Madison Neurology LLC: Compiled for Educational Purposes. Not for Clinical Use.

MADISON NEUROLOGY LLC

608 403 0000

Neurology Care 7 days a Week. Because Your Brain Matters.

Inclusion Body Myositis (IBM)

Patient education guide · Nerve & Muscle · Madison Neurology LLC

What is it?

Inclusion body myositis is the most common acquired muscle disease after age 50. It causes slowly progressive, painless weakness in a distinctive pattern: the finger flexors (weak grip, trouble with keys and jars), the thigh muscles (difficulty rising, knee buckling and falls), and the swallowing muscles. Unlike other myositides, it responds poorly to immune therapy.

How does it happen?

IBM has two components: abnormal protein accumulation within muscle fibers (a degenerative process) and inflammation — which is why anti-inflammatory drugs don't stop it. The trigger is unknown; it is not inherited. Men are affected more than women.

Common symptoms

- Slowly progressive weakness, often asymmetric, over years
- Weak grip and finger flexion — trouble opening jars, turning keys, buttoning
- Quadriceps weakness: knees buckling, falls, trouble rising from chairs or stairs
- Swallowing difficulty (dysphagia), sometimes the presenting symptom
- No pain or only mild discomfort; no rash

How is it diagnosed?

The pattern — finger flexor and quadriceps weakness after 50 — is highly suggestive. CK is mildly elevated; EMG and MRI show characteristic patterns; muscle biopsy is definitive. IBM is often initially misdiagnosed as polymyositis; the lack of response to steroids is a clue that prompts re-look.

How is it treated?

There is no proven disease-modifying treatment — immunosuppressants used for other myositides don't help and are generally avoided. Management is active and rehabilitative: strength and balance training (safe and beneficial), fall prevention, occupational therapy for hand function and adaptive devices, swallowing evaluation and strategies (and procedures such as dilation or, in severe cases, feeding options), and monitoring of breathing in advanced disease. Clinical trials targeting the degenerative process are ongoing.

What does the future hold?

IBM progresses slowly over 10-15 years or more; most people remain ambulatory with aids for a long time, though wheelchairs are eventually needed by many. Life expectancy is near normal; swallowing problems are the main health risk and are managed proactively. Staying strong and preventing falls preserves independence longest.

Questions patients commonly ask

Q: Why don't steroids help when they help other myositis?

A: IBM's core process is protein accumulation with secondary inflammation — suppressing immunity doesn't address the degenerative component.

Q: Is exercise harmful to my muscles?

A: No — moderate, supervised exercise is beneficial and recommended; it doesn't accelerate the disease.

Q: What should I watch for?

A: Falls and swallowing safety are the priorities — report coughing with meals or choking promptly.

National support groups & resources

- **The Myositis Association** — myositis.org
- **Muscular Dystrophy Association** — mda.org
- **National Organization for Rare Disorders** — rarediseases.org — 1-800-999-6673

(Organization contact details were current at the time of compilation; please verify online.)

Disclaimer — please read

This material is provided by Madison Neurology LLC for general educational purposes only. It is not medical advice, is not a substitute for the independent judgment of a qualified healthcare professional, and does not create a physician-patient relationship. Do not disregard, avoid, or delay seeking professional medical advice, diagnosis, or treatment because of anything in this material. Individual conditions, treatments, and outcomes vary; only your own healthcare team can evaluate your specific situation. If you think you may be experiencing a medical emergency, call 911 or go to the nearest emergency department immediately. To the fullest extent permitted by law, Madison Neurology LLC, its providers, and staff disclaim all liability for any loss, injury, or damage arising from the use of, reliance on, or inability to use this information. Organization contact details are provided as a courtesy, were current at the time of compilation, and may change; Madison Neurology LLC is not responsible for the content of external organizations.