Skin lymphoma

Skin lymphoma is a rare condition that can be hard to diagnose. This page may be helpful if you are worried that you could have a skin lymphoma or if your doctors suspect that you may have this condition. If you have already been diagnosed with a skin lymphoma, you might want to read our information on cutaneous B-cell lymphoma or cutaneous T-cell lymphoma instead.

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What is skin lymphoma?

Lymphoma is a cancer that starts in cells called lymphocytes, which are part of our immune system. Lymphocytes are normally found in the lymph nodes (glands). They are also found in other lymphoid tissues, for example, in the spleen, the gut and the skin.

If lymphocytes start to grow out of control, or don’t die after their normal lifespan, they can build up and form a cancerous collection of cells. This is a lymphoma. If the lymphoma starts in the lymphocytes in the skin, it is called a ‘cutaneous’ lymphoma, which means a lymphoma ‘of the skin’.
Skin lymphomas are rare. Fewer than 10 out of every million people in the UK develop a skin lymphoma each year. Although skin lymphomas are a form of cancer, in many cases they are very slow growing and do not affect life expectancy. They behave more like a long-term (chronic) skin condition than like a cancer.

**Note that a lymphoma that starts somewhere else, for example in the lymph nodes, and then spreads to the skin is not a skin lymphoma. If you have a lymphoma that has spread to the skin, our information on non-cutaneous lymphomas will be more relevant for you.**

There are 2 types of lymphocytes: B lymphocytes (B cells) and T lymphocytes (T cells). They each have a different job in the immune system. Skin lymphomas can develop from either T cells or B cells.

- **Cutaneous T-cell lymphomas (CTCLs)** are the most common kind of skin lymphoma. CTCLs often look red and dry like an eczema rash and can affect widespread parts of the body.

- **Cutaneous B-cell lymphomas (CBCLs)** more commonly cause lumps in the skin, usually in 1 or 2 areas of the body.

Skin lymphomas are often difficult to diagnose because they develop slowly and because they resemble more common skin conditions, such as eczema or psoriasis. It can take years for some people to get their skin lymphoma diagnosed. Fortunately, early treatment is not vital for these lymphomas and they respond well to a variety of available treatments.

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**Causes?**

Doctors don’t know exactly what causes skin lymphoma. Research has shown that:

- it isn’t caused by anything you’ve done
- it isn’t passed down in families (inherited)
- you can’t catch it or pass it on.

Scientists know from research that lymphocytes become cancerous because of changes to their chemical coding (DNA). They don’t yet understand
exactly why these changes happen, but age is a likely factor. The older people get, the more common these changes become. Most skin lymphomas occur in people over 50.

What does skin lymphoma look like?

Different types of skin lymphomas can look quite different to one another, particularly in the early stages.

This section includes photographs to illustrate the appearance of skin lymphomas. However, do not be alarmed if your skin has a similar appearance. There are many more likely and less serious skin conditions that may look similar, but can only be distinguished from skin lymphoma using specialised tests on the cells of the affected skin.

T-cell skin lymphomas

The most common skin lymphoma is a T-cell skin lymphoma called mycosis fungoides. At an early stage, patches of dry, red skin often appear. They can look like more common skin conditions such as dermatitis, eczema or psoriasis.
The patches tend to be dry, sometimes scaly and may be itchy. They are most common on the buttocks or torso but can occur anywhere on the body. CTCL can show up as patches of altered skin colour, particularly on Asian or black skin.

Areas of skin can become harder and thicker but still remain quite flattened. These are called plaques. They can be itchy and sometimes ulcerate (break down). They are most common on the buttocks, in the skin folds and on the face. In many people the skin lymphoma will never develop beyond the patch and plaque stage.
Figure: Plaques of mycosis fungoides
More advanced disease can appear as raised solid areas of skin that can look like a rash. They are called **papules**. Some people develop much larger, raised swellings in the skin, called **nodules** or **tumours**. These can ulcerate (break down) and become infected.
Some people with T-cell skin lymphoma develop **erythroderma** - generalised reddening of the skin, which can be intensely itchy, dry and scaly. The skin on the palms of the hands and soles of the feet can thicken and crack. Lymph nodes may swell.
B-cell skin lymphomas

B-cell skin lymphomas are much less common than T-cell skin lymphomas. They are most likely to appear on the head, neck, back or legs. You may have small, raised, solid areas of skin, called papules. Some people have thickened but still quite flattened areas called plaques, or larger lumps called nodules or tumours. These nodules are often deep-red or purplish in colour. They can ulcerate and become infected. You may only have 1 or 2 nodules but you may have several, either grouped together or more widely spread out.

