

## **Inclusion body myositis: Synopsis.**

**By William Tillier 12/2020**

**Overview:** IBM is a serious, chronic disease that attacks and kills muscle cells. It does not “go up and down,” it slowly marches on. How it affects individuals can differ 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 not fatal but has several complications that can lead to death. In many cases, individuals become completely disabled; they eventually must 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. Today, 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 that the medications used today are powerful and all come with some significant side effects (including costs).

**Management:** The best thing you can do today is to manage your life as the disease slowly progresses.

Management includes the critical components of keeping a positive mental attitude and watching for complications and effectively dealing with them.

**Complication — 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 some 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.

**Complication — Breathing.** In many cases, IBM weakens the diaphragm muscle leading to reduced air intake. IBM does not affect the ability of the lungs to get oxygen; it reduces your ability to get rid of carbon dioxide. If you have diaphragm weakness, you may need machines to help you breathe, but not oxygen (unless you have other lung issues that require oxygen). 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.

**Complication — Falling.** Weakness in the quadriceps muscles in 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 represent a major threat.

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

**Complication — Edema.** People who are confined to wheelchairs/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.

**Complication — Pain.** Many people with IBM report chronic and/or severe pain in the muscles.

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