

Functional Abilities and Disease Information

for _____

Who has **Inclusion Body Myositis**, an Idiopathic Inflammatory Myopathy

Swallowing

- Normal
- Early eating problems
- Choking
- Dietary consistency changes
- Frequent choking
- Requires water to drink all day and night
- Requires straw drinks
- Requires thickened liquids
- Needs tube feeding

Cutting food and handling utensils

- Normal
- Somewhat slow and clumsy, but no help needed
- Can cut most foods, although clumsy and slow; some help needed
- Food must be cut by someone, but can still feed slowly
- Needs to be fed

Fine motor tasks (opening doors, using keys, picking up small objects)

- Independent
- Slow or clumsy in completing task
- Requires modified techniques or assistive devices such as reacher/grabber.
- Due to weak upper and lower arm muscles, call button, TV remote and phone must be placed in an easy-to access place. For this reason, pulling the emergency chain may not be accessible to the patient.
- Frequently requires assistance from caregiver
- Unable to perform most fine motor skill tasks

Drinking:

- Is not able to lift a glass
- Is not able to pour own drink

Dressing

- Normal
- Independent but with increased effort or decreased efficiency
- Independent but requires assistive devices/modified techniques (Velcro snaps, shirts without buttons, etc)
- Requires assistance from another person for some clothing items
- Total dependence on another person

Hygiene (bathing and toileting)

- Normal, totally independent
- Independent but with increased effort or decreased activity
- Independent but requires use of assistive devices (shower chair, raised toilet seat)
- Cannot use trapeze to use bedpan
- Requires occasional assistance from caregiver or another person
- Completely dependent on other people

Turning in bed and adjusting covers

- Normal
- Somewhat slow and clumsy but no help needed
- Can turn alone or adjust sheets, but with great difficulty
- Can initiate, but not turn or adjust sheets alone
- Unable or requires total assistance

Sitting to standing abilities

- Independent (without use of arms)
- Performs with substitute motions (leaning forward, rocking) but without use of arms
- Requires use of arms
- Requires assistance from a device or person
- Inability to scoot, bend knees and moving legs
- Requires unusually high seating such as toilet, shower stool, hip chairs, bed, Rollator, elevating powerchair, high-density/non-slip cushions, leg lifters and leg extensions).
- Unable to stand

Walking

- Normal
- Slow or mild unsteadiness
- Intermittent use of an assistive device (ankle/foot orthosis, cane, walker)
- Dependent on assistive device (ankle/foot orthosis, cane, walker)
- Wheelchair dependent

Climbing stairs

- Normal
- Slow with hesitation or increased effort; uses hand rail intermittently
- Dependent on hand rail
- Dependent on hand rail and additional support (cane or person)
- Cannot climb stairs

Other Important Possible Considerations for Patients with Inclusion Body Myositis:

- May need accommodation for seated exam tables, prone X-rays and other scans. Examination may need to take place in power chair or bed.
- Lift chair, which may have to be supplanted by firm, thick cushions or a platform, may be necessary.
- Due to limited upper body strength, transfer danger, and possible injury because of lack of muscle and fragile bones, a transfer board and/or elevating power chair may be required.
- Wheelchairs with footrests are necessary for foot drop.
- Walker height is important if patient is still walking.
- If severely injured or late stage, a stander or Hoyer lift may be necessary.
- Check on more often, or given a body alarm, or an old fashioned cowbell.
- May not be able to hold a traditional phone to our ear. Leave cell phone nearby.
- Due to lack of stamina it may be necessary for PT and OT take place in patient's rooms.

Electronic Devices:

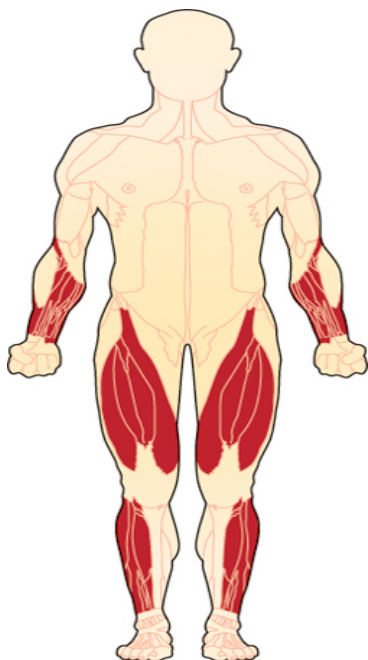
Smartphones, Bluetooth, headsets, laptops/tablets/pads are necessary to communicate with the outside world, with our online support groups and to provide information (such as this info sheet) to our caregivers. Please help us to charge our devices on a timely basis, and not get the cords caught in the hospital bed mechanism, even if that means allowing use of a surge suppressor or power strip and easy-to-plug in access.

Understanding Inclusion Body Myositis (IBM) Fact Sheet

Inclusion Body Myositis is a progressive, degenerative neuromuscular disease. IBM is considered to be 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.

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)
- 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 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, a 501(c)3 organization which provides support and education to Myositis patients, their support systems, and healthcare providers.



www.UnderstandingMyositis.org