



## **DERMATOMYOSITIS**

### **What are the aims of this leaflet?**

This leaflet has been written to help you understand more about dermatomyositis. It tells you what it is, what causes it, how to recognise some of the symptoms, what can be done about it, and where you can find out more.

### **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). Very rarely 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 the muscles. A skin rash usually appears before the muscle weakness starts; however, some people may only have the skin rash. People who have dermatomyositis also sometimes feel tired and run down.

Dermatomyositis usually affects the muscles involved in movement such as the neck, arms or hips. Due to the inflammation in the muscles they become weak and may also be tender. The muscle weakness may make it difficult to do things that require lifting the arms over the head, such as combing or drying the hair, and lifting/stretching the legs, such as going up the stairs.

### **What does dermatomyositis look like?**

The dermatomyositis rash may be patchy and usually a bluish-purple colour; is sometimes very itchy; affects the skin around the eyes, over the knuckles, on the face, the “V” of the neck and the cuticles at the base of the nails which may become fragile and discoloured.

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 in the body; however, some possible effects of these are listed below:

- *Oesophagus (Gullet)*  
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, then some people may develop shortness of breath and have difficulty breathing deeply.
- *Heart*  
The heart is also a muscle and can be affected in dermatomyositis, although this is rare. If the heart muscle is affected this can cause palpitations (an irregular or fast heart beat) and dizzy spells. Your doctor may recommend that you have 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 internal cancer. This occurs in a quarter of adults, but very rarely in children.

A dermatologist is fully aware of the risk of a tumour developing in association with dermatomyositis and will be checking to make sure this is spotted early. Unexpected weight loss, a change in bowel habits, bleeding from the back passage, a persistent cough or blood in the urine would be helpful things to be mentioned to the dermatologist at appointments.

### **How is dermatomyositis diagnosed?**

The dermatologist may organise a number of tests including a blood test, a skin biopsy (sample of skin taken for analysis with 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.

### **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 reduced as it improves. Your dermatologist will be familiar with the treatments mentioned below and will discuss the risks and benefits with you so you are involved in any decisions.

### **How can dermatomyositis be treated?**

Advice about treatment will be given, after discussion with you, by your 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 response of the immune system which reduces the amount of inflammation-causing antibodies. Steroids are immune suppressants and are used in many autoimmune diseases. High doses of tablets are given to start with then gradually reduced as the condition gets better. Your doctor may give you acid blocking drugs to help with heartburn and also tablets to prevent bone thinning if steroids are going to be used long term.

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 you have any concerns, discuss this with your doctor or dermatologist.

### *Other immune suppressants*

Drugs such as [methotrexate](#), [mycophenolate mofetil](#) and [azathioprine](#) are also immune suppressants that 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](http://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. Your GP will have details on local screening services.

**Remember to use the medication as prescribed and let your GP or specialist know if you have any concerns.**

You have been given this leaflet because your general practitioner or dermatologist has diagnosed or suspects you have dermatomyositis. Depending on the extent of your condition, there may be sharing of your care between the dermatologist, your general practitioner and other specialist doctors.

### **Where can I get more information on dermatomyositis?**

*Web links to detailed leaflets:*

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

For details of source materials used please contact the Clinical Standards Unit ([clinicalstandards@bad.org.uk](mailto: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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