



Improving Communication in Your Care

Improve Patient-Physician Communication:

- Support patients' ability to effectively communicate with their health care providers as an essential aspect of self-care.
- Provide physicians with ongoing measures of symptoms and lifestyle changes to assess disease progress and treatment.

Empower Patients to Participate in Care More Effectively:

- Provide easy-to-use tools that enable patients to fully participate in healthcare visits, and to keep track of important information between appointments.
- Encourage patients to take a more active role in their health tracking, and treatment plans.

Why is Patient-Doctor communication so important? Studies show patient outcomes are improved by positive doctor relationships and communication. The importance of this relationship cannot be overstated for those living with myositis.

Myositis patients must be a partner in the healthcare process. Not only because they deserve to be partners in their care, but healthcare is delivered more effectively and efficiently when patients are engaged. Failing to talk with your doctor can do more than leave unanswered questions after appointments. Poor communication can lead a physician to underestimate disease severity when patients don't report lifestyle changes.

To address gaps in communication and support patients in tracking symptoms and disease progress, TMA has developed a simple tool. See the "My Myositis Tracker" on the following pages. We encourage you to use this tool in your daily routine and future healthcare appointments.

Tracking is simple

Print the following pages and keep them in an accessible location like on the fridge, desk, or bedside table. Revisit the checklist weekly or daily to document changes in health ability. Space is provided to use tick marks to count incidents of choking, falls, and other symptoms.

Consistency matters

When used consistently, the *My Myositis Tracker* serves as a diary of disease progress. Mark your "start date" at the top of the form each time you begin tracking. The details you provide, along with therapy plans can give a more complete picture of your disease for yourself, and current, and future physicians.

Start the conversation

Use the *My Myositis Tracker* at doctor appointments as the basis of updates, questions, and conversations about changes in your health.

STRENGTH

1 **Overall weakness:** improved about the same slightly worse much worse

2 **Ability to climb stairs:** improved about the same worse unable (skip to 3)

- I can climb stairs: normally with difficulty only with hand rail only with assistance
- Climbing stairs is limited by: fatigue/exhaustion shortness of breath weakness

3 **Ability to walk:** improved about the same worse much worse unable (skip to 4)

- Walking is: normal, even outdoors normal if flat, firm surface slow or unsteady but independent often requires use of an assistive device requires an assistive device
- To help me walk I use: an ankle foot orthosis a cane a walker wheelchair occasionally
- I've had approximately ____ falls which typically occur from: imbalance knee giving out or buckling toe catching on floor/rug/step

4 **Ability to stand from seated position:** improved about the same worse unable (skip to 5)

- Standing from a chair is: normal requires substitute motions (leaning forward, rocking) requires use of arms requires assistance from a device or person
- Standing from a toilet is: normal requires substitute motions (leaning forward, rocking) requires use of arms requires assistance from a device or person

5 **Ability to hold arms overhead** (e.g. wash hair, reach cabinets): improved about the same slightly worse much worse

6 **Handwriting:** normal slow but legible some words are illegible unable to write

- Compared with before my myositis diagnosis it is: improved about the same worse

7 **Fine finger dexterity** (e.g. turning a key, picking up small object):

- normal slow or clumsy requires modified technique or device frequently requires assistance unable

8 **Ability to dress:** normal slow or increased effort requires modified technique or device requires assistance for some items total dependence on caregiver

9 **Ability to turn in bed and adjust covers:**

- normal slow or increased effort independent but with great difficulty requires assistance for completion total dependence on caregiver

BREATHING

- I find myself winded after simple tasks like climbing the stairs, getting the mail, making dinner, etc.
- I have a persistent dry cough

INFECTIONS & VACCINES

- I have experienced an increase in the number of colds, bouts of bronchitis, or have had pneumonia
- It takes me longer to recover from my colds
- I have had fevers, chills, or night sweats
- Vaccines I've had include: Flu-shot Pneumonia Shingles (Zoster) Other _____

SWALLOWING & SPEECH

- I have had approximately _____ episodes of choking or catching food in my throat
- I have had changes in my diet (e.g. consistency changes)
- I am drooling more often
- I have reflux symptoms (burning sensation in chest, worse after eating, sensation of lump in throat, or regurgitation of food)
- My speech is increasingly slurred

MUSCLE, SKIN, & JOINT

- I have increased rashes on my face, hands, or scalp
- I have increased calcinosis
- I have trouble keeping my skin moisturized
- My fingers turn blue or white when they get cold
- I have pain, swelling, redness, or warmth in my joints
- I have pain or swelling in my muscles or subcutaneous tissues

MEMORY & MENTAL HEALTH

- I have had increased difficulty remembering things
- I find myself increasingly frustrated or angry
- I am having difficulty finding joy
- I get in arguments with loved ones more frequently

OTHER HEALTH CHANGES, DOCTOR VISITS, OR HOSPITALIZATIONS

List any significant health changes that have taken place since your last visit: _____

MEDICATION

List any NEW medications, allergies, or changes to medications since your last visit: _____

TESTING

List any NEW tests, results, and where they were performed: _____

VITAL SIGNS (Especially important for telemedicine)

Weight: _____ Heart Rate: _____ Oxygen Saturation: _____
Temperature: _____ Blood Pressure: _____

WHAT ARE THE TWO MOST IMPORTANT TOPICS YOU'D LIKE TO COVER TODAY?

1. _____ 2. _____

The Myositis Association | www.myositis.org | Join the effort to find a cure

TMA is the leading international organization committed to the community of people living with myositis, their care partners, and loved ones. The nonprofit provides patient education and support, advocacy, physician education, and has funded more than \$7 million in myositis research.

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