

Living with skin lymphoma

This information outlines tips to help you live well with **skin (cutaneous) lymphoma**. Depending on your diagnosis, you might also be interested in our information about **skin (cutaneous) B-cell lymphoma** and **skin (cutaneous) T-cell lymphoma**.

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We have separate information about the topics in **bold font**. Please get in touch if you'd like to request copies or if you would like further information about any aspect of lymphoma. Phone 0808 808 5555 or email information@lymphoma-action.org.uk.

Skin lymphoma as a long-term condition

Skin lymphoma can be a long-term (chronic) condition so you might live with it for many years. It can take months or years to diagnose. Symptoms can come and go, and you might need treatment more than once. It's therefore important to find ways to **live well, both physically and emotionally**.

Most skin lymphomas are slow-growing (low-grade) and you might not have treatment straightaway. Instead, doctors might recommend **active monitoring ('watch and wait')**. It can be hard to have a diagnosis without being offered immediate treatment. Keep in mind that **early stage (localised) lymphoma** is slow to develop and is not life-threatening. It can be better to keep treatment until it is really needed than to have it right away.

You might be interested in [Ashley's story of living with skin lymphoma](#) for over 40 years. He shares his experience and some tips for living well.

Soothing your skin and minimising skin irritation

Skin lymphoma can cause thickened areas of skin (patches and plaques), which can be dry and itchy. It can also cause the skin all over your body to become red, inflamed, dry and flaky (erythroderma), which can be very itchy.

Your skin might also be more prone to irritation, which can affect your mood and sleep. Your lymphoma treatment might help to soothe itching. There are also [things you can try to help with itching and skin irritation](#), as well as to get a more [restful night's sleep](#).

Look out for signs of an [infection](#), including your skin becoming redder, hotter, more swollen or painful. You might also get a fluid (discharge) that is a yellow or green colour and smells unpleasant.

If you notice any symptoms or [signs of infection](#), seek medical attention quickly. It's important to treat the infection as soon as possible, and you might need to take antibiotics to prevent serious illness.

Your doctor can offer advice on how best to sooth your symptoms. In some cases, your doctor might prescribe:

- an unperfumed cream, ointment or lotion ([emollient](#)) – you might need to try a few different ones to find one that suits you
- a steroid cream or a cream containing 1% menthol
- an [antihistamine medicine](#) if your itching is very bad, though these are not helpful for all types of skin lymphoma
- other medications, such as [steroid treatment](#) if you have [erythroderma](#) and severe itching.

Avoid using herbal creams or massage oils as they could irritate dry, broken or inflamed skin. They might also cause an allergic reaction. Some can also increase your skin's sensitivity to sunlight, or to treatment with a type of [light treatment \(phototherapy\)](#) called [PUVA](#). You can find more [information about various herbal remedies on the Cancer Research UK website](#).

Controlling your body temperature

If a lot of your skin is reddened (inflamed), it can make it difficult to control your body temperature.

- Some people develop fevers, chills and shakes.
- In some cases, **hypothermia** develops (a drop in body temperature to below 35°C/95°F).
- Some treatments can prevent you from sweating in some areas of your body, which means that you're unable to cool yourself down so well when you're hot.

If the problem is mild, there are things you can do to manage your body temperature:

- Wear lightweight, loose-fitting clothes made from natural fibres, such as cotton, to help you keep cool.
- If you're visiting friends or family, you could ask them to turn down their heating before you arrive.
- In cold weather, cover your skin as much as possible to avoid losing heat.

If you are planning to **travel outside of the UK**, talk to **your medical team** about any precautions you should take. This might include, for example, **if your skin is sensitive to sunlight (photosensitive)**.

Inflamed skin (erythroderma) and loss of water in your body

If you have severe skin inflammation (**erythroderma**), it can affect the balance of fluid in your body. This can lead to a lack of fluid in your body (dehydration), which can cause health problems and put a strain on your heart.

To minimise the risk of dehydration:

- Drink plenty of fluids, especially when the weather is hot, to replace lost water from the skin. This is particularly important if you have a high temperature or **infection**.
- Use **emollients** regularly, to keep your skin moist and prevent water loss.

In severe cases, you might need to go into hospital. Staff can keep you in a stable environment and frequently apply emollients to your skin to manage the balance of fluid.

