



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.

Remember that mycosis fungoides affects different people in different ways. Some of this information is for people with more severe disease which is very rare.

What is mycosis fungoides?

Mycosis fungoides is a type of cutaneous or skin lymphoma. It is the commonest of a group of conditions known as *cutaneous T-cell lymphomas*. Cutaneous T-cell lymphomas are cancers that affect the skin and are caused by uncontrolled growth of the T-cell lymphocytes in the skin. T cell lymphocytes are white blood cells that can be found all over the body and in the blood stream.

Mycosis fungoides is a rare condition. Each year in the UK, approximately 450 people are newly diagnosed with mycosis fungoides. Most affected people live a normal life span.

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, mycosis fungoides, suggests that it is some sort of fungal infection.

Is mycosis fungoides hereditary?

No.

What are the symptoms of mycosis fungoides?

The commonest symptom of mycosis fungoides is itching and rarely pain in the affected areas.

What does mycosis fungoides look like?

The rash usually develops slowly, often over many years. At first, the skin may be affected by irregularly-shaped, dry patches. This is known as 'patch stage' disease. These patches often occur in areas of skin that are usually protected from the sun. It may be difficult to make a diagnosis of mycosis fungoides at this stage because mycosis fungoides can look like common skin conditions such as eczema or psoriasis.

Later, the patches of disease may thicken. This is called 'plaque stage' disease. Less commonly, the skin becomes red all over which is called erythroderma.

A few people develop lumps of mycosis fungoides in the skin. This is known as 'tumour stage' disease. Rarely tumours or plaques of disease may become ulcers. These areas may be painful and discharge fluid.

How will it be diagnosed?

A skin biopsy is usually needed to confirm the diagnosis.

It often takes several years before a definite diagnosis of mycosis fungoides can be made. The rash may not have any specific features and look like other skin conditions. Skin biopsies may also lack specific features and be difficult to distinguish from other conditions. Skin biopsies may have to be repeated several times over a period of time before a firm diagnosis can be made. Blood tests are usually normal.

Can it be cured?

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

Mycosis fungoides is a life-long condition which usually progresses slowly over many years. Many people live a normal life span with mycosis fungoides but it is difficult to predict how it will affect an individual person.

How can it be treated?

The aim of treatment is to improve symptoms and to control the disease. Treatment therefore depends on the symptoms that the disease is causing and the extent of the disease.

People with mycosis fungoides are advised to use regular moisturisers to try to reduce skin dryness and irritation. Different people find different moisturisers helpful, so it is worth trying different creams or ointments until you find one that suits you. We suggest discussing this with your doctor, as many moisturisers are available on prescription.

Most patients will only ever require 'skin directed therapy'. These are treatments that only treat the skin. These 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 light to treat all of the skin. The British Association of Dermatologists' Patient Information Leaflet on [Phototherapy](#) gives more detailed information on this treatment.

In people where skin directed therapy does not control their disease, other treatment may be needed. In this situation, treatment will be discussed by a team of doctors and nurses who specialise in skin lymphoma. They are called the Supranetwork Skin Lymphoma Multidisciplinary Team (MDT). There are a number of these teams across the UK. You may also be referred to the supraregional skin lymphoma clinic, which will be based in a regional NHS hospital.

Other treatment options which may be suggested include:

- Radiotherapy: This treatment uses high energy X-rays to destroy cancer cells in the area that is being treated. Radiotherapy can be used to treat specific areas of the skin or to treat the whole 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 the disease 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.
- Immunotherapy: These drugs encourage the body's immune system to fight cancer 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 different types of chemotherapy that can be used to treat skin lymphoma.
- Photophoresis: This treatment involves treating the blood with ultraviolet light.

Most patients do not need any of these other treatments. If you do need any of these other treatments, you will be given detailed information before you start the treatment.

What can I do?

Mycosis fungoides is not affected by your food so no special diet is needed, and there will usually be no restrictions on your day to day activities.

Where can I get more information about mycosis fungoides?

The information in this leaflet is provided for general information purposes only. If you want to know more about mycosis fungoides, please ask the consultant supervising your care.

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>

For details of source materials used to produce this leaflet, please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

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

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