

# Dermatomyositis

---

## What is dermatomyositis?

Dermatomyositis is the medical term for a disease that affects muscles and the skin. This term comes from several words in Greek:

- 'derma' means skin (the skin is affected)
- 'myo' means muscles (muscles are affected)
- 'itis' means inflamed (the skin and muscles become inflamed)

## What are the signs and symptoms of dermatomyositis?

Each person responds differently to the disease. The signs and symptoms usually appear gradually.

The most common signs of dermatomyositis are:

### **Skin rashes**

You may have a purple or red coloured rash around your eyes and a reddish rash on your face, neck, shoulders, upper chest and back. These areas may also be swollen.

The skin over your knuckles (Gottron's rash), elbows and knees may be scaly and red.

---

**Muscle weakness**

- Dermatomyositis commonly affects the muscles close to the body such as those in your neck, shoulders, chest, hips and thighs.
- The muscles become weak and may eventually waste away (atrophy).
- As you lose muscle strength, you may have difficulty getting up from a chair, climbing stairs, lifting, working with your arms up or holding your head up.

**Other signs or symptoms include:**

- feeling very tired (fatigue)
- a general feeling of discomfort, most often in your shoulders and thighs
- muscle pain or tenderness
- swallowing problems
- weight loss
- low fever
- hard lumps under the skin, caused by deposits of calcium (calcinosis)
- if your heart and lungs are affected, you may develop an irregular heart beat, heart failure or shortness of breath

Dermatomyositis is usually a chronic or life-long disease that affects people in different ways. Some people develop symptoms once, get better with treatment and are never affected again. Others continue to have “flare-ups” throughout their lives. This means that they develop symptoms now and again. In between, the disease is inactive and they have few or no symptoms (remission).

---

## What causes dermatomyositis?

We do not know the exact cause of dermatomyositis. However, these factors may be involved:

- inheritance – certain people may be more likely to get the disease because of their family history (genes passed down from parents)
- cancer – in about 15 out of 100 patients the disease is caused by having cancer
- infection – having an infection caused by a virus may increase the chances of getting dermatomyositis

Dermatomyositis is thought to be an autoimmune disorder. This means that your immune system, which normally works to protect you from germs, is attacking your own cells. The small blood vessels are most often affected, causing inflammation in the skin and muscles. We do not know what triggers this reaction.

## How do you know I have dermatomyositis?

Your doctor or specialist can tell if you have dermatomyositis from:

- talking with you about your symptoms and family history
- checking the strength of your muscles
- reviewing the results of the following tests

### Blood tests

- Muscle enzymes - When muscles are damaged by inflammation, they release enzymes into the blood (CK, AST, ALT, LDH, etc.). The amount of muscle enzymes in the blood shows how much inflammation is present.
-

**Electromyograph (EMG) and nerve conduction velocity**

- These tests measure the electrical activity in your muscles and nerves using a fine needle and mild electrical “shocks”. They can help detect dermatomyositis or other muscle diseases.

**Muscle biopsy**

- A biopsy is a procedure to take a tiny sample of muscle to be examined under a microscope.
- This procedure is done in the clinic and takes about 20 minutes.
- The sample is usually taken from the muscle in your thigh (quadriceps) or shoulder (deltoid). First the area is “frozen” or numbed with a local anesthetic. Then the doctor makes a tiny cut (incision) and removes a sample of muscle with a needle. The incision is closed with a stitch that will need to be removed in a few days.

**If the disease is found early, you will likely respond better to treatment.**

**How is dermatomyositis treated?**

Dermatomyositis is usually treated with a combination of methods. Your treatment plan will be designed to meet your needs.

**The goal of treatment is to prevent or lessen your symptoms and help you regain the strength in your muscles.**

---

## Corticosteroids

- The first treatment is usually a medication to decrease inflammation called a corticosteroid (for example, prednisone). This medication is similar to a hormone found naturally in the body. It may be given by mouth, through an intravenous (IV) and in an ointment for the skin. The dose is lowered as your symptoms improve.

## Immunosuppressive therapy

- If corticosteroids do not relieve your symptoms, you may be given medications to ‘turn off’ (suppress) your immune system. The medications used most often are azathioprine (Imuran) and methotrexate.

## Intravenous immunoglobulin therapy (IVIG)

- Immunoglobulin is an antibody treatment that is given through an IV to reduce the disease-causing antibodies and to strengthen your immune system.

## Physiotherapy

- After the inflammation settles down, you may begin physiotherapy. A physiotherapist will plan an exercise program to prevent muscle stiffness and wasting, regain muscle strength and promote full movement of your joints. This may include activities such as swimming, walking or biking.
- During a flare-up, you will need to stop exercising and limit your activity. You need to rest to prevent further muscle breakdown.

## Nutrition

- Your diet is also important to your treatment. Refer to **Eating Well with Canada’s Food Guide** to make sure you have enough protein and calories in your diet. Ask your family doctor for a copy or visit Health Canada’s website: <http://www.has.uwo.ca/hospitality/nutrition/pdf/foodguide.pdf>
  - We recommend that you take supplements of calcium (500 mg a day) and Vitamin D (400 iu a day).
  - A supplement of creatine monohydrate can also help relieve symptoms. Take ½ tsp (2 ml) in the morning and take ½ tsp (2 ml) in the evening. Do not take more than this amount. You can add it to a glass of juice or sprinkle it on cereal or yogurt.
-

## How will having dermatomyositis affect my life?

Each person responds differently to the disease. Most people do very well, especially if their disease is treated early.

You will visit the Neuromuscular and Neurometabolic Centre, where the health care team will plan your treatment and provide your care. When the disease is not active, your care will focus on regaining strength and rebuilding muscles (rehabilitation).

Living with a chronic condition can be challenging and emotional. Here are some ideas for living well with a chronic disease.

### **Educate yourself**

- Learn as much as you can about the disease and how to manage symptoms. If you have questions, ask your health care providers. This will help you make informed decisions about your care.

### **Take part in your care**

- Work closely with your health care providers, as a team. Follow your treatment plan. Keep track of your symptoms and your response to treatment. Tell your health care providers how you are doing.

### **Take care of yourself**

- Learn to listen to your body. Rest and conserve your energy when you feel tired. When you are active, go at your own pace.

### **Talk about your feelings**

- It is normal to have mixed emotions when you are living with a chronic illness. At times, you may feel sad, angry or helpless. It can help to talk about your feelings with your partner, someone close to you or another person who has faced a similar situation. Remember that your health care providers can also help.
-

**If you have any questions about dermatomyositis, please speak with your doctor or nurse at the Neuromuscular and Neurometabolic Centre.**

**Notes and Questions**

Lined area for notes and questions, featuring horizontal lines and a pen icon on the right side.

