

MYASTHENIA GRAVIS ACTIVITIES OF DAILY LIVING (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. 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. 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 are taking your current MG medications.
- If you are in doubt about how to answer a question, choose the option that is most appropriate for you most of the time over the last 7 days.
- 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. Exclude symptoms arising from any other illness you might have.

1. Talking

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
Normal <input type="radio"/>	Intermittent slurring or nasal speech <input type="radio"/>	Constant slurring or nasal, but can be understood <input type="radio"/>	Difficult to understand speech <input type="radio"/>

- This question mentions slurring and nasal speech. However, it is really asking about any change in speech that you think is related to MG. If you have had any MG related speech disturbance, indicate how much it has impacted your speech (intermittent, constant, or makes your speech difficult to understand).

2. Chewing

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
Normal <input type="radio"/>	Fatigue with solid food <input type="radio"/>	Fatigue with soft food <input type="radio"/>	Gastric tube <input type="radio"/>

- This question asks about fatigue while chewing food.
- You may have made changes to the consistency of your food to avoid jaw fatigue while chewing. If you avoid solid food because of chewing fatigue, but you can chew soft food, then score as 1.
- If you changed the way that you cut food in order to avoid fatigue while chewing (for example, cutting into smaller bites) or it takes longer to finish a meal, then score as 1.
- A gastric tube is any feeding tube used to provide nutrition into the stomach (e.g., inserted through the nose or through the skin)

3. Swallowing

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
Normal <input data-bbox="375 655 410 688" type="radio"/>	Rare episode of choking <input data-bbox="630 655 665 688" type="radio"/>	Frequent choking necessitating changes in diet <input data-bbox="911 655 946 688" type="radio"/>	Gastric tube <input data-bbox="1195 655 1230 688" type="radio"/>

- 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. You should score as a 2 even if the choking episodes have resolved since you changed your food consistency.
- A gastric tube is any feeding tube used to provide nutrition into the stomach (e.g., inserted through the nose or through the skin)

4. Breathing

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
Normal <input type="radio"/>	Shortness of breath with exertion <input type="radio"/>	Shortness of breath at rest <input type="radio"/>	Ventilator dependence <input type="radio"/>

- This question asks about shortness of breath or feeling “winded” due to MG.
- Exertion could mean physical activity or exercise, such as walking. It 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. Examples include just lying down, talking, or eating.
- 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. CPAP for sleep apnea). Remember, these questions are asking about the severity of MG-related symptoms.

5. Impairment of ability to brush teeth or comb hair

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
None <input type="radio"/>	Extra effort, but no rest periods needed <input type="radio"/>	Rest periods needed <input type="radio"/>	Cannot do one of these functions <input type="radio"/>

- This question asks about difficult you might have brushing your teeth or combing your hair. 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 arise from a chair

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
None	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- This question asks about difficulties you may have getting up from a chair. Do not consider other activities such as climbing stairs.
- The severity grades refer to the difficulty when getting up from a chair (mild, moderate, severe).
- Remember to focus only on whether you need to use your arms because of your MG.
- If the only reason you have trouble getting from a chair is not related to MG (e.g., back pain), score as 0.

7. Double vision

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
None <input type="radio"/>	Occurs, but not daily <input type="radio"/>	Daily, but not constant <input type="radio"/>	Constant <input type="radio"/>

- If you are blind in one eye, then score that you do not have double vision.
- If you wear a patch, wear prism glasses, use a cloudy glasses/contact lens, or squint sometimes to prevent double vision, then score as 1.
- If you wear a patch, wear prism glasses, or use a cloudy glasses/contact lens all the time to prevent double vision, then score as 2.
- If you have had double vision in the past 7 days, but it does not go away when you cover either eye, then score as 0.

8. Eyelid droop

Choose the one answer that best describes your average functioning over the last 7 days.

Read all the options before choosing an answer. Do not leave this item blank.

0	1	2	3
None <input type="radio"/>	Occurs, but not daily <input type="radio"/>	Daily, but not constant <input type="radio"/>	Constant <input type="radio"/>

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

Participant ID: _____

Visit ID: _____

Date of Evaluation: _____

MG-ADL Score Summary and Total Score

Enter the score selected by the participant

Item	Score (0, 1, 2, or 3)
1. Talking	
2. Chewing	
3. Swallowing	
4. Breathing	
5. Impairment of ability to brush teeth or comb hair	
6. Impairment of ability to arise from a chair	
7. Double vision	
8. Eyelid droop	
TOTAL SCORE (Sum of items 1-8)	

Evaluator Signature: _____ Date: _____