



CANCERcare®

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# fact sheet

## COPING WITH CUTANEOUS T-CELL LYMPHOMA

A diagnosis of cutaneous T-cell lymphoma (CTCL) likely raises many questions and concerns. However, it is important to keep in mind that there are many sources of information and support available to help you cope with this diagnosis. This fact sheet is intended to help you learn about CTCL, find answers to your questions and seek sources of support.

### WHAT IS CTCL?

CTCL is a rare cancer affecting white blood cells called T-lymphocytes (T-cells). T-cells are important to your immune system, which helps the body fight infection. When T-cells start to grow too quickly, they can accumulate in the body, resulting in a cancer called T-cell lymphoma. T-cell lymphoma primarily affecting the skin is called CTCL. Thanks to recent treatment advances, many patients are able to maintain their quality of life while managing their CTCL, and some are able to remain in remission (cancer stops growing) for long periods of time. The most common forms of CTCL are mycosis fungoides and Sezary syndrome but several other subtypes exist.

### COPING WITH SYMPTOMS OF CTCL

T-cells accumulating in the skin cause most patients to develop a rash or scaly patches that may be itchy. In its early stages, CTCL may be mistaken for a skin condition like eczema.

While most patients experience these symptoms without serious complications, it is very important to keep your health care team updated about any changes to your skin. Your doctor can prescribe medications to help you cope with these symptoms.

### THERE ARE ALSO SOME THINGS YOU CAN DO ON YOUR OWN

**Be gentle with your skin.** Shower or bathe in lukewarm water. Choose skin cleansers free of fragrances and alcohol. Avoid bubble bath and after-bath powders that may aggravate itching.

**Know how to cope with sun exposure.** One of the treatments for CTCL is ultraviolet light, so sunlight may have a beneficial effect on CTCL. For example, many patients experience improvements in their rash in the summer. However, it is still advisable to use precautions. Wear a hat with a brim and put on sunscreen for prolonged sun exposure or during the most intense sunlight. If your treatment includes ultraviolet light therapy with psoralen, you will have to wear sunglasses that block the sun's ultraviolet light. Talk with your health care team about how best to protect your skin from the sun.

**Keep a symptom diary.** It may take some time to find a skin care plan that works best for you. Keep notes on what you tried, what worked and what did not work.

### TREATMENTS FOR CTCL

The treatment of CTCL depends on several factors, including the extent of skin involved, the type of symptoms and the involvement of nodes or other organs. Treatment options for CTCL may include:

(over)

**Skin-directed therapy.** Skin-directed therapy for CTCL may include medicated gels or ointments, other medicines you put on your skin, ultraviolet light and radiation. The U.S. Food and Drug Administration approved mechlorethamine gel for the topical treatment of people coping with a type of CTCL called mycosis fungoides who have received prior skin-directed therapy.

**Systemic therapy.** This treatment involves one or more drugs that are absorbed and delivered across the entire body. The drugs bexarotene and vorinostat are approved to treat CTCL after the cancer has progressed or come back. Romidepsin is approved to treat patients who have received at least one prior chemotherapy drug. Pralatrexate is approved for the treatment of an advanced type of CTCL known as transformed MF (tMF). Recently brentuximab vedotin was approved to treat CTCL that has a certain marker on its surface called CD30. Your doctor will be able to tell you if your CTCL has CD30.

**Allogenic stem cell transplantation.** Rarely CTCL can become aggressive. In these cases your doctor might recommend an allogeneic stem cell transplantation. For this procedure, stem cells are taken from a donor (usually a brother or sister). Keeping the stem cells on hold, doctors give the patient high doses of chemotherapy to destroy as many cancer cells as possible. The stem cells are then transplanted to the patient to grow into healthy blood cells, forming new blood cells and boosting the person's defense against infection.

## COMMUNICATING WITH YOUR HEALTH CARE TEAM

Be sure you're comfortable talking with your health care team. Your health care team may include a dermatologist and cancer specialist as well as your primary care doctor, oncology nurses and oncology social workers. It is important for you to share your concerns and questions with them. Remember, you are a key member of the team.

**Be involved in your care.** Make a list of questions to ask your doctor or health care team. Taking notes during appointments will help you remember what was discussed.

## THE IMPORTANCE OF CLINICAL TRIALS

None of the advances in CTCL treatment would be possible without clinical trials. People who take part in these studies receive state-of-the-art care and often gain access to and benefit from new medicines, which are being developed every year.

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things you should know:

- Before you participate in a clinical trial, you will be fully informed as to the risks and benefits of the trial, including any possible side effects.
- Most clinical trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any added benefit.
- You can stop taking part in a clinical trial at any time for any reason.

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