

Staying close

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

Relationships can bring meaning to life. While work and hobbies can be fulfilling, it is often our relationships that enrich who we are and provide us comfort when we need it.

The comfort that comes from an intimate relationship can matter deeply when you have CTCL. Because CTCL is chronic, it is a condition that you and your partner will need to learn to live with over time. You may find that there are times when CTCL has a bigger impact on your relationship than other times.

CTCL symptoms can be both emotionally and physically painful, which can affect your intimate relationship. In addition to the worry that CTCL can cause, the visible skin symptoms of CTCL can affect a

person's feelings of attractiveness to a partner. This can change the way couples show each other affection, but it does not need to stop them from sharing an affectionate and intimate bond.

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In this issue of *CTCL Links*, you can learn about some of the ways CTCL can affect an intimate relationship. In all relationships, affection and touch are important ways to show care and concern. And in intimate relationships, sex can be one part of the physical affection couples share. Learn more about how you and your partner can maintain or enhance affection, touch, and sexual intimacy in your relationship. This can help you grow closer together.

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If you missed any of the first 3 issues of *CTCL Links*, please request one from your doctor.



Understanding the changes to your relationship

While having CTCL does not change what matters most in your relationship, it helps to be aware of the challenges CTCL can present to a relationship. This can help you protect and improve the intimacy you share.

Feeling alone even when you are not

In close relationships, there is much that you may share. However, because you have CTCL and your partner does not, you may feel that CTCL separates you. And because CTCL is not common, you may not know others who have the disease. This can cause you to feel alone. Withdrawing from your partner may be a natural reaction to your feelings of isolation; however, the comfort that a close relationship can bring is more important now than ever.

In addition to the feelings of isolation you may have, there are other ways that CTCL can impact you and your relationships. You may feel embarrassed about or ashamed of your skin condition. You may feel tired and depressed, both of which can affect how close you feel to your partner.

In one study, people with CTCL reported that the disease:

- Affected how close they could be with partners
- Affected their desire to be with others
- Made showing affection difficult
- Caused them to feel ashamed and unattractive
- Interfered with their sex lives

Not everyone with CTCL feels this way, but if you do, please know that you are not alone. There are ways you can manage the changes to your relationship so that you and your partner can enjoy affection and remain close.

It is helpful to be aware of the strain CTCL can place on your relationship. It is also important to focus on the strengths of your relationship. After all, you and your partner share more than the experience of having CTCL.

Facing the challenges together

Living with CTCL *together*, you and your partner may find that you share a deeper bond than ever. Talking openly about the changes to your relationship can help you remain close. Physical affection and sexual intimacy can also improve your relationship and your sense of well-being. The article on the next page may help you to restore intimacy to your relationship.



Growing closer together

If CTCL has affected the intimacy you enjoy with your partner, you may want to “start at the beginning,” suggests Les Gallo-Silver, ACSW, director of clinical programs for CancerCare. Think back to when you first met. You may have approached your relationship gently and gradually then. When your relationship is affected by CTCL, improving the intimacy you share with your partner is also a gentle and slow process. “If someone has a hip replaced, he or she starts off standing, not running,” says Gallo-Silver.

Talking it over

Open communication is at the heart of improving the intimacy you share with your partner. Keeping an open mind about ways you can express and experience intimacy can make a difference. While your experience of intimacy may change because of CTCL, finding a “new normal” can be satisfying, too. “There are many ways that people enjoy each other physically,” Gallo-Silver points out. Understanding the value of touch in relationships is an important next step in restoring intimacy.

The importance of touch

As human beings, we are designed to be “social and connected,” says Gallo-Silver. And touch is a way human beings “communicate their involvement with each other.” So, even if CTCL affects some parts of the body, “we have sensations throughout our bodies...and there is always somewhere on the body you can be touched that will feel comforting and good.” Talk with each other about where and how to touch. For some, avoiding the affected areas entirely is the right choice. Other couples find that gently touching the affected areas communicates acceptance and support for the person with CTCL.

“As human beings, we are designed to be ‘social and connected.’”

—Les Gallo-Silver, director of clinical programs for CancerCare

Taking it step-by-step

Kissing can be a next step to restoring intimacy. In long-term relationships, kissing can sometimes become brief and routine. When couples try to slow down the process of kissing, it can be “wonderfully connective and very tender,” Gallo-Silver says. For some couples, cuddling and kissing are ways to stay close. For others, lovemaking is important, too. If you choose to be sexually active with your partner, talking openly about what is comfortable will help both of you.

Learning more

You may want to talk with your doctor about any concerns you have about being sexually active. Your doctor may suggest ways to

manage fatigue, depression, or other symptoms that can affect intimacy. You may also choose to protect affected areas with clothing so that lovemaking can be comfortable.





Care-partner's corner

Communication is a key part of caregiving. It can help break through the isolation that some people with cancer and their care partners feel. There are many ways to communicate meaningfully. But at the core of all good communication is one thing: **listening with your heart.**

Staying emotionally and physically close

You may find it hard to talk about sensitive issues, such as how CTCL may be affecting your relationship. You may feel guilty about shifting the focus away from cancer. But being emotionally close to someone and wanting physical affection are important desires for *all* people. “Restoring intimacy restores a sense of balance and reassurance,” says Les Gallo-Silver, ACSW, director of clinical programs for CancerCare. Remaining physically and emotionally close can give people “a sense that their life is more normal.”

Recognizing the obstacles

Several things may get in the way of intimacy.

Care partners may feel:

- Unsure of how to talk about intimacy
- Fearful that touching will be uncomfortable or painful
- Worried that their partners may not feel ready to be physically affectionate

What you can say

It is sometimes hard to find words to express your feelings. Here are several things that you might say:

- “I miss you. When you’re ready to be close, I’m ready too.”
- “I’m not sure how to say this, but I’d like to be closer to you.”
- “I love you and want to still be able to touch you. Let’s work together to figure out how.”

It is helpful not to accuse or demand. Avoid saying things like “You never touch me anymore” or “I’m frustrated. When are you going to be ready?”

What you can do

- Help your partner feel closer to you by offering love, support, and understanding.
- Know that there are many ways to express affection if your partner does not feel ready for sexual activity.
 - Hugging, holding hands, fondling, caressing, kissing, and cuddling can bring you closer together.
- Talk with your partner, and listen carefully to each other. For help in expressing your feelings, try meeting with a counselor or social worker.

Learning more about intimacy

The booklets listed below can provide useful information for both the care partner and the person with CTCL.

Sexuality and Cancer — For the Woman Who Has Cancer and Her Partner
Sexuality and Cancer — For the Man Who Has Cancer and His Partner

These booklets are available from:
American Cancer Society
www.cancer.org
1-800-ACS-2345 (1-800-227-2345)



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