



Myositis Support and Understanding

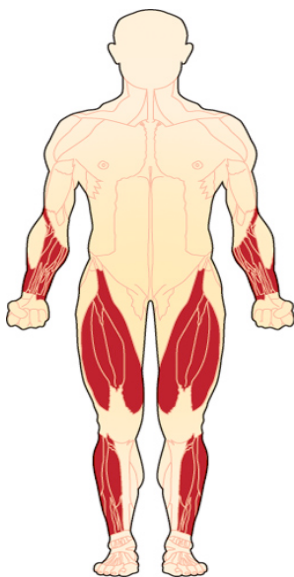
Inclusion Body Myositis (IBM) Fact Sheet

Inclusion Body Myositis is the most common inflammatory myopathy in older adults and is a progressive, degenerative, neuromuscular disease. IBM is considered a rare disease, with an annual diagnosis rate of approximately 5 people per million.

Muscle weakness tends to develop over a period of months or years and commonly includes proximal leg and distal arm muscles, wrist and forearm finger flexors, ankles, dorsiflexors, and swallowing muscle weakness. This weakness is often asymmetrical.

Inflammatory cells invading muscle tissue is one characteristic of IBM, but the disease is distinct from other inflammatory myopathies in that muscle degeneration also occurs. Inclusion Body Myositis is named for the clumps of discarded cellular material — the “bodies” — that collect in the muscle tissues.

Tripping and falling can be the first noticeable symptoms of IBM and the weakness in the wrists and fingers causes difficulty with gripping objects, pinching, and buttoning. Atrophy of the forearm muscles and quadriceps muscles in the legs may become apparent visually. Difficulty swallowing occurs in approximately half of IBM cases.



MUSCLES AFFECTED BY IBM

The muscles affected in Inclusion Body Myositis are usually those of the wrists, fingers, forearms, and the muscles at the front of the thigh, hip flexors, and calves. These symptoms are often asymmetrical.

The muscles that lift the front of the foot, dorsiflexors, also may be affected which can cause a condition called “drop foot,” which leads to tripping and falling.

*Illustration Courtesy of
Muscular Dystrophy Association*

Symptoms of IBM

- Weakness of the quadriceps
- Weakness in distal parts of arms (muscles farther away from body's core)
- Weakness of ankles and dorsiflexors (used to flex toes towards shin) causing tripping and falling due to “foot drop”
- Weakness in wrists and fingers
- Diminished deep tendon reflexes
- Atrophy of forearm
- Buckling of the knee
- Difficulty pinching, buttoning, and making a fist

Complications and Progression of IBM

- Difficulty swallowing (dysphagia) and choking
- Aspiration pneumonia (pneumonia cause by food taken into lungs)
- Weak throat muscles making eating difficult
- Weakened diaphragm causing respiratory dysfunction
- Increased difficulty rising from seated position due to loss of quadriceps muscles
- Increased difficulty climbing steps due to hip-flexor atrophy
- Increased risk of falls from balance issues, collapsing knee, or foot drop
- Progressive weakness in other parts of body
- Restricted mobility necessitating use of wheelchair and other assistive devices
- Swelling (edema), especially of the feet
- Pressure sores from immobility
- Difficulty turning over in bed
- Wasting syndrome (loss of weight and appetite, muscle atrophy, fatigue - cachexia)
- Peripheral neuropathy
- Progressive weakness in hands and fingers causing problems with typing, writing, and using eating utensils

For more information about IBM, the following websites are recommended:

- Myositis Support and Understanding Association- www.UnderstandingMyositis.org
- The Myositis Association - www.Myositis.org
- Muscular Dystrophy Association - www.MDA.org

Websites by Inclusion Body Myositis patients:

- www.ibmmyositis.com
- www.lifedisabled.com
- www.myomusings.com

** This information was compiled by Myositis Support and Understanding Association, a 501(c)(3) organization which provides support and education to Myositis patients, their support systems, and healthcare providers. For more information visit our website at UnderstandingMyositis.org.*

** The information contained in this document is not intended to be taken as medical advice. Be sure to consult with your physician and other healthcare providers before making any healthcare decisions.*

