

PATIENT INFORMATION LEAFLET

MYCOSIS FUNGOIDES

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help you understand more about mycosis fungoides. It tells you what it is, what can be done about it, and where you can find out more about it.

It is important to know that mycosis fungoides affects people in different ways. Some of this information is for people who are more severely affected, and this is very rare.

WHAT IS MYCOSIS FUNGOIDES?

Mycosis fungoides is a type of skin lymphoma (cancer). It is the most common type in a group of conditions known as *cutaneous (skin) T-cell lymphomas*. T-cells are white blood cells that are found all over the body and in the blood stream. These cells normally help your body's germ fighting immune system. In cutaneous T-cell lymphoma, the T-cells develop abnormalities that make them attack the skin.

Mycosis fungoides is a rare condition. In the UK about 450 people are diagnosed each year. Most of those affected have a normal life span, but people with a more advanced stage may have worse outcomes.

Mycosis fungoides can occur at any age but it most often starts between the ages of 50 and 70 years.

WHAT CAUSES MYCOSIS FUNGOIDES?

The cause is unknown.

You cannot catch or pass on mycosis fungoides to anyone else. It is not an infection, even though the name suggests that it is some sort of fungal infection.

IS MYCOSIS FUNGOIDES HEREDITARY?

No. There have been very rare cases when multiple family members have developed mycosis fungoides.

WHAT DOES MYCOSIS FUNGOIDES FEEL AND LOOK LIKE?

The most common symptom of mycosis fungoides is long-term, generalised itching (pruritus). Rarely there may be pain in the affected areas.

The rash usually develops slowly, often over many years. At first, irregularly shaped, dry patches may appear on the skin. This is known as the 'patch stage'. These patches often occur on skin that is usually not exposed to the sun. They may look like common skin conditions such as [eczema](#) or [psoriasis](#). This can make a diagnosis of mycosis fungoides difficult.

Later, the patches may thicken appearing as raised areas of skin. This is the 'plaque stage'. Rarely, the skin can become red all over. This is called erythroderma.

In some people, mycosis fungoides may cause large deep red lumps in the skin. This is known as the 'tumour stage'. Rarely, tumours or plaques may become ulcers. They may be painful and discharge fluid.

HOW WILL MYCOSIS FUNGOIDES BE DIAGNOSED?

Skin biopsies are usually needed to confirm the diagnosis. This is carried out using a local anesthetic and then a small sample of skin is taken to be examined under a microscope.

The rash and skin biopsies may not show any specific features and can resemble other skin conditions. So, skin biopsies

may have to be repeated several times over a period of time before a firm diagnosis can be made. Blood test results are usually normal. This means that a firm diagnosis of mycosis fungoides may take months or even years.

CAN MYCOSIS FUNGOIDES BE CURED?

No. There is no known cure for mycosis fungoides. Treatment often clears the rash for some time. Even after effective treatment, the condition usually comes back.

Mycosis fungoides is a life-long condition which usually progresses slowly over many years. It is difficult to predict how it will affect each person. Many people affected by mycosis fungoides live a normal life span.

HOW CAN MYCOSIS FUNGOIDES BE TREATED?

The aim of treatment is to control symptoms and improve quality of life. Treatment depends on the symptoms that the condition is causing, the stage and type of skin changes. No treatments have been shown to improve survival, although with early diagnosis and treatment, people often live for many years without symptoms. Periods of time with no treatment are common.

Good skin care with regular moisturisers ([emollients](#)) to reduce skin dryness and irritation. It is worth trying different creams or ointments until you find one that suits you. Many moisturisers are available on prescription so please discuss this with your doctor.

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

- [Steroid creams or ointments](#). It is important to use them correctly. The doctors or nurses at the dermatology department or skin lymphoma clinic will guide you.
- [Chlormethine gel](#) is a chemotherapy gel which works on the skin.
- [Phototherapy](#) (or light therapy): This treatment uses light to treat all of the skin.

If skin directed therapy does not control the condition, you may need other treatment. It will be discussed by a team of doctors and nurses who specialise in skin lymphoma. The team is called the Supranetwork Skin Lymphoma Multidisciplinary Team (MDT). There are several teams across the UK. You may also be referred to the designated skin lymphoma clinic in an NHS hospital.

Other treatment options may be suggested. However, most patients do not need any of these other treatments. If you do need any of these, you will be given detailed information before you start the treatment. They include:

- [Radiotherapy](#): This treatment uses high energy X-rays to destroy cancer cells in the area that is being treated. It can treat specific areas of the skin, or the whole surface of your skin. Radiotherapy used to treat the whole skin is called Total Skin Electron Beam Therapy or TSEBT.
- [Methotrexate](#) tablets: These tablets are taken once a week. They control mycosis fungoides by slowing down the production of new cells. The British Association of Dermatologists' Patient Information Leaflet on [methotrexate](#) gives more detailed information on this treatment.
- [Interferon alpha](#): This treatment encourages the body's immune system to fight cancer cells.
- [Antibody therapy](#): These treatments (mogamulizumab and brentuximab) act against mycosis fungoides cells.



- Bexarotene tablets: This belongs to a group of drugs called retinoids and works by stopping the growth of cancer cells.
- Chemotherapy (chemo): This is a treatment that uses anti-cancer drugs to destroy cancer cells. There are several types of chemotherapy that can be used to treat skin lymphoma.
- Extracorporeal photopheresis: This treatment involves treating the blood with ultraviolet light.
- Allogeneic haematopoietic stem cell transplant: This involves the transplant of stem cells from a healthy donor. It may be offered to some patients with advanced mycosis fungoides.

SELF-CARE (WHAT CAN I DO?)

Mycosis fungoides is 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.

WHERE CAN I GET MORE INFORMATION ABOUT MYCOSIS FUNGOIDES?

This leaflet provides an overview of mycosis fungoides. If you would like further information, then please discuss this with the consultant supervising your care.

*Web links to patient support groups:
Cutaneous Lymphoma Foundation*

www.clfoundation.org

Lymphoma Action

<https://lymphoma-action.org.uk/types-lymphoma-skin-lymphoma/skin-cutaneous-t-cell-lymphoma>

Web links to detailed leaflets:

<https://www.dermnetnz.org/topics/cutaneous-t-cell-lymphoma>

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of 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
PATIENT INFORMATION LEAFLET
PRODUCED | AUGUST 2004
UPDATED | SEPTEMBER 2009,
OCTOBER 2012,
NOVEMBER 2015, FEBRUARY 2019,
AUGUST 2023
NEXT REVIEW DATE | AUGUST 2026**

