



## Explaining Myositis to others In Focus

Explaining myositis (Idiopathic Inflammatory Myopathy) and how it affects our lives is difficult. There isn't a simple, clear-cut answer for us. Myositis affects each person differently including changing symptoms, abilities, therapies and side effects. Sometimes these changes even occur on the same day. We hope this information will help you explain myositis and its impact on your life.

### **First, we can tell others what Myositis is not:**

- Myositis is not contagious. You cannot transmit myositis to, nor can you get it from, someone else.
- Myositis is not caused by something you did and is not your "fault."
- Myositis is not "all in your head."
- Myositis is not "normal aging."

### **Next, we can tell others what Myositis is:**

- Myositis is the general term referring to the Idiopathic Inflammatory Myopathies (IIM). Idiopathic means it is a disease that comes on spontaneously with no known cause and myopathy means muscle disorder. Myositis means inflammation of the muscles.
- There are several types of Inflammatory Myopathies: Dermatomyositis (DM), Polymyositis (PM) Necrotizing Autoimmune Myopathy (NAM), and, a bit different from the others, Inclusion Body Myositis. There are also juvenile forms of dermatomyositis and polymyositis.
- Collectively, myositis is a group of rare diseases affecting an estimated 50-75K people in the U.S. with 5-10 people per million diagnosed yearly.
- Each type of myositis (inflammatory myopathy) is a rare disease.
- Myositis is an autoimmune disease where the body attacks its own healthy muscle, skin, lungs, and other organ systems, much like it would attack a virus or bacterial infection. The immune system goes haywire, becomes overactive, and sees the body's own tissues as foreign invaders.
- Myositis is a chronic disease and you will have myositis for the rest of your life, although some do achieve remission. Off-label use of some medications (with the exception of inclusion body myositis) along with lifestyle changes such as exercise, diet, and stress reduction may help you to live a relatively active and productive life.
- Myositis can be an invisible illness, meaning you may look perfectly healthy on the outside but are terribly ill nonetheless.
- Myositis can cause "brain fog" and even memory loss, making concentration, organization, and other related tasks difficult.
- Myositis causes a variety of symptoms and affects each person differently. Muscle weakness, muscle pain, uncomfortable-itchy-painful skin rashes, debilitating fatigue, trouble breathing, achy joints, heart arrhythmias, and many other symptoms makes myositis a very complex disease.
- Myositis is unpredictable. Some may reach remission (symptoms stabilize or improve) and some may battle ongoing disease and/or periods of flares (symptoms worsen). The unpredictability can be frustrating for us as patients and for family members and friends. What we did one day we may not be able to do the next. The disease will evolve and change, as will your abilities and limitations.



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### Finally, we can tell others how Myositis affects our lives:

