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.

- 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.

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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