



DERMATOMYOSITIS

What are the aims of this leaflet?

This leaflet has been written to help patients understand more about dermatomyositis. It explains what it is, what causes it, how to recognise some of the symptoms, what can be done about it, and where more information can be found.

What is dermatomyositis?

Dermatomyositis is a rare condition that causes inflammation in both the skin and the muscles. The word comes from the Latin for skin (dermis), muscles (myos) and inflammation (-itis). In rare cases, only the skin is affected and not the muscles.

What causes dermatomyositis?

The exact cause of dermatomyositis is unknown. We do know that the body's own immune system, which should defend us from infection, begins to attack the muscles and possibly the skin. This is known as an "autoimmune condition".

Who can get dermatomyositis?

Dermatomyositis is a rare condition and is known to affect women more than men. While dermatomyositis can occur at any age, even occasionally in children, it is more common in adults over the age of 50.

What are the symptoms of dermatomyositis?

Dermatomyositis affects the skin and muscles. A skin rash usually appears before the muscle weakness starts; however, some people may only have the skin rash. People who have dermatomyositis sometimes feel tired and run down.

Dermatomyositis usually affects the muscles involved in movement such as the neck, arms, or hips. Due to inflammation the muscles may become weak, stiff, sore, and tender. Muscle weakness may make it difficult to do things such as raising the arms above the shoulders, climbing the stairs, and lifting/stretching the legs.

What does dermatomyositis look like?

The rash seen in dermatomyositis can be quite variable but may affect the skin around the eyes (heliotrope rash), over the knuckles (Gottrons papules), on the face and the “V” at the front of the neck and other regions. It is often red or purple in colour and can be very itchy, particularly when the scalp is affected. The fingernails may be ragged and the skin around the fingernails may be inflamed.

The rash is often made worse by sunlight and is therefore more obvious on areas of the skin which are exposed to the sun.

Are any conditions associated with dermatomyositis?

Dermatomyositis may rarely affect other muscles, or organs, in the body. Some possible effects of these are listed below:

- *Oesophagus (throat)*
If the muscles of the oesophagus (passage from the mouth to the stomach) are affected, the stomach acid can leak up (reflux) into the oesophagus and cause heartburn. This can be treated with acid blocking drugs. If more severely affected, swallowing may be difficult.
- *Lungs*
If the chest wall muscles are affected, some people may develop shortness of breath and have difficulty breathing deeply. Sometimes the lung tissue may be affected and lead to stiffness of the lungs causing breathing difficulties. This can be assessed by testing lung function or scanning the chest.
- *Heart*

The heart is also a muscle and can be affected in dermatomyositis, although this is rare. If the heart muscle is involved this can cause palpitations (an irregular or fast heartbeat) and dizzy spells. The doctor may recommend having a heart tracing or electrocardiogram (ECG) to check for this.

- *Calcinosis*

Calcinosis is the presence of firm yellow or white deposits (lump/spot) of calcium in the skin and sometimes the muscles. This can be painful but may improve once treatment is started. If the lump/spot becomes painful and/or causes problems with movement then surgical removal may be suggested.

- *Malignancy*

In adults who have dermatomyositis it is important for doctors to look for signs of any underlying cancer. This occurs in a quarter of adults, but very rarely in children.

Unexpected weight loss, a change in bowel habits, bleeding from the back passage, a persistent cough or blood in the urine are important symptoms which should be reported to the doctor to help direct any tests that may detect an underlying cancer.

How is dermatomyositis diagnosed?

The dermatologist may organise a number of tests, including a blood test, a skin biopsy (sample of skin taken to be analysed under a microscope), an MRI scan to look at the muscles, a muscle biopsy, or an electromyography (EMG) to record the electrical impulses that control the muscles. They may also consider other investigations to look for underlying causes to the dermatomyositis which can be discussed during a clinic appointment.

Can dermatomyositis be cured?

Dermatomyositis cannot be cured, but it often goes away after a number of years and is then said to be in remission. The aim is to control the condition. When the condition is more active, stronger treatments are used and then reduced as it improves. The dermatologist will be familiar with the treatments mentioned below and will discuss the risks and benefits during the clinic appointment.

How can dermatomyositis be treated?

After discussion, advice about treatment will be given, by the dermatologist and also other specialists, if different parts of the body are involved. Some of the possible treatments are listed here:

Corticosteroids

Steroids are often used to lower the immune response and reduce symptoms and/or signs of disease. Initially a high dose of steroid is often used to control symptoms before gradually reducing the dose over several weeks or months. Long-term steroid use can be associated with a range of side effects including irritation of the stomach, thinning of the bones (osteoporosis), diabetes, cataracts, glaucoma, and weight gain. The doctor may prescribe medication to reduce the risk of stomach irritation or thinning of the bones. If steroids have been taken for more than 6 weeks continuously, they should never be suddenly stopped without discussion with the dermatologist or GP.

[Strong steroid ointments](#) are usually given for the skin rash for all areas including the face. The patient leaflet for the ointment may advise against using it on the face; however, due to the severity of dermatomyositis the benefits of use outweigh the risks. If there are any concerns these should be discussed this with the doctor or dermatologist.

Other immune suppressants

Drugs such as [methotrexate](#), [mycophenolate mofetil](#) and [azathioprine](#) are also immune suppressants which have different side effects to steroids. They can be used on their own or in combination with steroids to help dermatomyositis. [Hydroxychloroquine](#) may be useful for treating the rash. Sometimes injections such as rituximab or intravenous immunoglobulin may be used. More information on these drugs can be found on the British Association of Dermatologists website (www.bad.org.uk).

Self-care (What can I do?)

Sun protection

Dermatomyositis is made worse by sunlight; it is therefore advisable to stay in the shade between 10am and 3pm. It is important to wear a high protection sunscreen (SPF 50 or more) to protect against UVB and UVA (look for the UVA circle logo and/or 4 or 5 UVA stars). Apply plenty of sunscreen 15 to 30 minutes before going out in the sun and reapply every 2 hours.

Protecting your skin with clothing and wearing a wide-brimmed hat to protect your face, neck and ears will further help sun avoidance. Ultraviolet protective sunglasses will also help, and the larger, wrap-around sunglasses would offer better protection to the skin around the eyes.

Regular exercise

Whilst it is difficult to move about easily when muscles are weak, it has been shown that regular aerobic or resistance exercise can help maintain movement and reduce the problems associated with muscle weakness and pain.

Screening programmes

Many countries operate a cancer screening service at certain ages. Cervical screening, breast screening and bowel screening are provided nationally in the United Kingdom. It is important for everyone to take part in cancer screening programmes, but with the higher risk of cancer associated with dermatomyositis it is especially important. The GP will have details on local screening services.

Remember to use the medication as prescribed and inform the GP or specialist if there are any concerns.

This leaflet has been provided because a GP or dermatologist has diagnosed or suspects dermatomyositis. Depending on the extent of the condition, there may be sharing of care between the dermatologist, the GP and other specialist doctors.

Where can I get more information on dermatomyositis?

Web links to detailed leaflets:

<http://www.dermnetnz.org/immune/dermatomyositis.html>

Please note: The BAD provides links to help people access a range of information about their skin disease. The views expressed in these links may not be those of the BAD or its members.

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 APRIL 2013
UPDATED JULY 2016, SEPTEMBER 2019, JUNE 2022
REVIEW DATE JUNE 2025**