CONDITION

# Dermatomyositis

Dermatomyositis is an immune-related condition that causes a distinctive skin rash and often muscle inflammation and weakness.

**WHAT IT IS**
Autoimmune inflammation affecting skin and often muscles

**BODY SYSTEM**
Skin, muscles, lungs, and immune system

**MAIN SYMPTOMS**
Distinctive rash, muscle weakness, fatigue, swallowing difficulty

**WHAT CAUSES IT**
Immune system attack; exact trigger unknown

**HOW IT IS DIAGNOSED**
Examination, blood tests, MRI, and skin or muscle biopsy

**MAIN TREATMENT**
Immune-suppressing medicines, skin care, and rehabilitation

**CAN IT BE CURED?**
Sometimes - lasting remission can occur

**IS IT AN EMERGENCY?**
Sometimes - new breathing or severe swallowing problems

**LONG-TERM OUTLOOK**
Many improve, but relapses and organ complications can occur

## Overview

Dermatomyositis is a long-term inflammatory condition. The immune system, which normally protects you from infection, mistakenly damages the skin and sometimes the muscles and other organs.

The name comes from "dermato," meaning skin, and "myositis," meaning muscle inflammation. Most people develop a distinctive rash, along with weakness in the muscles closest to the centre of the body. These include the muscles around the shoulders, upper arms, hips, and thighs.

Some people have the skin changes without noticeable muscle weakness. This is called clinically amyopathic dermatomyositis. It still needs medical follow-up because lung problems or other complications can occasionally occur even when muscle symptoms are absent.

Dermatomyositis can begin during childhood or adulthood. The childhood form is called juvenile dermatomyositis. Children and adults share many symptoms, but their patterns of complications and follow-up are not identical.

The condition matters because it can affect movement, swallowing, breathing, and daily activities. In adults, it can also be associated with a higher chance of an underlying cancer, particularly around the time dermatomyositis is diagnosed. Most people with dermatomyositis do not have cancer, but appropriate screening is an important part of assessment.

## Symptoms

Skin changes may appear before, during, or after muscle symptoms. The rash can be subtle, especially on darker skin, where redness may look purple, brown, grey, or darker than the surrounding skin.

Typical skin findings include:

Small blood vessels around the fingernails may become enlarged or irregular. The skin on the sides of the fingers can become rough and cracked, sometimes described as "mechanic's hands."

Muscle weakness usually develops on both sides of the body. You may notice difficulty climbing stairs, rising from a low chair, lifting objects onto a shelf, washing your hair, or getting up from the floor. Weakness is usually more prominent than muscle pain, although aching and tenderness can occur.

Other possible symptoms include fatigue, fever, loss of appetite, unplanned weight loss, joint pain, or stiffness.

Inflammation in the throat and swallowing muscles can make food feel stuck or cause coughing during meals. Lung involvement may cause a dry cough or breathlessness. Rarely, inflammation affects the heart.

Hard calcium deposits under the skin, called calcinosis, are more common in juvenile dermatomyositis. They may be painful or restrict movement.

- Purple or dusky swelling around the eyelids, called a heliotrope rash
- Raised or flat patches over the knuckles, called Gottron papules or signs
- A sun-sensitive rash on the face, upper chest, shoulders, upper back, or arms
- An itchy, painful, or scaly scalp, sometimes with hair thinning

## Causes and risk factors

The exact cause is unknown. Dermatomyositis is considered an autoimmune condition because the immune system attacks healthy tissue and small blood vessels.

It is not caused by poor hygiene, diet, exercise habits, or something you did. It is not contagious.

Genes may influence a person's susceptibility, but dermatomyositis is not usually inherited in a simple, predictable way. Most people do not have another family member with the condition.

Possible triggers may include infections, medicines, and environmental exposure in people who are already susceptible. Ultraviolet light from the sun can trigger or worsen the skin rash, but it is not the sole cause of the condition.

Certain immune proteins in the blood, called myositis-specific antibodies, are associated with different patterns of symptoms. For example, some are linked with lung involvement, prominent skin changes, or a greater cancer association. An antibody result indicates a pattern of risk; it does not prove that a complication is present.

