

Frequently Asked Questions

1. WHAT IS CUTANEOUS LYMPHOMA?

Cutaneous lymphomas are cancers of lymphocytes (a type of white blood cell that play an important role in a functioning immune system) that primarily involve the skin. They are sometimes called skin lymphomas, however cutaneous lymphomas are different from skin cancers, which develop from other non-lymphoid cells.

2. WHAT ARE THE SIGNS OR SYMPTOMS OF CUTANEOUS LYMPHOMAS?

The signs and symptoms of cutaneous lymphomas do not present the same in every patient. All patients present with lesions on the skin, which can appear anywhere on the body. This can be patches that look like a rash, plaques that are thicker and raised, papules that are small raised bumps or tumours that are raised bumps on the skin.

Commonly experienced symptoms are itching and burning sensations.

3. WHY CAN IT BE DIFFICULT TO DIAGNOSE CUTANEOUS LYMPHOMA?

The signs and symptoms of cutaneous lymphoma often resemble other more common conditions, like eczema or psoriasis, which makes them difficult to diagnose.

Patients most often see their primary care physician first. After ruling out more common conditions, they would be referred to a specialist – either a dermatologist (a specialist in skin diseases) or a haematologist (a specialist in diseases of the blood and the lymphatic system) – for an assessment.

4. HOW COMMON IS CUTANEOUS LYMPHOMA?

Cutaneous lymphoma is a rare type of lymphoma. It is estimated to affect 1 in 100,000 people in most Western countries.¹

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5. ARE THERE DIFFERENT TYPES OF CUTANEOUS LYMPHOMA?

Yes. Cutaneous lymphomas are classified by the type of lymphocyte, or white blood cell, affected.

T cells are a type of white blood cell that play an important role in the immune system by attacking viruses, foreign cells and cancer cells. Cutaneous T cell lymphomas occur when cancerous T cells travel to the upper layers of the skin. The affected area often looks dry and red, hyperpigmented (a darker skin tone than normal) or hypopigmented (white patches, especially on darker skin). Cutaneous T cell lymphomas are more common than cutaneous B cell lymphomas.

B cells are a type of white blood cell that play an important role in the immune system by producing antibodies which fight infections. Cutaneous B cell lymphomas occur when the lymphoma develops from B cells. It commonly causes red or purple bumps or nodules on the skin and affects one or two areas of the body. Cutaneous B cell lymphomas are less common.

Within each category of cutaneous lymphomas, there are different subtypes. Knowing your subtype is very important because each subtype has unique characteristics, treatment protocols and potential outcomes

6. WHAT CAUSES CUTANEOUS LYMPHOMA? IS IT GENETIC?

Doctors don't know exactly what causes cutaneous lymphoma. Like other types of lymphomas, cutaneous lymphomas are acquired diseases that begin during a person's life. They are not hereditary nor is there any clear genetic linkage.

7. HOW IS CUTANEOUS LYMPHOMA TREATED?

Treatment varies depending on the patient's cutaneous lymphoma subtype, stage and health profile. Generally, treatments fall into two categories:

- **Skin-directed therapies are applied to the skin.** They are most often used in the early stages of the disease to control the lymphoma and manage symptoms. This may include topical medications and steroids, light therapy, local radiation, and in rare cases surgery.
- **Systemic therapies affect the whole body.** They are used in advanced cutaneous lymphomas or when there is no response to skin-directed therapies. This may include retinoids, biologics, immunotherapies, extra-corporeal photopheresis (ECP), oral steroids and in advanced cases, chemotherapy and stem cell transplants.

Some cutaneous B cell lymphomas don't require treatment in the early stages. Instead, the healthcare team, along with the patient, will monitor the condition for any changes. This process is called active surveillance or active monitoring.

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8. IS THERE A CURE FOR CUTANEOUS LYMPHOMA?

While there is currently no known cure for cutaneous lymphomas, in many cases they are slow-growing and do not affect life expectancy.

9. WHO IS TYPICALLY PART OF A CARE TEAM FOR CUTANEOUS LYMPHOMA?

Depending on where you live and where you are receiving treatment, several healthcare experts may be involved in your diagnosis and care, including:

- Dermatologist
(a doctor who specialises in skin diseases or conditions)
- Haematologist
(a doctor who specialises in blood and lymphatic system disease)
- Oncologist
(a doctor who specialises in cancer)
- Histopathologist
(a doctor who diagnoses and studies disease in tissue samples)
- Radiologist
- Nurse practitioner
- Nurse
- Care navigator
- Social worker
- Pharmacist
- Psychologist or therapist
- Nutritionist

10. HOW DOES CUTANEOUS LYMPHOMA AFFECT EVERYDAY ASPECTS OF PEOPLE'S LIVES?

Living with cutaneous lymphoma can have a physical impact on your life. Skin can be dry, itchy and scaly, which can disrupt sleep, make it difficult to find comfortable clothes to wear, and even prevent participation in activities like work and exercise. Other more serious concerns include the risk of bacterial infections on the skin, or fissures or painful cracks in the skin. Adopting a skincare routine that includes moisturising, choosing fragrance-free products and reducing sun exposure can help.

People may also experience cancer-related fatigue, which can make it difficult to participate in life's activities, including work and social engagements, and can have an emotional impact on the person. If you think you are experiencing fatigue, speak to your healthcare team about an assessment and treatment options.

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11. WHAT ARE THE EMOTIONAL EFFECTS OF LIVING WITH CUTANEOUS LYMPHOMA?

Changes to one's life due to cutaneous lymphoma may be met with feelings of depression, anger or feeling isolated due to the inability to participate in activities as previously able. Also, the physical effects on the body, such as plaques, lesions and rashes, can lead to feelings of self-consciousness and affect how you interact with others, including intimacy. Talking about your concerns and feelings with a family member, friend, or someone on your healthcare team can help you find solutions and support. Your local patient group may also have support programs.

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