



Benefits of Keeping a Journal

Jotting down a few notes a day can be an invaluable resource for you and your doctors by providing a timeline of your condition in relation to medications and other factors. It can be used as an accurate tool to measure the subtle changes that you don't always notice or remember.

Here are examples of items to include in your Myositis journal:

- **Physical abilities:** Notations such as “rose from the kitchen chair,” or “able to shampoo my hair,” or “swallowing is better” will give you a timeline which can be used as actual measurements to chart how you are doing. It also can provide a great reminder of how far you've come.
- **Medications and Supplements:** Indicating medication names, dates, and dosages, when started and ceased, and tuning into any changes as noted in the other parts of your journal can help identify side effects or improvements that can be caused by medications and supplements. This can also be used to continue to monitor changes because sometimes initial side effects wear off once your body gets used to a medication. This documentation can be just as important in the future because you may be prescribed a medicine which may have given you an adverse reaction. Remember that medications have different names so make sure when you note the medicine you also note alternative names.
- **Physical symptoms:** New or changed symptoms such as intestinal or breathing problems, muscle cramping or tingling are examples of symptoms to note. This creates an accurate picture and timeline for your doctor to pinpoint when symptoms started and whether they are cause for concern.
- **Pain:** It's important to be specific about the type (sharp, dull, ache), location (thigh, neck, right calf), frequency (24/7 or a couple of times a day), and whether it's worse or better than normal. You can download a “pain chart” from the Internet and use it to describe the intensity of the pain.
- **Energy and fatigue status:** Autoimmune disease is notorious for causing fatigue, but documenting the ups and downs also help your doctor identify if your meds needs to be adjusted or if you may have something like an overlap condition.
- **Emotional state:** Stress is believed to be a contributor to many health issues, so noting how you are feeling emotionally can help document possible triggers or even reactions to medications. Your emotional state may be a link to your pain or weakness just as much as the pain and weakness of your disease may cause emotional distress. Depression is not uncommon with chronic disease, so detailing your ups and downs could help indicate if you suffer from depression far before it reaches a critical stage.

- **Diet.** What we feed our bodies can be a large factor in how we feel physically and emotionally. Many people find that certain foods cause more pain and inflammation. Of course, it's always wise to keep an eye on our weight, especially since many Myositis patients take corticosteroids, which can cause both hunger and weight gain. Making note of the types of food we eat on a daily basis (processed foods, gluten, sugar, salt/sodium, artificial sweeteners, or absence of those foods) can create a clear trend of how our nutrition plays into our disease.
- **Physical activity:** Did you wake up feeling rotten but convinced yourself to do some exercise? Did you feel better afterwards or have to rest the next 2 days? Did the exercise cause any pain during or after? Making notes about what type and how much you do (or don't do) on a daily basis can help you identify what is helpful to you.
- **Weather conditions:** Changes in weather, humidity, cold, and heat affect many people's symptoms, so noting these changes can help identify your triggers.
- **Vitals:** Weight, blood pressure, and glucose are also noteworthy, so make sure you keep an eye on these numbers. The medications prescribed for many Myositis patients put us at high risk for weight gain, high blood pressure, and Diabetes, so knowing and tracking your numbers can be an important tool to controlling these numbers.

Arming yourself with facts by documenting what you are going through on a daily basis can help you in many ways as well as give you accurate information to pass on to your doctor rather than wasting time in the exam room trying to remember how long you have been experiencing something.

** This information was compiled by Myositis Support and Understanding Association, a 501(c)(3) organization which provides support and education to Myositis patients, their support systems, and healthcare providers. For more information visit our website at UnderstandingMyositis.org.*

** The information contained in this document is not intended to be taken as medical advice. Be sure to consult with your physician and other healthcare providers before making any healthcare decisions.*