



## IRA E-BULLETIN : ISSUE 2 | APRIL 2020

### MYOSITIS: EXPERT SPEAK

#### 1) What is my disease, myositis, what does it actually mean?

Myositis means inflammation within the muscles. The word inflammation usually includes within it increased temperature, pain, swelling and redness. Your muscles are undergoing these changes.

#### 2) What are the symptoms of myositis?

The most common symptom of myositis is the weakness of the muscles. This means a loss of strength of the muscles. Movements become difficult to complete often even in the absence of pain.

#### 3) Can other parts of my body be affected by this disease?

Myositis, which refers to inflammation of muscles, may be associated with inflammation elsewhere in the body also. Commonly affected organs of the body are joints and skin. On occasion, the lungs and heart may be affected. Sometimes this muscle inflammation is the major problem and sometimes it is a part of other diseases like lupus or scleroderma.

#### 4) How/why did I get this disease? Is it related to pollution, environmental stress, infection or diet?

Each of us carries within all our cells machinery called genes. The genetic makeup of individuals have minor variations that may make a person more easily affected by stresses in the environment than others. These two, the genes and the environment combine to form disease. Usually the body constantly repairs any defect arising out of this combination, but when it cannot contain the bad effects of this combination disease occurs.

#### 5) Why is my immune system attacking my muscles?

Because your immune system is sensing that there is something different in your muscle cells. So it is seeing them as foreign. The immune cells are trained to sense foreign particles from bacteria, viruses or cancer cells and eliminate them, they try to remove what they think is a foreign particle. This process leads to inflammation which goes on for a long time before the patient can realize the symptoms.

#### 6) How is the diagnosis confirmed (what all tests do I have to undergo)?

You will need blood tests. These will help to confirm muscle injury. The most common tests performed are blood CPK and LDH levels. The other tests may be ENMG in which a needle will be put in your muscle and the activity of your muscles will be seen on a monitor. The third test is a muscle biopsy. With a small incision, most

often in your left thigh, a small piece of your muscle will be taken and examined under the microscope. This is safe and no damage results from the procedure to the muscle. In young children or if there is doubt even after the above tests you may be suggested to undergo an MRI of the muscles. The doctor may decide to do certain special antibody tests for diagnosis if the above tests do not help.

7) How is myositis treated? What side effects should I be concerned about?

Myositis is treated with steroids. These medicines are very important especially if the muscle weakness is severe. The side effects may include weight gain, acne, change in the shape of the body. Over some time there may be an increase in blood sugar values, a decrease in strength of bones and occasional muscles. When taken over a longer period there may be formation of cataract or development of infections. However, the doctor assesses risk-benefit ratio and decides how much steroids to give and in what dose and when to reduce it so that the disease does not come back. To support the steroids and reduce their doses other medicines like methotrexate, mycophenolate mofetil, rituximab may also be chosen.

8) Can myositis be cured? Will I have to take medications lifelong? Does this disease shorten my lifespan?

Myositis can occasionally be cured. This means that once the treatment is withdrawn it never comes back. More often however the disease may come back at this time. Sometimes it is controlled only partially. Depending on this assessment it is decided how long the medicine has to be continued. The life span is not shortened unless there is the involvement of organs like the lung and heart or very rarely the development of cancer.

9) What about physical activity and exercise? Will they help or harm me?

After the initial phase when the muscles are weak and sometimes painful, exercise is always encouraged. Exercise in the initial phases may not be possible. Even then it is suggested that someone helps with the movement of muscles. Later as strength improves it is wise to get coached in how to use exercise to strengthen the muscles.

10) Is there any specific diet that will help my disease or worsen it?

No special diet is recommended or avoided in myositis.

11) Will my children inherit my disease?

The risk of inheriting myositis is very low.

12) Any self-care tips?

Keep yourself active. Keep talking to your doctor at frequent intervals about your disease. Eat healthily. Lots of plant-based food, with minimal oil, low sugar, and salt. Exercise regularly.

**Any significant new symptom please discuss with your doctor.**



**Expert**

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