Cancer does not cause every case of adult dermatomyositis. However, the two can occasionally occur together because of the immune system's response to a tumour. The level of concern is influenced by age, symptoms, examination findings, antibody results, and how the condition responds to treatment.

## Diagnosis

There is no single test that diagnoses every case. Assessment usually combines your symptoms, the appearance of the rash, a muscle examination, and several tests.

Blood tests can measure muscle enzymes such as creatine kinase, often called CK. These enzymes enter the blood when muscle is damaged. Normal muscle enzymes do not fully rule out dermatomyositis, especially when the condition mainly affects the skin. Blood tests may also look for inflammation, organ function, and myositis-specific antibodies.

An MRI scan can identify inflammation in particular muscles and help select an area for biopsy. Electromyography, or EMG, measures electrical activity in muscles and may help show a pattern of muscle damage.

A skin biopsy removes a small skin sample for examination under a microscope. A muscle biopsy does the same with muscle tissue. A biopsy can support the diagnosis and help rule out other causes, although it is not needed in every case.

Other assessments may include:

Conditions such as lupus, other inflammatory muscle conditions, inherited muscle disorders, medication-related muscle damage, and some hormonal conditions can cause overlapping symptoms. Careful assessment helps distinguish between them.

- Breathing tests or a chest CT scan to check for lung inflammation
- A swallowing assessment if eating or drinking is difficult
- Heart tests when symptoms suggest heart involvement
- Cancer screening based on age, symptoms, examination, and individual risk

## Treatment and management

Treatment aims to control inflammation, improve strength and function, relieve skin symptoms, and protect affected organs. Care may involve rheumatology, dermatology, neurology, respiratory medicine, physiotherapy, and other specialties.

A corticosteroid like prednisone or hydrocortisone is often used to control active muscle or organ inflammation. Because long-term corticosteroid use can cause complications, another immune-suppressing medicine is commonly used to reduce steroid exposure and maintain control. Options include medicines such as methotrexate, azathioprine, or mycophenolate. The choice depends on which organs are affected and your wider health.

Intravenous immunoglobulin, or IVIG, is an infusion made from purified antibodies donated from blood plasma. It can help some adults with active dermatomyositis, including people with significant muscle, skin, or swallowing symptoms. Other immune treatments, including biologic medicines, may be considered when the condition remains active.

Skin treatment may include creams or ointments that reduce inflammation. Medicines that act throughout the body may be needed when the rash is extensive or persistent.

Sun protection is part of treatment because ultraviolet light can worsen the rash. Helpful measures include broad-spectrum sunscreen, protective clothing, shade, and avoiding deliberate tanning.

Physiotherapy supports mobility and gradually rebuilds strength. Exercise is usually introduced according to disease activity and ability. Pushing through major weakness without guidance may worsen fatigue or increase the chance of injury. Occupational therapy can suggest ways to make dressing, bathing, work, or school activities easier.

Management may also include bone protection, vaccination planning, infection monitoring, nutritional support, and help for swallowing problems. Treatment should not be stopped suddenly without medical guidance, particularly corticosteroids.

## Complications

Dermatomyositis can cause complications from the condition itself or from immune-suppressing treatment.

Possible complications include:

Some forms of lung involvement develop slowly. Others can worsen more quickly, which is why a new cough or increasing breathlessness should be assessed promptly.

Adults may need additional cancer screening. This does not mean cancer will be found. The purpose is to identify an associated cancer early if one is present.

- Difficulty swallowing, choking, poor nutrition, or food entering the lungs
- Interstitial lung disease, meaning inflammation and scarring around the lung's air sacs
- Falls, reduced mobility, and loss of muscle conditioning
- Painful calcium deposits, particularly in children
- Skin ulcers, scarring, or changes in skin colour
- Infection, bone thinning, or other effects of treatment
- Rare inflammation affecting the heart

## Prevention

There is no established way to prevent dermatomyositis because its underlying immune reaction is not fully understood.

