

PATIENT INFORMATION LEAFLET

LYMPHOPROLIFERATIVE/ T-CELL SKIN CONDITIONS IN CHILDREN AND YOUNG PEOPLE

Written for key stage 2 and above

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about a group of rare skin conditions called lymphoproliferative skin conditions. These conditions come with long Latin names, but all of them have the same thing in common, which is cells called lymphocytes (also known as T-cells) found gathered together in the skin.

The word “lympho-” refers to the lymphocytes or T-cells. The word “-proliferative” refers to growth or collections of these cells in the skin.

Lymphoproliferative skin conditions include:

- Lymphomatoid papulosis (LyP)
- Pityriasis lichenoides chronica (PLC)
- Cutaneous T-Cell Lymphoma (CTCL)
- **Mycosis fungoides** (MF) - This is the most common subgroup of CTCL

This leaflet tells you what these conditions are, what can be done about them and how you can find out more about them. Lymphoproliferative conditions cover a broad range of conditions which affect different people in different ways, and you may find that some of the information in this leaflet may not apply to you.

This spectrum of conditions ranges from inflammation in the skin (e.g. lymphomatoid papulosis) to cutaneous lymphoma (where the cells are cancerous). Lymphoproliferative conditions may appear on any area of the skin.

WHAT ARE T-CELLS AND WHAT ARE THEY DOING IN THE SKIN?

T-cells are a type of white blood cell, called lymphocytes. They are part of the immune system and help to recognise and fight infections in your body. They are found in blood and travel around the body, including the skin. In the skin, the number of T-cells can also increase in number in inflammatory conditions, such as:

- **eczema** (the skin here can change colour, become red or darker or paler, and possibly hot and itchy), and
- cancerous skin conditions, such as lymphoproliferative conditions where the T-cells are abnormal.

Cancer and lymphoma sound like scary words. You may have heard of a condition called **lymphoma**, which is a cancer of the lymph nodes (glands). This is a more serious condition that requires treatment with chemotherapy.

Skin lymphoma (also known as CTCL or **mycosis fungoides**) is a **very different** type of lymphoma which is limited to the skin for most people - it does not usually involve the glands or inside the body. Although some lymphoproliferative conditions are considered forms of cancer these are usually very stable conditions that are unlikely to need chemotherapy, or be of long term harm to your health.

WHAT CAUSES LYMPHOPROLIFERATIVE SKIN CONDITIONS?

The cause for the growth of T-cells is unknown but it is certainly not your fault or due to anything you have done wrong.

You cannot catch or pass on a lymphoproliferative skin condition to anyone, as they are not infectious.

ARE LYMPHOPROLIFERATIVE SKIN CONDITIONS INHERITED?

No.

WHAT DO LYMPHOPROLIFERATIVE SKIN CONDITIONS LOOK LIKE?

This will depend on the type and the background colour (pigment) of your skin. A lymphoproliferative condition can include pale (**hypopigmented**) areas, dry scaly areas, spots or bumps, which can appear red or darker than the surrounding unaffected skin. Occasionally, skin lesions can become lumpy, or the skin can be broken on the surface (also known as ulcerated). Some lymphoproliferative conditions can also look like more common skin conditions such as **eczema** or **psoriasis**.

WHAT ARE THE SYMPTOMS OF LYMPHOPROLIFERATIVE SKIN CONDITIONS?

The skin may feel normal but can also be flaky, itchy or sore in the affected areas. Some people find they don't like the way their skin looks, and this can be upsetting.

HOW WILL LYMPHOPROLIFERATIVE SKIN CONDITIONS BE DIAGNOSED?

If your dermatology team thinks you are affected by a lymphoproliferative skin condition after examining your skin, then a **biopsy** may be needed to confirm the diagnosis. A biopsy involves numbing injection (local anaesthetic) into the skin and taking a small sample to be looked at under the microscope.

