COPING WITH CUTANEOUS T-CELL LYMPHOMA (CTCL)

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, causing 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.

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:

Skin-directed therapy, treatment applied directly to the skin. Skin-directed therapy for CTCL may include medicated gels or ointments, ultraviolet light and radiation.

Systemic therapy, cancer treatment with one or more drugs that are
absorbed and delivered across the entire body. One drug used to treat CTCL, bexarotene (Targretin), may be applied to the skin as a gel or taken as a tablet. The drugs vorinostat (Zolinza) and denileukin diftitox (Ontak) are approved to treat CTCL after the cancer has progressed or come back. Romidepsin (Istodax) is approved to treat patients who have received at least one prior chemotherapy drug. Pralatrexate (Folotyn) is approved for the treatment of an advanced type of CTCL known as transformed MF (tMF). Brentuximab vedotin (Adcetris) is being studied to treat people with a subset of CTCL called CD30-positive, primary cutaneous anaplastic large cell lymphoma.

**Allogenic stem cell transplantation** is being studied as a treatment for CTCL. 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.

**Understand your treatment plan.** Many factors need to be considered in choosing the treatment that’s best for you. Be sure that you understand and are comfortable with the treatment plan your doctor has proposed. Consider getting a second opinion from a specialist in CTCL.

**Share your feelings.** When you have CTCL, you may feel uncomfortable because of skin itching or embarrassed by how your skin looks. Consider joining a support group where you can share experiences and learn from other people coping with CTCL. CancerCare’s free support groups, led by professional oncology social workers, connect you with others who are in a similar situation. Organizations such as the Cutaneous Lymphoma Foundation (www.clfoundation.org) also offer support groups for people coping with CTCL.

**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 take part in a clinical trial, you will be fully informed as to the risks and benefits of the trial.
- No patient receives a placebo (a look-alike containing no active ingredient) unless there is an effective standard treatment available. Most clinical trials are designed to compare a new treatment to 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.

**CancerCare Can Help**

CancerCare’s professional oncology social workers are available to help you cope with the emotional and practical challenges of cancer. CancerCare also provides support groups, education, financial assistance and referrals to other resources. To learn more about how we help, call us at 800-813-HOPE (4673) or visit www.cancercare.org.

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