

Living each day with CTCL

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

Whether you have recently received a diagnosis or have had CTCL (also called mycosis fungoides or Sézary syndrome) for many years, **living each day with CTCL is your own unique experience.** Only you know how you feel each day. And only you know what helps you. But learning how others cope with their disease each day can be a big help. Because it is so rare, you may not know others with CTCL. Reading *CTCL Links* may help you realize that you are *not* alone. There are others who share your experience. And there is much you can do to live each day with CTCL.

Continue to do what you enjoy, such as being with your family, or enjoying your hobbies.

With CTCL, you may be going through a lot. Along the way, you—and those who care for you—may need new ideas and more support. *CTCL Links* provides both. You can learn how the experience of CTCL differs from that of other diseases. That may give you perspective on what you have been going through and why you feel the way you do. Learning to be an active participant in your treatment can help you as well. You can get more from your treatment when you are actively involved and stick with it.

Your experience with CTCL is just that—your own. Along the way, *CTCL Links* will connect you to new ideas that can make a difference.

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Understanding the unique challenges of CTCL

CTCL differs from other kinds of cancer in ways that can matter to you. Those differences can add to the challenge of living with CTCL. Understanding those challenges does not solve them but can lead to new ways of thinking about them.

Adjusting to appearances

Unique to CTCL is that, unlike other blood cancers, it is visible. Because people with CTCL see the condition every day, “it remains in the forefront of their minds,” stated Dr. Steven Horwitz, a lymphoma expert. People with

Moving forward

“The cancer has a place in your life, but it doesn’t have to become your life.”

—Steven M. Horwitz, MD

CTCL may worry about their appearance and may choose to stay away from others. Or they may spend much time and effort on their appearance before leaving home, which adds to the stress of living with the disease. Yet being with others can provide the comfort that makes living with a chronic illness easier. It may help to keep in mind that appearances are only a small part of human relationships. Relationships that matter are made of much more than that.

Controlling the disease

The way CTCL is treated is unique not just to CTCL but to a certain group of cancers. For most people, CTCL is a chronic disease that is treated over time. It may not be curable, but for most people, it is controllable. “We usually don’t treat CTCL with the idea of getting rid of it. We treat it to control it,” said Dr. Horwitz. It may help to think of yourself as *living with CTCL over time*. You can then focus on what is truly important to you in your life.

Keeping cancer in its place

Figuring out how cancer fits into your life can be a challenge. As hard as it may be to do, it helps to focus on the cancer a little less. In fact, Dr. Horwitz contends, “It’s much harder to deal with if you focus on it all the time. If you can try to think of the illness as something you will continue to have but are very unlikely to die of, it may become less of a burden.”

To help you keep your cancer in the proper perspective, try to continue doing what you enjoy, such as having a career, being with your family, or pursuing your hobbies. “Then the cancer has a place in your life, but it doesn’t have to become your life,” said Dr. Horwitz.

Steven M. Horwitz, MD, is a medical oncologist specializing in the care of patients with lymphoma at Memorial Sloan-Kettering Cancer Center, New York, New York.

Actively participating in your treatment

In the past, patients were not expected to be actively involved in their treatment. Doctors simply told patients what to do and patients did it. Today, we know how important it is for patients to understand and participate in their treatment. This can help them get the most from their treatment and have better outcomes. Because you may be on CTCL treatment for a long time, it matters all the more that you are active in your care.

Feeling in control and making informed decisions

There are many benefits to being actively involved in your care. Fighting the loss of control that some people with CTCL feel is a key benefit. “When you are actively involved, you feel like you have more control over what’s going on,” advises Mary Ann Fieffer, APRN, an expert in CTCL care. Educating yourself about the disease and its treatment is the first step toward being more active in your care. “When you’ve researched your disease and the potential treatments, you can make more informed decisions about your care,” she said.

Getting the most from your treatment

While you are being treated for CTCL, only you know how you are feeling, what side effects you are having, and what issues you are facing. Your healthcare providers rely on you to share your concerns. That’s especially true for patients who take oral medicines as part of their CTCL treatment regimen. “Patients who are taking oral medicines need to know exactly how and when to take them,” said Ms. Fieffer. Working closely with your healthcare provider can help ensure that you understand your treatment. Because it is up to you to remember to take your medicine, it is also up to you to share issues that prevent you from taking your medicine as prescribed.



Tips for being an active participant

To help you be actively involved with your care, consider:

- ✓ **Writing your questions down before your doctor appointments.** Then, when the doctor comes in, you can say, “I have 3 questions for you today.”
- ✓ **Bringing along a friend or a family member.** He or she can help you understand and remember what you and your healthcare provider talked about during the visit.
- ✓ **Being completely honest.** Let your doctor and nurse know exactly how you are feeling. Tell them about any new symptoms, any side effects, and any changes in other medicines you are taking. Let them know, too, if there is anything that’s stopping you from taking your medicine as prescribed. Sticking with your treatment is very important in managing CTCL.

Mary Ann Fieffer, APRN, works with patients with CTCL at Yale Cancer Center in New Haven, Connecticut.



Care-partner's corner

Caregiving may be one of the most important, rewarding, and difficult things you will ever do. A care partner is a counselor, supervisor, researcher, accountant, nurse, driver, housekeeper, and more—often in a single day! It can be a challenge.

Here are a few things that may help:

1 Pace yourself.

To be able to provide care over time, be sure to conserve your energy. Take the focus off the cancer once in a while so that you can keep it in its place.

2 Take care of yourself.

Your physical health and emotional health matter to both of you. Many people with cancer feel better knowing that their caregivers are taking care of themselves, too.

3 Ride the roller coaster—

and know that it's normal. You may feel sad, worried, or angry one minute, and relieved and happy the next. Many care partners say that it's like a roller coaster of feelings. And all of those feelings are normal.

Taking care of you

- ▶ **Every day, do something just for you.** Even if you don't have much time, take a few minutes to read a book, work in the garden, or take a nap.
- ▶ **Set limits.** Find your own strengths and limitations as a care partner. It's OK to say, "I can do this, but I cannot do that."
- ▶ **Recruit a team.** You may be the captain of the team, but you do not have to be the whole team. Ask people to help you. Your team can include family members, friends, and healthcare providers.
- ▶ **Watch out for your own health.** Keep up with your own checkups. And remember to take your own medicines as prescribed.

Learn more about CTCL...

Consider attending one of the Cutaneous Lymphoma Patient Educational Forums listed below.

Boston, Massachusetts *† June 16, 2007	San Francisco, California *† September 15, 2007
Nashville, Tennessee * June 30, 2007	New York, New York *† October 12–14, 2007
Philadelphia, Pennsylvania * June 30, 2007	Minneapolis, Minnesota *† November 3, 2007

*Sponsored by the Cutaneous Lymphoma Foundation. †Sponsored by the Lymphoma Research Foundation.

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