DERMATOMYOSITIS (DM)

Myositis Support & Understanding
Empowering the Myositis Community

What is DM?

Dermatomyositis, one of the Idiopathic Inflammatory Myopathies (IIM), is a rare, systemic autoimmune disease. There are variations of DM, including amyopathic dermatomyositis (ADM), which is DM with only skin symptoms, and juvenile dermatomyositis, when the person diagnosed is under the age of 18. Some people may also have antibody-specific variations of DM, like MDA5, often associated with ADM.

What are the symptoms of DM?

DM often causes a violet, itchy skin rash that can appear all over the body, including face, hands, body, and scalp. These rashes often precede or accompany progressive weakness in the muscles closest to the trunk, like the hips, neck, shoulders, upper arms, and thighs. Muscle weakness and pain can make getting out of a chair, raising arms over the head, combing hair, lifting, brushing teeth, walking, and other activities difficult.

Other symptoms can include:

- Skin complications like Mechanic's hands, Gottron's papules, ulcers, or calcinosis.
- Debilitating fatigue, joint pain, and trouble swallowing.
- Damage to other organs of the body, such as the heart and lungs.

How is DM diagnosed?

Diagnosing DM can be difficult. The process often includes exams and several tests:

- First, doctors usually get a patient history and conduct a physical exam.
- Then, they may order blood tests to check for myositis-specific antibodies, muscle enzymes (CK), and other inflammatory, autoimmune, and cancer markers.
- Often, diagnosis is confirmed after an MRI, nerve conduction test, EMG, and skin and/or muscle biopsy.

Some people lack typical findings of DM (such as high CK levels), making diagnosis more challenging.

How is DM managed?

There are a variety of medications that can be used to treat DM. Avoiding skin triggers and using assistive devices can also help manage symptoms. Most people with DM manage with a combination of the following:

- **Medication.** DM treatments often start with topical, oral, and IV steroids. Off-label use of other medications may be successful, including antimalarials, immunosuppressive agents, chemotherapy medications, and infusion therapies, like IVIG, and monoclonal antibodies, like rituximab.
- **Sun protection.** Sun avoidance, sunscreen, and physical sun blockers, like UV protective clothing, can help control rashes and photosensitivity.
- **Assistive devices.** A cane, walker, rollator, or wheelchair can help balance or weakness. Assistive devices can be used for short periods, such as during flares, or for long-term muscle weakness or damage.
- **Movement.** Physical therapy and exercise are usually recommended for all myositis patients. Talk with your doctor before starting any exercise routine.

What are other complications?

DM can cause other complications:

- There is a higher risk for **cancer** 3-5 years pre-and-post disease onset of DM. The presence of autoantibodies like TIF1-γ or NXP2 are a higher cancer risk factor for DM patients.
- Some people with DM can develop **interstitial lung disease (ILD)**. The risk is higher for certain antibody types, like MDA5. Some people may eventually require supplemental oxygen or a lung transplant.
- **Dysphagia,** or difficulty swallowing, can be caused by muscle weakness in the throat. Dysphagia can lead to choking and aspiration pneumonia.

Where can I find more information?

Myositis Support and Understanding has a robust website full of resources including information about IIM, how to manage these difficult conditions, and where to find support. Go to **www.understandingmyositis.org** or use this QR code to learn more!