You can help reduce avoidable skin flares by protecting your skin from ultraviolet light. Taking prescribed treatment consistently and attending follow-up appointments can also reduce the chance that silent muscle, lung, or swallowing problems go unnoticed.

If you take immune-suppressing medicine, discuss vaccinations and infection precautions with your healthcare team. Some vaccines or their timing may need to be planned around treatment.

## Living with it and what to expect

The course differs from person to person. Some people have one active period followed by long-term remission. Others have ongoing symptoms or episodes that improve and then return. Skin and muscle activity do not always change together.

Improvement in strength often takes time, even after inflammation begins to settle. Muscles may need weeks or months of rehabilitation. Long-standing muscle damage can leave some persistent weakness, while early control of inflammation may allow better recovery.

The rash can remain active when muscle symptoms are controlled. It may itch, affect sleep, or change how you feel about your appearance. Consistent sun protection and dermatology care can make an important difference.

Regular follow-up commonly includes checks of strength, skin, blood tests, treatment effects, and symptoms involving the lungs or swallowing. Adults may receive cancer screening during the period when the association is most relevant. Children are monitored for growth, movement, and calcium deposits.

Many people continue school, work, family life, and physical activity, although temporary adjustments may be needed during active periods. Pacing activities, using rehabilitation support, and discussing fatigue or emotional strain can help make day-to-day life more manageable.

## When to get medical help

Arrange a routine medical appointment if you develop a persistent rash over the eyelids, knuckles, chest, or shoulders, especially if it occurs with new muscle weakness. Also seek assessment for gradually increasing difficulty climbing stairs, lifting your arms, or getting out of a chair.

Contact your healthcare team promptly if you have:

Call emergency services for severe trouble breathing, choking that does not clear, blue or grey lips, chest pain, fainting, or an inability to swallow saliva. These symptoms need immediate assessment rather than routine follow-up.

- New or worsening cough or breathlessness
- Increasing difficulty swallowing or repeated coughing during meals
- Rapidly worsening weakness or more frequent falls
- Fever or signs of infection while taking immune-suppressing medicine
- New lumps, unexplained bleeding, or persistent unplanned weight loss

## Common questions

Is dermatomyositis a type of cancer?

No. It is an inflammatory autoimmune condition. However, adult dermatomyositis can sometimes occur alongside cancer. Screening is based on your age, symptoms, antibody pattern, and other risk factors.

Can I have dermatomyositis without muscle weakness?

Yes. Clinically amyopathic dermatomyositis causes characteristic skin changes without clear muscle weakness for a prolonged period. Follow-up is still important because lung disease or later muscle involvement can occur.

Will dermatomyositis go away?

Some people enter long-lasting remission, while others have persistent or recurring symptoms. Treatment can often control inflammation, but it cannot guarantee that the condition will never return.

Is dermatomyositis contagious or inherited?

It is not contagious. Genes may contribute to susceptibility, but the condition is not usually passed directly from parent to child.

Can I exercise with dermatomyositis?

Exercise is often helpful when it is matched to your strength and the activity of the condition. A physiotherapist can guide a gradual programme that avoids falls, overexertion, and loss of conditioning.

Why does sunlight make the rash worse?

Ultraviolet light can activate inflammation in dermatomyositis-affected skin. Sun protection can reduce this trigger, although it cannot prevent the underlying condition.

## Sources

- National Institute of Neurological Disorders and Stroke - Dermatomyositis
- American College of Rheumatology - Inflammatory Myopathies
- British Society for Rheumatology guideline on management of paediatric, adolescent and adult idiopathic inflammatory myopathy, Rheumatology , 2022
- Lundberg and colleagues - 2017 EULAR/ACR classification criteria for adult and juvenile idiopathic inflammatory myopathies, Annals of the Rheumatic Diseases

- Oldroyd and colleagues - International guideline for cancer screening in people with idiopathic inflammatory myopathy, Nature Reviews Rheumatology , 2023
- Aggarwal and colleagues - Trial of intravenous immune globulin in dermatomyositis, The New England Journal of Medicine , 2022