- Day-to-day functioning with myositis looks different for each of us. Some require the use of mobility devices such as a cane, walker, rollator, wheelchair, or power chair. Others may use oxygen, have a feeding tube, or visible PICC lines or ports for infusions. Some have itchy skin rashes that are intense enough to disturb sleep and may need to avoid the sun completely, while others may need to wear long-sleeves, hats, and gloves, even on the hottest days to protect them from the sun. Some require assistance with activities of daily living (ADL's) like bathing, dressing, feeding, toileting, and help to get to appointments. Many patients have a combination of these.
- Chronic pain may be a factor for myositis patients. Understanding chronic pain is not easy for those who have never experienced it. Try to describe what your pain feels like to others in words they can understand.
- Pain, Brain Fog, Fatigue, along with the standard treatment of steroids, can all cause mood swings, irritability, behavior changes, and even an exacerbation of depression and anxiety. Tell your friends you need help getting through these difficult times and that you are not intentionally acting this way.
- Many do not realize the emotional challenges that come with a chronic disease diagnosis like myositis. It can feel very lonely, isolating, and even cause bouts of depression and anxiety. Having the support of family and friends is extremely important, as is having them understand your limitations.
- Knowing that myositis is unpredictable may help others to understand your physical and emotional ups and downs as well as the changes that you may have to make to schedules, plans, and commitments.
- Asking for help can be very difficult but something we must do. Talk to your family and friends about this and explain you have trouble asking for help. Hopefully, this will make it easier when you get confirmation that they want to help you.
- Explain that certain words and phrases hurt your feelings. Not everyone understands what they say is hurtful. Things like "you don't look sick," "you are being lazy," "you just need to eat the right food," or "I saw this supplement and it says it cures all autoimmune diseases," are some examples of others not understanding myositis, a disease with no cure.
- "But you did it yesterday!" There are times when you may be confronted with this exclamation and feel you have to start over explaining myositis. What you did one day may take multiple days to recover from, or you may be weaker or in more pain the next time you are asked to do that same thing. Try and stay calm and provide the exact reasoning.
- Toxic relationships can be a stressor and you may need to make difficult decisions about who you allow to remain in your life or limit communication with.
- Grieving the loss of our "normal" lives is a normal process that can take time. When you add disease progression, you may find you are going through the process of grieving many times during your life such as when you lose another ability. Take the time to grieve.



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### Communicating your Myositis Life:

- Write a letter to family and friends to explain your Myositis Life. Communicating this way may help to get the information across in a non-confrontational way and it is something they can refer back to.
- When talking with your family and friends, use “I” statements as these promote better communication. “I feel \_\_\_\_.”
- Using social media platforms such as Facebook can also be a great way to explain your disease and provide updates on your health. Facebook allows you to customize privacy settings and allows you to choose who can see individual posts so you can target who can read your myositis-related postings.
- Blogging for your health can also be a great way to release your feelings in a constructive manner and allows you to also share on social networking sites, or individually with family members and friends.
- Keeping a journal is a great way to communicate with you! Consider keeping a journal of some type to track your symptoms, testing, appointments, and other details that can help you advocate for yourself.
- Share resources with your family members and friends that can help them better understand the chronic and often invisible aspects of myositis, such as those listed below.
- Caregivers, Family Members, and Friends can join the closed MSU Facebook group
- Share articles and personal stories from the MSU website, UnderstandingMyositis.org
- Search and share articles from other chronic illness related blogs such as The Mighty.
- Share a copy of “The Marvelous Transformation: Living Well with Autoimmune Disease” by author and cofounding director of MSU, Emily A. Filmore. Purchase using Amazon Smile and help support MSU.
- Share “The Spoon Theory” as a way to explain life with a chronic illness.

### Talking to your employer about myositis, if appropriate for you

Talking to your employer about your health is a very personal decision and may not be appropriate for everyone. There are some benefits in doing so if you decide it is what is best for you. We have provided some resources below that you can use to help make the decision and refer to later when needed.

- Myositis is protected under the Americans with Disabilities Act, depending on specific limitations. Visit [www.ada.gov](http://www.ada.gov)
- Review the rules and regulations of the Family and Medical Leave Act (FMLA). Visit [www.dol.gov/whd/fmla](http://www.dol.gov/whd/fmla)
- Talk to your doctor about completing forms for intermittent leave under FMLA. Visit [www.dol.gov/whd/forms/WH-380-E.pdf](http://www.dol.gov/whd/forms/WH-380-E.pdf)
- Review information about Reasonable Accommodation For Individuals With Disabilities in the workplace. Visit [www1.eeoc.gov//eeoc/internal/reasonable\\_accommodation.cfm](http://www1.eeoc.gov//eeoc/internal/reasonable_accommodation.cfm)
- If you happen to be in school, register with the school’s office of disability services.

Myositis Support and Understanding Association (MSU) is a patient-centered 501(c)(3) nonprofit organization “Empowering the Myositis Community.” Learn more about MSU at [UnderstandingMyositis.org](http://UnderstandingMyositis.org) and register for free membership.