Diagnosis

Skin lymphoma often looks like other skin conditions. The treatments for some of these other conditions (steroid creams, for example) can also be used to treat skin lymphoma. If you are given treatment for a different skin condition, your skin might improve for a while before a skin lymphoma is suspected or firmly diagnosed. Skin rashes that can look very similar to skin lymphoma include:

- **skin diseases**, such as
  - eczema or atopic dermatitis
  - psoriasis
  - lichen planus
  - lupus erythematosus
  - a group of rashes of unknown cause, eg chronic superficial dermatitis, digitate dermatosis or parapsoriasis
  - granulomatous skin diseases such as sarcoidosis or granuloma annulare

- **fungal skin infections**, such as tinea corporis (ringworm)

- **skin reactions** to
- substances in contact with the skin, such as metals (e.g., nickel in jewellery or in buttons) or cosmetics; this type of reaction is called ‘contact dermatitis’
- drugs, which can cause a widespread rash or even erythroderma
- sunlight (photosensitivity), particularly on the exposed skin of the face; this is called ‘actinic reticuloid’ or ‘chronic actinic dermatitis’
- **lymphocytoma cutis**, also known as pseudolymphoma, which can be triggered by
  - drugs (sometimes called a ‘drug eruption’)
  - vaccinations
  - some infections, such as shingles
  - tattoo dyes
  - insect bites
  - scabies.

Some people make many visits to the GP or skin clinic before getting a final diagnosis. This is because there are so many other, more likely possibilities and because skin lymphomas can develop over as long as 10–40 years. Even if your doctor suspects a skin lymphoma, you may have to have tests repeated several times before the diagnosis is confirmed.

**How is skin lymphoma diagnosed?**

Diagnosing skin lymphoma is a bit like solving a jigsaw puzzle. A team of people are involved in identifying the pieces and putting them together, including:

- dermatologists – specialists in skin diseases
- haematologists or oncologists – specialists in blood cancers
- histopathologists and dermatopathologists – doctors who specialise in examining and testing tissues at the microscopic level in the laboratory
- clinical nurse specialists (CNSs) – specialised nurses who focus on patient care in certain conditions or treatment.
These people form a multidisciplinary team (MDT), which meet regularly to discuss patients’ test results and treatments.

The starting piece of the jigsaw is usually what you tell the specialist about your skin rash, how long you’ve had it (the history) and what it looks like. The doctor then asks how the rash has behaved in the past, whether it comes and goes, whether it has got gradually worse and whether it is itchy. Afterwards, they also ask about your general health and whether you’ve had any other symptoms, such as weight loss or fevers.

The team are likely to want to monitor your rash for many months in the clinic. This isn’t time wasted. It is important to build up a picture of the condition over time.

**Tests for skin lymphoma**

The most important test in diagnosing a skin lymphoma is a biopsy. The doctor numbs the area with a local anaesthetic and removes a small piece of affected skin. This is then sent to be examined under a microscope. Specialised tests are done on the cells, their genes and proteins. You might hear your doctor say that the sample of skin is going for ‘immunophenotyping’ or ‘immunohistochemistry’, ‘immunogenotyping’, ‘flow cytometry’ or ‘cytogenetics’ tests.

The tests often have to be done in a laboratory at another centre. Results can take 2–3 weeks to come back. Quite often the biopsy results aren’t clear-cut. You may need to have several biopsies over months or even years to confirm a diagnosis. This can be a frustrating and anxious time, but it is important to get the right diagnosis so that you can have the best treatment.

You may have other tests in the clinic, such as blood tests or a chest X-ray. You may have your skin photographed. You may have other biopsies, for example from your enlarged lymph nodes or your bone marrow (the spongy tissue in the centre of your bones where blood cells are made). You are only likely to have these if it is looking increasingly likely that you have a skin lymphoma.
After diagnosis

What happens if a skin lymphoma is confirmed?

Many people with a slow-growing skin lymphoma don’t need treatment straightaway. Instead, the doctor monitors their condition. This active monitoring is called ‘watch and wait’ and is often used for persistent early-stage disease that would not benefit from treatment.

Many people find ‘watch and wait’ very difficult to deal with. It can be hard to wait for repeat appointments and tests and then hear that having no treatment is the best option. However, research and many years of experience have shown that this is the best approach for some types and stages of skin lymphoma.

If your doctors feel that treatment would help you, several types are available. The treatment they recommend depends on the type of skin lymphoma you have and on how much of your body is affected. You may have treatment applied directly to affected skin (topical treatments) or given to your whole body (systemic treatments).

If you have been diagnosed with skin lymphoma, the following sections have more detail on specific types:

- cutaneous T-cell lymphomas (CTCLs)
- cutaneous B-cell lymphomas (CBCLs).

What happens if it isn’t lymphoma after all?

Sometimes your MDT will have discussed the possibility of a skin lymphoma diagnosis with you and you might have readied yourself to hear that you have a cancerous condition. After monitoring your condition and carrying out tests, they may diagnose a benign (non-cancerous) skin condition instead.

Although you might expect to be pleased with this news, you might find it emotionally difficult to deal with. If you have difficulty coming to terms with your diagnosis, talk to your doctor or specialist nurse. They have helped people in your situation before and are able to explain what happens next.
Whether or not you have a skin lymphoma, you are probably trying to cope with symptoms and may be struggling with the appearance of your skin. You might want to contact a specialist organisation working with people affected by visible skin conditions.

Further reading

- Skin (cutaneous) T-cell lymphoma
- Skin (cutaneous) B-cell lymphoma
- Treatments for skin lymphoma
- Managing symptoms of skin lymphoma
- Living with skin lymphoma
- Useful organisations for people with skin lymphoma

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Tell us what you think and help us to improve our resources for people affected by lymphoma. If you have any feedback, please visit www.lymphoma-action.org.uk/feedback or email publications@lymphoma-action.org.uk.

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