

Information for patients with inclusion body myositis, their families and caregivers.

§ IBM is a slowly progressive skeletal muscle disease. Patients typically experience weakness in the muscles that bend the fingers (finger flexors) and extend the knee (the quadriceps). These clinical findings distinguish IBM from most other muscle diseases.

§ Inclusion Body Myositis (IBM), also called sporadic inclusion body myositis (sIBM), is often seen as a mysterious disease, due to uncertainties about its cause, diagnosis, classification and treatment. No effective treatment is available.

§ IBM is the most common acquired muscle disorder in people over 50, usually coming on between 61-68, but 20% of patients show symptoms before 50, some starting in the 30's and 40's. IBM is somewhat more common in men.

§ Symptoms/complications may include fatigue, a weakened diaphragm, and trouble swallowing (dysphagia), which can cause choking and aspiration (food going into the lungs) that can lead to dangerous pneumonias.

§ IBM is first misdiagnosed as another condition in 40 to 53 percent of patients. Symptoms are often, wrongly, attributed to “normal aging.” Misdiagnosis of polymyositis (PM), or motor neuron disease (ALS) is common.

§ A correct diagnosis of IBM takes on average 4.6 to 5.8 years. Finding a doctor with experience is essential.

§ Medications used to treat IBM have included drugs like prednisone, IVIG, and corticosteroids. Some treated patients report short-term gains and “feeling stronger” but no treatment has been shown to improve the underlying disease, some treatments may make it worse.

§ Exercise is suggested for patients, working in coordination with a doctor and physical therapist.

§ Having care in place from family members and/or external help becomes an essential, and invaluable, part of the IBM patient's life. Assistance is often needed with activities of daily living (ADL's) such as feeding, dressing, bathing, and toileting. Caregivers can also help in dealing with the emotional aspects of life with IBM. Anxiety and depression are common in IBM patients.

§ IBM is different from person-to-person, as is the progression of the disease. Overall, within 7-10 years patients require assistive devices for mobility (cane, walker, rollator) and within 13-15 years, patients usually require a power wheelchair.

§ Making positive adaptations to changing abilities and limitations is challenging, both physically and emotionally, and is a critical part of life with IBM.

§ There is an urgent need for therapies to treat IBM. Research and clinical trials continue.

§ Also see: [ibmmyositis.com](http://ibmmyositis.com) <https://understandingmyositis.org/> <https://www.myositis.org/>