



Patient-Centred **Monitoring in MG**

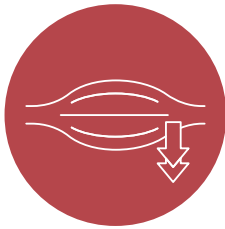
A practical guide to MG-ADL
and MGC scoring tools



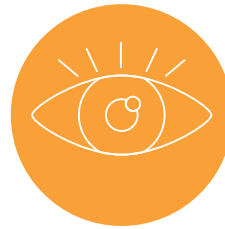
Inspired by **patients**.
Driven by **science**.



The importance of **standardised assessment** in myasthenia gravis (MG)



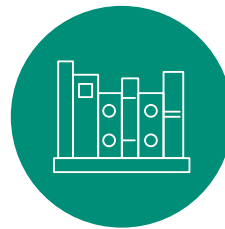
MG is a rare, chronic, and heterogenous autoimmune disease of the neuromuscular junction, which is characterised by signs of muscle weakness.^{1,2}



Clinical presentation of MG ranges from mild ocular deficits to severe widespread weakness and myasthenic crisis.^{1,2}



The fluctuating nature of MG symptoms makes it challenging to consistently assess disease severity and its impact on patients' daily lives.³



Over the past few decades, multiple assessment tools have been developed to reflect clinician-reported (objective), patient-reported, and composite measures of MG disease severity.³

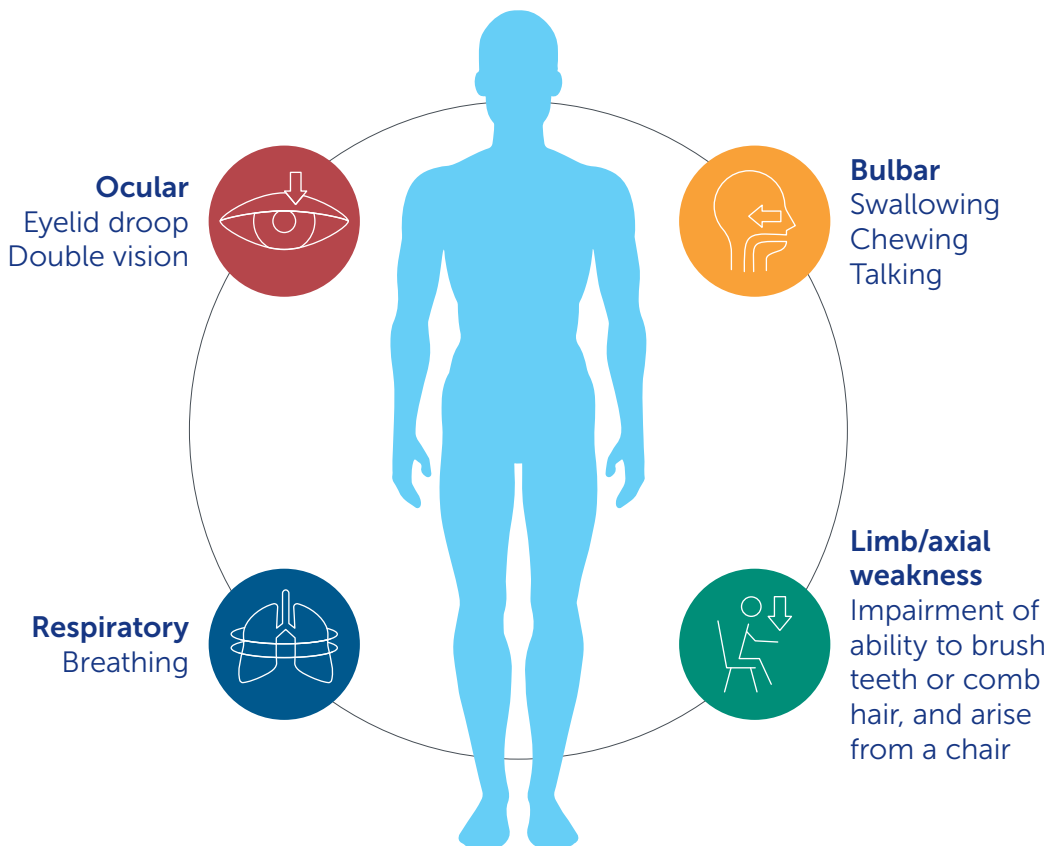
The Myasthenia Gravis Activities of Daily Living (**MG-ADL**) scale

- The MG-ADL scale is a PRO tool that assesses MG symptoms and functional status on a scale from 0–24.^{4,5}
- The MG-ADL scale is comprised of 8 items, each scored from 0 (normal) to 3 (most severe); the higher the total score, the greater the symptom severity.^{4,5}
- The scale is an easy-to-use tool which can be administered in under 10 minutes.⁴

