PATIENT INFORMATION LEAFLET

DERMATOMYOSITIS

WHAT ARE THE AIMS OF THIS LEAFLET?

This leaflet has been written to help patients learn about dermatomyositis. It explains what dermatomyositis is and what causes it. It also explains the symptoms, and what treatments are available. It also shows where to find more information about the condition.

WHAT IS DERMATOMYOSITIS?

Dermatomyositis is a rare health condition. It is estimated to affect 9-10 out of a million people. It causes inflammation in the skin and the muscles. The word comes from the Latin for skin (dermis-), muscles (-myos-) and inflammation (-itis). Rarely, only the skin is affected.

WHAT CAUSES DERMATOMYOSITIS?

The cause of dermatomyositis is unknown, but it is believed to be an autoimmune condition. This means the body's defence system becomes overactive and attacks its own cells.

WHO CAN GET DERMATOMYOSITIS?

Dermatomyositis affects women more than men and can occur at any age. Sometimes children can be affected, but it is more common in adults over the age of 50.

WHAT DOES DERMATOMYOSITIS FEEL AND LOOK LIKE?

The symptoms can include:

- Skin rash that can be itchy. This usually appears before the muscle weakness starts. Sunlight makes the rash worse.
- Feeling tired and run down.
- Muscles may feel sore and stiff.
- Muscle weakness most often affects the neck, arms or hips. This may make it difficult to do some movements such as lifting the arms above the shoulders or climbing the stairs.

Some patients may only have a skin rash, with no muscle symptoms. Others may have both skin rash and muscle symptoms. These symptoms can occur all at once, or at different times.

In white skin tones the rash can appear red or purple; in brown and black skin tones the rash can appear purple or brown. The rash can get worse in sunlight and is usually more severe on areas exposed to the sun.
The areas of skin most often affected by dermatomyositis are:

- Around the eyes
- Over the finger and hand knuckles
- The front of the neck, most often in a 'V' shape
- The skin around the fingernails.

ARE ANY CONDITIONS LINKED WITH DERMATOMYOSITIS?

Rarely, dermatomyositis can affect muscles that line the organs in the body, for example:

Oesophagus (throat)

The oesophagus is the passage from the mouth to the stomach. If the muscles of the oesophagus are affected, acid can leak out of the stomach. This is heartburn (acid reflux). Heartburn can be treated with acid blocking medicines. If the muscles are more severely affected, it may be hard to swallow.

Lungs

If the chest wall muscles are affected, it can be hard to breathe deeply. Sometimes the lungs may be affected and over time they can become stiff. This can make it hard to breathe deeply. This can be looked for by scanning the chest or testing lung function.

Heart

The heart is a muscle and can rarely be affected in dermatomyositis. If the heart is involved, this can cause palpitations (an irregular or fast heartbeat) and dizzy spells. The healthcare

professional may suggest having a heart tracing test (ECG) to check for this.

Dermatomyositis also can lead to the following:

Calcinosis

Calcinosis is when calcium is deposited in the skin or muscles. These look like small firm yellow or white lumps underneath the skin. Sometimes, these can be sore. If the lump becomes painful or causes problems, then an operation to remove them may be suggested.

Cancer

In adults who have dermatomyositis, it is important to look for signs of underlying cancer. This occurs in 1 in 4 adults with dermatomyositis. It is rare that children with dermatomyositis have cancer. It is important to tell your healthcare professional if you have any of these symptoms:

- Unexplained weight loss
- Change in bowel habit
- Bleeding from the back passage
- A cough that lasts more than 3 weeks
- Blood in the urine
- Night sweats

HOW IS DERMATOMYOSITIS DIAGNOSED?

Healthcare professionals managing dermatomyositis may organise tests including:

- Blood tests
- Skin biopsies - small sample of skin taken to be looked at under a microscope.
- Investigations of muscles including MRI scan, biopsy and/or electromyography (EMG) to record electrical activity of the muscles.

Other tests to look for causes of the dermatomyositis may also be considered This would be talked about during a clinic appointment.

CAN DERMATOMYOSITIS BE CURED?

Dermatomyositis cannot be cured. However, it often goes away after several years. This is called remission. The aim of treatment is to control the symptoms of the condition. When dermatomyositis is more active, stronger treatments are used. When it is less active, fewer or milder treatments are used.

HOW CAN DERMATOMYOSITIS BE TREATED?

Treatment options will be discussed during clinic appointments. If different body parts are involved, the treatment may also involve other specialists.
Some of the possible treatments are listed here:

Corticosteroids

Oral corticosteroids are tablets that lower the response of the immune system. This can help to reduce symptoms and signs of disease. At first, a high dose is often used. This dose is then slowly reduced over several weeks or months. Long-term steroid use can be linked to a range of side effects. These include

- Irritation of the stomach
- Thinning of the bones (osteoporosis)
- Diabetes
- Eye problems (cataracts, glaucoma) and
- Weight gain

Your healthcare professional may prescribe a medicine to lower the risk of stomach irritation or bone thinning. If steroids have been taken for more than 6 weeks in a row, they should never be suddenly stopped without talking to a healthcare professional.

Strong steroid ointments are often given for all areas of the skin rash. This includes the face. The patient leaflet for the ointment may say not to use it on the face. However, due to the severity of dermatomyositis the benefits of use outweigh the risks. Any concerns should be discussed with a healthcare professional or dermatologist.

Other immune suppressants

They are medicines such as methotrexate, mycophenolate mofetil and azathioprine. They can be used on their own or with steroids to help dermatomyositis symptoms.
Hydroxychloroquine may be useful for treating the rash. Sometimes injections such as rituximab or intravenous immunoglobulin can be used.

SELF-CARE (WHAT CAN I DO?)

Sun protection

Dermatomyositis can get worse after exposure to sunlight. It is recommended to stay in the shade between 10am and 3pm. It is important to wear a sunscreen (SPF 50 or more) to protect against the sun. 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. Reapply sunscreen every 2 hours.

It is also important to protect your skin with clothes. A wide-brimmed hat to protect your face, neck and ears will further help. Large ultraviolet protective sunglasses help to protect the skin around the eyes.

Regular exercise

Regular exercise can help to reduce problems linked with muscle weakness.

Screening programmes

Many countries operate cancer screening services at certain ages. In the United Kingdom, cervical screening, breast screening and bowel screening are provided. People affected by dermatomyositis have a higher risk of cancer. It is important to attend all cancer screening appointments.

WHERE CAN I GET MORE INFORMATION ON DERMATOMYOSITIS?

Web links to other relevant sources:

RDS:
https://www.rheumaderm-society.org/dermatomyositis-information-for-patients/

DermNetNZ:
https://dermnetnz.org/topics/adult-onset-dermatomyositis

Jargon Buster:
www.skinhealthinfo.org.uk/support-resources/jargon-buster/

Please note that the British Association of Dermatologists (BAD) provides web links to additional resources to help people access a range of information about their treatment or skin condition. The views expressed in these external resources may not be shared by the BAD or its members. The BAD has no control of and does not endorse the content of external links.

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, JULY 2026
NEXT REVIEW DATE | JULY 2029