

INCLUSION BODY MYOSITIS (IBM)

What is IBM?

Inclusion body myositis (IBM), one of the Idiopathic Inflammatory Myopathies (IIM), is a complex, rare, and incurable autoimmune and degenerative muscle disease. The cause is unknown. IBM causes slowly progressing muscle weakness and wasting over months and years. While many different types of people can be diagnosed with IBM, it is more prevalent in men and those over the age of 50.

Unexplained frequent falls, difficulty standing up from a chair, difficulty swallowing, and a weak handgrip may be early signs of IBM.

How is IBM diagnosed?

Diagnosing IBM can be difficult, and it is often misdiagnosed. “Normal aging” is a very common misdiagnosis, but symptoms associated with IBM are not normally expected aspects of aging. Additionally, a misdiagnosis of a motor neuron disease like ALS or one of the other inflammatory myopathies, like polymyositis (PM), is not uncommon.

Diagnosis may include 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 muscle biopsy.

What are the symptoms of IBM?

IBM symptoms typically begin with asymmetric muscle weakness in the muscles furthest from the body's core. This includes muscles of the hands, fingers, arms and legs, the thigh muscles (quadriceps), and muscles in the lower legs that move the feet.

Muscle weakness and atrophy of the hands may affect your ability to pinch, grip, button, and hold items. Weakened neck muscles can cause the head to drop and rest on the chest. Leg muscle weakness can cause difficulty rising from a chair and walking up stairs.

What are other complications?

IBM can cause other complications. They include:

- **Trouble swallowing (dysphagia).** Dysphagia can increase the risk of choking and aspiration. Aspiration pneumonia is caused by food or water going into the lungs. As many as 50-70% of people with IBM report dysphagia.
- **Weakened diaphragm.** Respiratory dysfunction can be caused by muscle weakness in the diaphragm. This can increase the risk of other pneumonias.
- **Restricted mobility.** Muscle weakness can limit mobility. Foot drop and difficulty lifting the leg can increase the risk of falls.

How is IBM managed?

While research is ongoing, there are no currently available treatments or cures for IBM. Most people with IBM manage with a combination of the following:

- **Assistive devices.** A cane, walker, rollator, or wheelchair can help improve balance or weakness. Orthotics for the knee or foot can be helpful as well. Assistive devices can be used for long-term muscle weakness or damage.
- **Movement.** Physical therapy, occupational therapy, and speech therapy can all be helpful to manage symptoms. Regular exercise is usually recommended for all myositis patients. Talk with your doctor before starting any exercise routine.
- **Support system.** Care Partners become an essential and invaluable part of the IBM patient's life. Assistance is often needed with activities of daily living (ADLs) such as feeding, dressing, bathing, and toileting. Having support in place can also help with the emotional aspects of an IBM diagnosis. Adapting to changing abilities and limitations is a large part of living with IBM.

Where can I find more information?

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