Domains of MG-ADL

The MG-ADL questionnaire is comprised of 4 domains, ocular, bulbar, respiratory and limb/axial weakness, which correspond to the 8 items assessing patient functional abilities:⁴

Domains included in the MG-ADL⁴



MG-ADL Assessment⁴

MG-ADL					
Grade	0	1	2	3	Score
Talking	Normal	Intermittent slurring or nasal speech	Constant slurring or nasal speech, but can be understood	Difficult-to-understand speech	
Chewing	Normal	Fatigue with solid food	Fatigue with soft food	Gastric tube	
Swallowing	Normal	Rare episode of choking	Frequent choking necessitating changes in diet	Gastric tube	
Breathing	Normal	Shortness of breath with exertion	Shortness of breath at rest	Ventilator dependence	
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	
Impairment of ability to arise from chair	None	Mild, sometimes uses arms	Moderate, always uses arms	Severe, requires assistance	
Double vision	None	Occurs, but not daily	Daily, but not constant	Constant	
Eyelid droop	None	Occurs, but not daily	Daily, but not constant	Constant	
Total score					

Interpreting MG-ADL

High total score = greater symptom severity⁴

Key considerations:

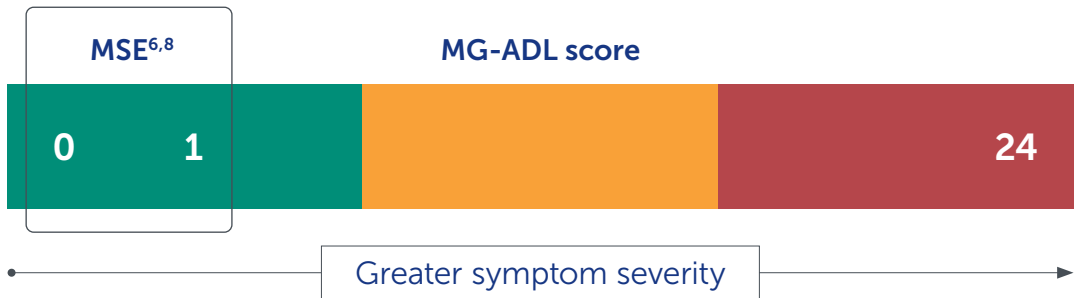
- In MG-ADL, equal weight is given to all items; however clinical relevance will vary. It is important to review individual item scores to determine where the disease is active and to guide personalised treatment for your patient.
- The total score will help provide a quick standardised way of tracking symptoms over time and ultimately detect early signs of relapse or treatment failure.⁶

Clinically meaningful improvement = a 2-point reduction in score⁷

- A drop of at least 2 points in MG-ADL indicates a clinically meaningful improvement in your patient's daily functioning and symptom burden.⁷

MG-ADL score of 0 or 1^{6,8}

- Minimum Symptom Expression (MSE) has become a treatment goal for patients with MG in recent years.⁸
- MSE is defined as an MG-ADL score of 0 or 1 and is a useful tool to measure treatment effectiveness.^{6,8}



Insights into use in clinical practice and research settings

- MG-ADL is a validated and regulatory accepted endpoint in clinical trials and observational studies to measure MG symptoms and response to treatment.⁶



Validity:

MG-ADL has showed high correlation with MGC and MG-QoL⁷



Reliability:

Test-retest reliability coefficient of 93.7% among 20 patients⁷

- MG-ADL has been used increasingly in recent years as a primary endpoint in clinical trials.⁶
- MSE has emerged as a meaningful treatment goal in MG, being utilised as an endpoint in some clinical trials and becoming increasingly relevant given the evolving MG treatment landscape.⁶
- Limitations of MG-ADL may include, being prone to floor effects leading to it being insensitive to change; several symptoms of MG are not assessed (e.g., fatigue); and the negative consequences of treatment (e.g., side effects) are not addressed.^{1,5}

The Myasthenia Gravis Composite (MGC)

- MGC is a hybrid of 6 clinician- and 4 patient-reported items from the patient's medical history, that covers the 10 items of most relevance to people living with MG.^{9,10}
 - The outcome measure incorporates items from MG-ADL, QMG, and the MMT.^{3,9}
 - The clinician-reported assessments evaluate ocular, neck, and proximal limb muscles; patient-reported items are derived from MG-ADL and/or collected by clinicians from patient history, and assess bulbar and respiratory functions.^{3,10}
 - Test items are weighted based on input from global MG experts, considering factors such as QoL, disease severity, risk, prognosis, estimated validity, and reliability; with a total score that ranges from 0–50.^{3,9}
 - No recall time is specified.⁹
- MGC is easy to administer (<5 minutes) and easy to interpret (<10 seconds to calculate total score).¹⁰



Validity:

