There is much more to you and to your life than a list of physical symptoms. You, after all, are much more than your disease.



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# Quality of life — understanding the impact CTCL can have

How does CTCL affect the quality of your life? Because no two people with CTCL are alike, no two answers to this question will be the same. Studies of people with CTCL provide useful information about the general experience of CTCL. Your experience with CTCL, however, is your own.

## Learning from others with CTCL

Although having CTCL is your own experience, it may be helpful to learn about how CTCL affects the lives of others with the disease. People with CTCL report that the disease has a serious impact on what they do each day, including their ability to work, enjoy family activities, and get restful sleep. They also report feeling frustrated, depressed, and embarrassed by the disease. Worrying about the seriousness of the disease is common to people with CTCL regardless of the stage of their disease. As would be expected, people in later stages of the disease report a lower quality of life than those in earlier stages. Many people feel that the disease affects them financially. And most people feel that their CTCL treatment makes living with the disease more manageable.

“If you talk about it as a family, you’ll only grow closer and stronger.”

—Dawn, a mother, writer, and CTCL patient

## How is CTCL affecting your quality of life?

Understanding the ways CTCL is affecting you can help you find the support you need to have a better quality of life. Think about the emotional, physical, social, and functional impact of CTCL on your life. Be sure to share with your treatment team the impact CTCL is having on *all* areas of your life. They may have resources to help you.

## The Emotional Impact of CTCL

How do you feel emotionally about your disease?

For example:

- I feel sad or depressed about having CTCL.
- I feel worried or anxious about the disease and my future.
- I feel ashamed of my skin condition.
- I feel frustrated by my disease.

## The Physical Impact of CTCL

How do you feel physically?

For example:

- My skin hurts, itches, and bleeds.
- My skin is sensitive and irritated.
- Water bothers my skin.

## The Social Impact of CTCL

How does CTCL affect you socially?

For example:

- I want to stay home because of my CTCL.
- Showing affection to others is difficult because of my CTCL.
- My skin condition interferes with my sex life.\*

## The Functional Impact of CTCL

How does CTCL affect your activities and responsibilities?

For example:

- CTCL makes it hard for me to work.
- CTCL prevents me from getting a good night's sleep.
- CTCL makes it painful for me to wash dishes.
- CTCL makes it hard for me to do my daily activities.

\*The next issue of CTCL Links explores the impact CTCL can have on intimate relationships and offers ways to stay close with someone you care about.

# Changing your thinking

While you cannot control the fact that you have CTCL, you can change how you think about it. Lynne Wagner, PhD, a clinical psychologist at Northwestern University, helps people with CTCL move beyond black-and-white thinking, such as “I love working on model airplanes, so if I can’t do that, then I can’t enjoy my life,” to thinking more flexibly, such as “These are the cards I’ve been dealt, so what activities can I do?”

## HAVE YOU FOUND YOURSELF THINKING...

“I’m too embarrassed by my skin condition to go to the wedding.”

### Try recognizing your fears and tell yourself:

“This wedding means too much to me to let the condition of my skin stop me from attending.”

“CTCL keeps me from enjoying my large outdoor garden because I’m too tired to keep up with it.”

### Why not let yourself imagine what COULD be?

“I’ll grow an indoor container garden by the window.”

“I don’t want to bother my friends with my problems. They have busy lives.”

### It is okay to take a new approach and try thinking:

“My friends want to be there for me, as I have often done for them. That’s what friendship is all about.”

“I can’t do the dishes because my skin hurts.”

### Try to focus on what you CAN do:

“I can always use paper plates. Or, better yet, I’ll ask someone else to help do the dishes!”



## Finding what you enjoy

Sometimes, the most ordinary activity can bring the most joy. It may help to focus on what you *can* do rather than what you cannot. Consider trying the activities that you enjoy most, such as those listed:

- ✓ Reading a good book.
- ✓ Walking with your family pet.
- ✓ Watching your favorite sports team.
- ✓ Visiting with a friend.
- ✓ Playing chess or checkers.
- ✓ Listening to music.

Take out your list when you are feeling down. It can help to remind you of the many simple pleasures in your life.



# Care-partner's corner

When you are caring for someone with CTCL, your quality of life can change, too. While serving as a caregiver is valuable, your life has many other aspects to it as well. One important goal is to find balance between serving as a caregiver and being a person with your own interests and needs.

Think about how caring for someone with CTCL may be affecting your life. Are there ways you could think differently about CTCL and the role it plays?

## *a new way* of thinking

You know that CTCL has an impact on the person you care for. You may not realize, however, that CTCL may have changed the way you think about your life, too.

### Recently, have you found yourself saying

"I want to go to the concert, but I should stay with Joe when he is tired."

**Why not think of a solution that works for both of you?**

"Joe needs to rest. I can go to the concert and enjoy time with Joe when he wakes up."

"When my family or friends ask how I am, I should say, 'I'm fine.'"

**It's okay to be honest. You might want to say something like this:**

"When I'm feeling worried and stressed, it would help to talk with someone about my feelings."

"I can do this on my own."

**You don't have to do everything so give yourself a break.**

"I need help. I'll ask for the support I need."

"Others have it so much worse. I shouldn't complain."

**Be kind to yourself and acknowledge your true feelings.**

"I'm allowed to feel frustrated and overwhelmed. This is hard, and I'm doing the best that I can."

## Resource

The **Cancer Survival Toolbox** is a free resource for both patients and caregivers. It can help you develop skills in the areas of talking with others about healthcare issues, finding information, decision making, problem solving, and caregiving.

### Contact:

National Coalition for Cancer Survivorship  
1010 Wayne Avenue  
Suite 770  
Silver Spring, MD 20910  
301-650-9127  
[www.cancersurvivaltoolbox.org](http://www.cancersurvivaltoolbox.org)



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