



THE MYOSITIS ASSOCIATION

The Myositis Association (TMA) is a non-profit, voluntary health agency dedicated to improving the lives of people affected by myositis. Formed in 1993, TMA has grown from 16 patients, who helped form the organization, to more than 6,000 members who have been served by TMA.

TMA is governed by a volunteer Board of Directors that includes patients, family members and interested professionals, bringing diverse strengths and perspectives to the organization.

Through member newsletters, publications, support groups, research and advocacy, TMA helps those who have myositis today and works to prevent any others from having to experience myositis in the future.



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Dermatomyositis

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“Myositis” describes inflammation or swelling of the muscle tissue. General muscle inflammation can occur after exercising or taking certain medication, or it can be from a chronic inflammatory muscle disorder like dermatomyositis (DM). Although the underlying causes of the DM inflammation are not known, some doctors believe there is an environmental exposure (perhaps to an infection or sunlight) that triggers the disease in someone who has certain specific but not yet fully defined genes or gene sequences that predispose him or her. DM is a rare disease, and all forms of myositis (polymyositis, dermatomyositis, and inclusion-body myositis) combined affect about 50,000 people in the U.S.

DM affects people of any age or gender but it is more common in women than men. It is the most recognizable form of myositis – and therefore easiest to diagnose – because of the visible skin rash. Some of the first signs of DM are:

- A patchy, dusky, reddish-purple rash on the eyelids, elbows, knees, or knuckles. Rashes may also occur on the cheeks, nose, back, and upper chest;
- General tiredness;
- Trouble climbing stairs, standing from a seated position, or reaching up;
- Scaly, dry and/or rough skin.

Several sub-types of DM are: overlap myositis, when the patient has at least one other autoimmune disease (such as lupus, scleroderma, or arthritis) along with myositis; amyopathic dermatomyositis, or DM sine myositis, when the skin is affected but muscles are not involved; and cancer-associated myositis, when the diagnoses of myositis and cancer occur within two to three years of one another.

Inflammatory myopathies are classified as autoimmune diseases, meaning the body's immune system, which normally fights infections and viruses, does not stop fighting once the infection or virus is gone. The immune system is misdirected and attacks the body's own normal, healthy tissue through inflammation.

WHAT ARE THE SYMPTOMS OF DM?

Patients often experience the skin rash of DM before the muscle weakness. The rash may be painful or itchy, or it may cause no discomfort. The rash and weakness are caused by inflammation of the blood vessels under the skin and in the muscles.

Patients usually experience muscle weakness gradually, developing over a period of weeks or months, and some patients experience muscle pain. The muscles most often affected are those closest to and within the trunk of the body – neck, hip, back, and shoulder muscles, for example. Some people have trouble swallowing (dysphagia), hoarse voice (dysphonia), painful joints, and other complications.

HOW DO DOCTORS TEST FOR DM?

Your doctor may first ask you questions about your health in general, including your health history and when you first saw signs of skin rash or muscle weakness. He or she will then do a physical exam to assess muscle strength and skin symptoms, and will typically ask the hospital's lab to run one or more of the following tests:

- Blood tests for muscle enzymes (including CPK and aldolase tests) and other blood factors
- Muscle biopsy
- Electromyogram (EMG) and nerve conduction velocities (NCV)
- Magnetic resonance imaging (MRI) of the leg muscles

Your doctor may order other tests to rule out other diseases or conditions. If you have questions about any test, be sure to talk with your doctor or lab technicians, or visit TMA's web site at www.myositis.org.

HOW IS DM TREATED?

Medicines used to treat DM aim to slow the immune system and stop the inflammatory attack on the muscle, skin and other body systems. Prednisone, a corticosteroid medicine, is often effective as a first-line treatment in controlling the inflammation and increasing muscle strength. Your doctor will monitor you for possible negative side effects, including weight gain from fluid retention, osteoporosis, cataracts, mood swings, high blood pressure, and diabetes. (Diabetes is an increased risk if the patient has a family history of adult-onset type-2 diabetes, or is overweight.) You and your physician should carefully consider the potential benefits and risks of this and other medicines.

Your doctor may prescribe other immunosuppressant medicines – medicines that also slow the body's immune system and inflammatory response – to be used in place of or in addition to corticosteroids. When used in combination with a corticosteroid, the additional immunosuppressant allows patients to use a lower dose of the corticosteroid, thereby lessening the corticosteroid's undesirable side effects. Immunosuppressants include methotrexate, azathioprine, and cyclosporine. Intravenous immunoglobulin (IVIg) has been used with some success in treating difficult cases of DM. Some medicines require extra caution, and your doctor will monitor your blood tests closely. Other immunosuppressants are being studied, and there is considerable work currently underway to develop new and more effective treatments.

Sometimes physicians prescribe topical forms of corticosteroids or other medicines to treat the skin symptoms. Your doctor will talk to you about complementary, non-medical treatment like physical and occupational therapy, appropriate exercise, and especially sun protection, since in many cases exposure to sunlight exacerbates the disease.