

## **Inclusion body myositis: Synopsis for patients and caregivers.** By William Tillier 06/2022

**Overview:** IBM is a poorly understood and very complicated disease that attacks muscle. It has no known cause and is serious, chronic, and progressive. It appears that IBM may be a type of autoimmune disorder. No effective treatment has been developed. How it affects individuals differs widely and the rate of progression can differ widely between people. It primarily starts with the muscles of the arms and legs. The heart is not impacted. The disease is generally not considered fatal but has several complications that can lead to death. In many cases, individuals become completely disabled; eventually having to use a power wheelchair.

**Cause and treatment:** No cause has been discovered. No effective IBM treatment has been recognized. In the past, treatment using prednisone led to terrible side effects. There is some evidence that prednisone may even make IBM worse. Today, individualized exercise programs are increasingly being recommended, especially during the early stages of the illness. Patients often pressure doctors and/or doctors often feel that they “have to try something.” The problem with trying medication “just to see if it works” is the medications used are powerful and all come with significant side effects (including costs) and there is no evidence that they work. Unfortunately, there are many “scam” treatments advertised including stem cells, supplements, and special diets. If in doubt, please consult your doctor for advice.

**Impact:** as IBM progresses, most people find it difficult to use their hands in everyday functions. Eventually, lifting items over the head becomes difficult, and it may be challenging to raise or use the arms. Initially, IBM causes tripping and falling due to weakness in leg muscles. Eventually, it becomes difficult to climb stairs and walk. Roughly ten years after diagnosis, many patients must use power wheelchairs.

**Management:** The best thing you can do today is to manage your life and make adaptations as the disease slowly progresses. Management includes keeping a positive mental attitude and watching for complications and effectively dealing with them. Again, having an individualized exercise program may help.

**Complications:** — Swallowing. In many cases, IBM impacts the muscles of the throat used in swallowing. Food may get stuck in the throat leading to choking. If food gets into your lungs it can cause a type of pneumonia that can be fatal. In some cases, people simply become afraid to eat, and some die of malnutrition. In many cases, a tube may have to be inserted into the stomach for feeding. Signs: you have to swallow over and over to get food down. Food gets stuck “halfway down.” You frequently choke.

— Breathing. In many cases, IBM weakens the diaphragm muscle leading to a reduced air intake. IBM does not affect the ability of the lungs to take in oxygen; because you're not breathing enough, it reduces your ability to get rid of carbon dioxide. If you have diaphragm weakness, you may need machines to help you breathe (you may also need oxygen if you have other lung issues). Machines used are the BiPAP (vPAP) at night, and, if needed, during the day, a respirator that provides air through a tube to the mouth. Signs: during sleep your partner notices you waking up often; usually with a gasp or “snort” (you won't notice this). You are very tired during the day. The symptoms look exactly like sleep apnea.

— Falling. Weakness in the quadriceps muscles in the front of the legs often leads to unexpected and sudden falling; you fall straight down, hitting the ground before you realize you are falling. Or, you lose your balance and slowly fall over without being able to do anything about it (you do not have enough arm strength to grab onto something). Falling leading to broken bones or concussions represents a major threat.

— Nerves. In some cases, the nerves in the hands and feet may develop what is called neuropathy. Signs: the inability to feel hot and cold, pain, tingling, and lack of sensation in the hands and/or feet.

— Edema. People who are confined to wheelchairs or who do not move around a lot are prone to get swelling of the feet and ankles. The daily use of compression stockings helps prevent swelling as does a low-salt diet. If unchecked, swelling can become a major problem.

— Pain. Many people with IBM report chronic and/or severe pain in the muscles. If you have pain, work closely with your doctor to find solutions.

For more information see: <http://ibmmyositis.com/>