MGC has shown correlation with the MG-QoL15 total score, the MG-ADL score and the MMT total score¹⁰



Reliability:

Test-retest reliability coefficient of the MGC among 38 patients was 98%¹⁰

- The use of weighted scores may capture more clinically relevant information concerning disease severity.³
- MGC may serve as an alternative to linear disease measures, complementing PROs, e.g., MG-QoL15, Neuro-QoL-Fatigue-SF, and QMG.³
- The MGC items were selected based on their performance in two clinical trials that did not include patients with ocular-only, muscle-specific kinase-positive, double seronegative, or severe MG. Therefore, further study on the suitability of the MGC in these patient populations is required.⁹

MGC Assessment¹⁰

MGC				
Ptosis, upward gaze (physician examination)	>45 seconds = 0	11–45 seconds = 1	1–10 seconds = 2	Immediate = 3
Double vision on lateral gaze, left or right (physician examination)	>45 seconds = 0	11–45 seconds = 1	1–10 seconds = 3	Immediate = 4
Eye closure (physician examination)	Normal = 0	Mild weakness (can be forced open with effort) = 0	Moderate weakness (can be forced open easily) = 1	Severe weakness (unable to keep eyes closed) = 2
Talking (patient history)	Normal = 0	Intermittent slurring or nasal speech = 2	Constant slurring or nasal speech, but can be understood = 4	Difficult-to-understand speech = 6
Chewing (patient history)	Normal = 0	Fatigue with solid food = 2	Fatigue with soft food = 4	Gastric tube = 6
Swallowing (patient history)	Normal = 0	Rare episode of choking or trouble swallowing = 2	Frequent trouble swallowing (e.g., necessitating change in diet) = 5	Gastric tube = 6
Breathing (thought to be caused by MG)	Normal = 0	Shortness of breath with exertion = 2	Shortness of breath at rest = 4	Ventilator dependence = 9
Neck flexion or extension (weakest; physician examination)	Normal = 0	Mild weakness = 1	Moderate weakness = 3*	Severe weakness = 4
Shoulder abduction (physician examination)	Normal = 0	Mild weakness = 2	Moderate weakness = 4*	Severe weakness = 5
Hip flexion (physician examination)	Normal = 0	Mild weakness = 2	Moderate weakness = 4*	Severe weakness = 5

*Moderate weakness for neck and limb items should be construed as weakness that equals $\sim 50\% \pm 15\%$ of expected normal strength. Any weakness less than that would be classified as mild and any weakness greater than that would be classified as severe.¹⁰

Interpreting MGC

High total score = greater impairment¹⁰

Key considerations:

- Always interpret scores alongside MG-ADL, physical examination, and PROs.
- MGC scores are weighted, i.e. respiratory items contribute more heavily to the total score than ocular items, meaning a higher score in one domain can indicate greater impairment even if other domains are less affected.

Clinically meaningful improvement = a 3-point reduction in score¹⁰

- A drop of at least 3 points in MGC signifies a clinically meaningful change in the severity of MG symptoms.



Summary of MG-ADL and MGC key features

Feature	MG-ADL ^{4,7}	MGC ^{9,10}
Who completes	Patient	Clinician
Domains	8 daily activities	10 clinical items
Score range	0–24	0–50
MCID	2 points	3 points
Time to complete	<10 minutes	<5 minutes

Clinical integration tips

To accurately assess disease burden, guide treatment decisions and track patient progress with confidence, speak to your patients about symptom tracking with MG-ADL and MGC.

- MG-ADL can help clinicians understand the impact of MG on a patient’s daily activities,⁴ while the MGC complements this information by including both patient, and clinician-reported outcomes.¹⁰
- Expert opinion suggests that weekly measurements of PROs, such as the MG-ADL, can optimise patient symptom recall.¹¹

MG-ADL resources

The following tools can be used to help you and your patients track their MG-ADL score:

HCP resources



MG-ADL
1 pager summary

Patient resources



My MG
Tracking Diary



MG-ADL
Educational Video



myastheniaalliance.org.au*

*The information a reader is about to be referred to may not comply with the Australian regulatory requirements. Further information relevant to the Australian environment is available from the Company or via the Product Information.



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Abbreviations: **MG**, Myasthenia Gravis; **MG-ADL**, Myasthenia Gravis Activities of Daily Living; **MGC**, Myasthenia Gravis Composite; **MG-QoL**, Myasthenia Gravis Quality of Life; **MG-QoL-15r**, Myasthenia Gravis Quality of Life 15-item revised scale; **MMT**, Manual Muscle Test; **Neuro-QoL-Fatigue-SF**, Neurology Quality of Life Fatigue Short Form; **PROs**, Patient-Reported Outcomes; **QMG**, Quantitative Myasthenia Gravis score.

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