It can take a long time (months or even years) before a definite diagnosis of a lymphoproliferative condition can be made. This is because the rash can look like other skin conditions, such as **eczema** and **psoriasis**. Skin biopsy is usually

necessary to confirm the diagnosis of a lymphoproliferative skin condition. However, skin biopsy results may also look similar to other skin conditions, making it difficult to be certain. Skin biopsies may have to be repeated more than once over a number of months or years before a final diagnosis can be made.

A combination of the way your skin rash looks and feels and what the skin biopsy shows need to be taken into careful consideration to make a diagnosis.

Blood tests may be taken but are usually normal. If your doctor has any concerns, sometimes other investigations (such as imaging scans in radiology) may be put in place. For most people these are not necessary.

CAN LYMPHOPROLIFERATIVE CONDITIONS BE CURED?

Some types of lymphoproliferative conditions will get better over time, for example pityriasis lichenoides chronica (PLC). Some conditions may be persistent (lasting for years and never going away completely). Some may slowly spread and get worse over months to years.

There are treatments that can help improve your symptoms and the appearance of your skin. Although they may help control the condition, these treatments do not always change how long it lasts or what will happen in the long term.

Remember - these conditions can be variable and are very rare. Because of this, it can be difficult for your dermatology team to be specific about the exact type. It may also be difficult to know what might happen in the future, which can be unsettling. However, we do know that in children and young people it is extremely unusual for these skin conditions to cause serious problems or affect your general health. This is the case even if you are diagnosed with a cutaneous lymphoma.



HOW CAN LYMPHOPROLIFERATIVE CONDITIONS BE TREATED?

The aim of treatment is to improve symptoms and to control the condition. Treatment, therefore, depends on the symptoms, how much they are bothering you and the extent of the skin involved.

Applying moisturisers regularly can help reduce skin dryness and irritation. People find different moisturisers helpful, so it is worth trying a selection of creams or ointments until you find one that suits you. We suggest discussing this with your doctor.

It is completely normal to be upset by the appearance of your skin. If this is worrying you, please do talk about this when you are seen in clinic for advice and support.

Depending on the background pigment of your skin, fake tan moisturising products can be useful cosmetically for some people.

Most patients will only ever require 'skin-directed therapy'. These are treatments that only treat the skin and include:

- **Steroid creams or ointments.** It is important that these are used correctly. Your doctor or nurses at the dermatology department or skin lymphoma clinic will be able to advise you about this.
- Light therapy or **phototherapy**: This treatment uses ultraviolet light to treat all of the skin. The British Association of Dermatologists' Patient Information Leaflet on Phototherapy gives more detailed information on this treatment. <https://www.skinhealthinfo.org.uk/condition/phototherapy-nb-uvb/>
- Very rarely, patients may need treatment with **radiotherapy** to lesions that are causing symptoms and have not responded to other treatments.

If skin directed therapy does not help control the condition that is affecting you, other treatment may be needed. In this situation, treatment will be discussed by a medical team that specialises in skin lymphoma. This is to make an appropriate management plan.

SELF-CARE (WHAT CAN I DO?)

These conditions are not affected by what you eat or drink, so no special diet is needed. There will usually be no restrictions on your day-to-day activities so you can continue to take part in your hobbies, school and social activities.

If you or your family are worrying a lot about your skin, then you should talk to your doctor about this. It may be helpful to get support from a specialist, such as a psychologist.

WHERE CAN I GET MORE INFORMATION?

It can be difficult to look up appropriate information for each individual as these conditions are rare and variable. These conditions behave differently (can be more severe) if they start in adults, so information for older people will not apply to you. We would suggest you talk to the dermatology team who is supervising your care if you have any questions.



This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Society for Paediatric and Adolescent Dermatology and the British Association of Dermatologists: individual patient circumstances may differ, which might alter both the advice and course of therapy given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

**BRITISH ASSOCIATION OF
DERMATOLOGISTS**

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