Managing pain

Inflamed skin can be painful, particularly in areas with **tumours**, and especially if it 'weeps' (fluid comes out of it) or becomes **infected**.

Skincare

A good skincare routine can help to manage pain:

- Use **emollients** to keep your skin supple and moist. Your doctor might give you emollient that contains antiseptics or urea.
- Use any medication given to you as prescribed – for example, you might be given a short course of a strong **steroid cream** (topical steroid).

Pain relief medications

It should be safe for you to take mild painkillers such as paracetamol, but seek medical advice before taking any stronger pain relief medication – some can interact with other medications and might not be safe for you to take.

You can read more about **managing pain** on the NHS website.

Coping with changes in the appearance of your skin

Skin lymphoma can change how your skin looks. If you choose to, there are **things you can do to help improve the appearance of your skin**. It's also important to **find ways to cope emotionally with any changes**.

Your emotions

Changes in the appearance of your skin can affect your mood and self-confidence.

Following a general healthy lifestyle can help with your overall physical and **emotional wellbeing**, to help you to **live well, with and beyond lymphoma**. This includes **eating well**, taking **exercise, getting enough sleep**, and **managing stress**. You can also speak to your medical team for advice about managing any symptoms of skin lymphoma and **side effects of treatment**.

You might be interested in **complementary therapies**, which can be used **in addition to** your lymphoma treatment. Although these cannot treat or cure your lymphoma, many people find they help with relaxation, and to improve their general sense of wellbeing.

Coping with difficult feelings

Take time to acknowledge your **thoughts and feelings**. If you feel low or anxious about your skin, speak to your GP or a member of your medical team – your **clinical nurse specialist** can be a good person to approach.

Some people find it helps to speak to a trained professional about how they feel, for example, a **counsellor**. You can also contact **our helpline team** to talk about how you feel.

I no longer felt alone and my anxieties significantly lessened. The importance of finding the answers that I needed was life-changing. I feel empowered not to let my lymphoma define me and how I feel about myself. I am determined to live well with it, and to not let it live my life for me. Now, when I look in the mirror I don't feel confused, upset and sad. My focus on what's important in life has sharpened.

Harriet, affected by a rare T-cell lymphoma

You might also be interested in **Skinship UK**, a confidential general dermatology helpline offering information and support to anyone living with a skin condition, including skin cancer.

Talking to other people about your skin's appearance

You might feel uncomfortable about what other people might think, for example that your skin's appearance could reflect lifestyle factors, such as cleanliness or diet. You might worry that people think that you have a contagious condition.

You might find it helpful to have people understand a bit about your skin's appearance. Consider explaining to them about your lymphoma, and try to answer their questions. You could also signpost them to our website for information about **skin lymphoma**.

You might feel uncomfortable with people you meet for the first time or don't know very well. Try to have something ready to say. For example, a light conversation starter or perhaps something about your skin. Talking can help to reduce awkwardness as people often say they feel relieved to have something 'out in the open'.

Our information on **relationships, family and friends** offers more suggestions that you might find helpful when speaking to others. This includes tips on **communicating with the people around you**.

Improving the appearance of your skin

Some people choose to use products to help improve the appearance of their skin. This, in turn, can help with the **emotional impact** of changes in skin appearance.

Regular make-up

If skin lymphoma affects your face but it is not wide-spread or marked, regular make-up might help to cover it. Check with your medical team which products are safe to use before you apply them. In general, fragrance-free products and those labelled 'hypoallergenic' (less likely to trigger an allergic reaction) are preferable.

Camouflage creams

If the affected areas of your skin are difficult to cover, you could try using a camouflage cream – these are carefully matched to your skin colour. Camouflage creams are designed to stay in place for much longer than ordinary foundations, even if they get wet.

Check with your GP or clinical nurse specialist before using a camouflage cream. They might not be safe for you if your skin is particularly dry, inflamed or broken. If a camouflage cream is suitable for you, you could ask whether it's possible to have one prescribed.

Changing Faces is a charity that supports people who have a scar, mark or condition that affects their appearance. They offer a range of **support services**, including a **support and information line**, a **skin camouflage service**, and an **online self-guided tool** for people aged 18 or over to get tips on living with a visible difference.

References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619409 if you would like a copy.

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✓	Evidence-based
✓	Approved by experts
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