

## **MG-ADL Instructions**

### Introduction

The MG-ADL was designed to assess the severity of 8 MG symptoms (2 ocular, 3 oropharyngeal, 1 respiratory and 2 extremity). These symptoms were selected based on their anticipated impact on activities of daily living. Although originally designed as an instrument to be administered by a trained technician, consensus among experts is that the MG-ADL, as a patient reported outcome measure (PROM), should be self-reported by the patient.

### Procedures for Administration

The patient should be provided with the MG-ADL form that includes instructions for self-completion. The patient with MG should complete the MG-ADL without evaluator input or guidance. Similarly, no family members or other visit attendees should provide input to the patient on how to answer the items.

### Evaluator Review

The evaluator should review the MG-ADL once the patient has completed the form.

- If an MG-ADL item is not completed by the patient, inquire whether the omission was intentional or not. If omitted in error, then ask the patient to complete.
- If a patient asks for clarification about a question, please simply remind the patient to answer questions based on the severity of their MG-related symptoms. Do not help the patient to tease apart relative contributions from MG and non-MG causes.
- If a patient makes a mark on the boundary line between two scores or marks two scores, ask the patient to clearly select only one score. If the patient cannot decide between two scores, record the higher score.

### **MG Activities of Daily Living (MG-ADL)**

This form includes 8 questions about the severity of your MG-related symptoms.

For each item, read the instruction first, and then choose the one answer that best describes your average functioning over the last 7 days. You may have had good days and bad days, but select the answer that best describes how you felt on average.

Please answer all questions by circling the response that best describes your MG-related symptoms, and do not leave any blank.

Please keep in mind the following as you complete the form:

- Do not try to imagine how severe your symptoms might be if you were not taking your MG medication. Score each item based on how you feel given that you're taking the MG medications that you are.
- If you are in doubt about how to answer a question, select the higher (more severe) score.
- Sometimes it can be difficult to determine whether a particular symptom is related to MG or to some other condition. When responding, please use your best judgement and try to consider only symptoms related to your MG, and exclude symptoms arising from any other illness you might have.

#### **1. Talking**

- The question about talking mentions slurring and nasal speech, but is really asking about any disturbance of speech that you attribute to your MG. If you have had any MG related speech disturbance over the past 7 days, indicate whether it has been intermittent, constant, or makes your speech difficult to understand.

#### **2. Chewing**

- This question asks about fatigue while chewing food.
- You may have made changes to the consistency of your food to avoid fatigue while chewing. If, for example, you avoid solid food because of fatigue with chewing, but you are able to chew soft food, then score as 1.
- If you have changed the way that you cut your food in order to avoid fatigue while chewing (for example, cutting into smaller bites), then also score as 1.

#### **3. Swallowing**

- If you choke on saliva occasionally, score as 1.
- If you have changed the consistency of foods you eat because of choking, score as a 2, even if the choking episodes have resolved since you changed your food consistency.

#### **4. Breathing**

- This question asks about shortness of breath or feeling “winded” due to MG.

- Exertion could mean physical activity or exercise, such as walking, but could also include everyday activities such as getting dressed or eating.
- Shortness of breath at rest means that you feel winded even if not physically active at all (including just laying down).
- Ventilator dependence means any need for a ventilator, including noninvasive ventilation (e.g., bipap), even if only during the night. But do not count ventilator at night for another reason (e.g. sleep apnea). Remember, these questions are asking about the severity of MG-related symptoms.

**5. Impairment of ability to brush teeth or comb hair**

- This question asks about difficult you might have brushing your teeth or combing your hair, but when answering this question, please also consider other activities that require you to elevate your arms/shoulders such as washing or blow-drying your hair.
- If you have made modifications or any type of adaptation (e.g. rest your elbows on table) for these activities, score as at least 1.

**6. Impairment of ability to rise from a chair**

- This question asks about difficulties you may have arising from a chair. Do not consider other activities such as climbing stairs.
- The severity grades refer to the difficulty when rising from a chair (mild, moderate, severe).
- Remember to focus only on whether you need to use your arms because of your myasthenia. You should exclude the role that other conditions may play in affecting your ability to rise from a chair (e.g. back pain, arthritis).

**7. Double vision**

- If you are blind in one eye, then score that you do not have double vision.
- If you wear a patch sometimes to prevent double vision, then score as 1.
- If you wear a patch all the time to prevent double vision, then score as 2.
- If you have blurred vision, but it resolves (goes away) when you cover either eye, then consider the blurred vision as double vision. If you are unsure whether the blurred vision goes away when covering one eye, make your best judgement as to whether the blurred vision is coming from your MG.

**8. Eyelid droop**

- This is about how you feel and function related to drooping eyelids. Do not score eyelid drooping than you are not aware of. For example, do not score eyelid drooping of which you're unaware, but someone else has noticed it and brought it to your attention.

**MG- ADL**

| Grade  | 0      | 1  | 2   | 3                                | Score<br>(0, 1, 2, 3)    |
|--|--------|--|---|----------------------------------|--------------------------|
| 1. Talking   | Normal | Intermittent slurring of nasal speech    | Constant slurring or nasal, but can be understood | Difficult to understand speech   |                          |
| 2. Chewing   | Normal | Fatigue with solid food                  | Fatigue with soft food                            | Gastric tube                     |                          |
| 3. Swallowing  | Normal | Rare episode of choking                  | Frequent choking necessitating changes in diet    | Gastric tube                     |                          |
| 4. Breathing   | Normal | Shortness of breath with exertion        | Shortness of breath at rest                       | Ventilator dependence            |                          |
| 5. Impairment of ability to brush teeth or comb hair | None   | Extra effort, but no rest periods needed | Rest periods needed                               | Cannot do one of these functions |                          |
| 6. Impairment of ability to arise from a chair       | None   | Mild, sometimes uses arms                | Moderate, always uses arms                        | Severe, requires assistance      |                          |
| 7. Double vision                                     | None   | Occurs, but not daily                    | Daily, but not constant                           | Constant                         |                          |
| 8. Eyelid droop                                      | None   | Occurs, but not daily                    | Daily, but not constant                           | Constant                         |                          |
|  |        |  |   |                                  | MG-ADL score (items 1–8) |