gMG AWARENESS ADVANCES ACTION

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CLINICAL PRACTICE AID:

MYASTHENIA GRAVIS CARE COMPANION

This guide is designed to support healthcare professionals (HCPs) in delivering more personalized, patient-centered care for individuals with myasthenia gravis (MG). This tool helps HCPs align clinical priorities with what matters most to their patients, whether they are initiating treatment conversations or reassessing management plans.

In this guide, you will find actionable strategies to assess and integrate patient-reported outcomes (PROs) and quality of life (QoL) metrics into your consultations. These insights are essential for evaluating treatment success beyond clinical endpoints − capturing how patients truly experience their disease and its management.

This guide is designed for real-time use during patient consultations to support meaningful discussions, establish shared goals, and deliver a patient-centered experience for individuals living with MG.

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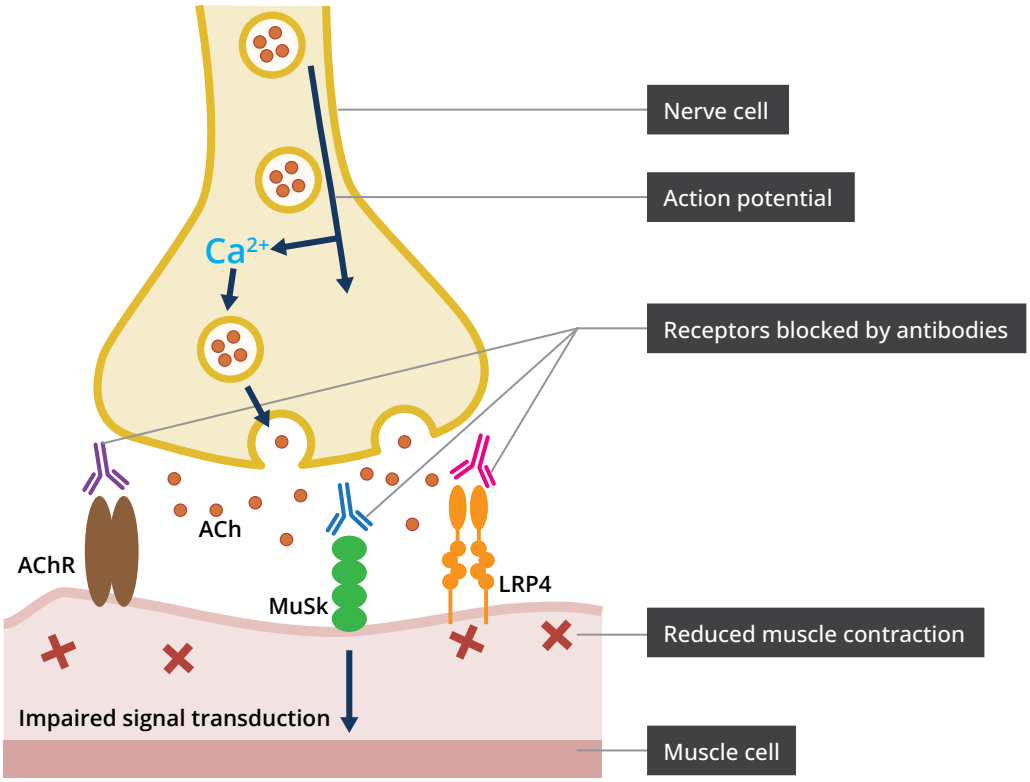
MG pathophysiology

MG is a neuromuscular junction transmission disorder caused by autoantibodies directed at different components of the postsynaptic muscle membrane, as shown in the figure.[1]

Neuromuscular junction in MG



ACh=acetylcholine; AChR=acetylcholine receptor; Ca=calcium; LRP4=low-density lipoprotein receptor-related protein 4; MuSK=muscle-specific tyrosine kinase.

MG symptoms

Presenting symptoms of MG vary widely among individuals and may include ocular, bulbar, limb, and truncal weakness, as well as respiratory symptoms such as dyspnea and myasthenic crisis.

Ocular presentation	Generalized symptoms	Myasthenic crisis
Patients can have a predominantly ocular presentation, characterized by symptoms of ptosis and diplopia. Most patients with MG initially present with ocular symptoms, with 50–80% progressing to gMG.[2,3]	Patients may present with generalized symptoms that also include fatigable weakness of limb, bulbar (15%), and respiratory muscles.[4]	5–17% of **pediatric** patients will experience an MG crisis.[5,6] ~15–20% of **adults** with MG will experience at least one myasthenic crisis.[7] Up to 50% of patients with MuSK+ MG will experience a myasthenic crisis at some point during their illness.[8] Up to 50% of those experiencing a myasthenic crisis may not be able to identify a specific trigger.[7]

gMG=generalized myasthenia gravis; MG=myasthenia gravis; MuSK=muscle-specific tyrosine kinase.

MG diagnosis

Diagnosis is confirmed by serum antibody testing, including acetylcholine receptor (AChR), muscle-specific tyrosine kinase (MuSK), and low-density lipoprotein receptor-related protein 4 (LRP4) antibodies.[9-11]

Seropositive (+) MG	Seropositive (-) MG
Most patients with gMG test positive for AChR antibodies.[9,10] A smaller proportion test positive for MuSK or LRP4 antibodies.[11,12] Among adult patients with gMG: ▶ Up to 90% are **AChR+** ▶ 5–8% are **MuSK+** ▶ 1–5% are **LRP4+** Among patients with juvenile MG:[6,13,14] ▶ **AChR+**: pre-pubertal, 31–71%; pubertal, 68–92% ▶ **MuSK+**: 1–7% Electrodiagnostic testing can support diagnosis even in seropositive cases. When false positive antibodies are suspected or when assessing disease activity, SFEMG may provide valuable additional clinical insight.[2,3,15]	Children and young people with MG often have higher rates of seronegativity (no detectable antibodies) and negative neurophysiological findings.[6] ~15% of adult patients with MG are seronegative.[16] 50% of adult patients with ocular MG are seronegative.[17] In patients with seronegative MG, electrodiagnostic testing with RNS or SFEMG can aid confirmation of diagnosis in those with typical MG clinical features.[1] When the diagnosis is uncertain, it is important to seek the opinion of an MG specialist early, particularly before initiating long-term immunomodulatory treatments. This helps to avoid unnecessary treatment-related risks and ensures that alternative diagnoses, such as congenital myasthenic syndrome, are appropriately considered.

AChR=acetylcholine receptor; gMG=generalized myasthenia gravis; LRP4=low-density lipoprotein receptor-related protein 4; MG=myasthenia gravis; MuSK=muscle-specific tyrosine kinase; RNS=repetitive nerve stimulation; SFEMG=single-fiber electromyography.

Differentiating MG exacerbations from myasthenic crises:
Both MG exacerbations and myasthenic crises result in muscle weakness, but myasthenic crisis is distinguished by the requirement for mechanical ventilation due to severe respiratory muscle disease.

As an HCP, it is important to educate patients about the signs and symptoms of a myasthenic crisis. Effective ways to convey this are:

Recognizing the early signs of a myasthenic crisis and seeking immediate medical attention can significantly improve your chances of a positive outcome. Please do not hesitate to contact medical services if you experience any symptoms.
If you experience significant difficulty swallowing or breathing, call 911 or go to the emergency department – especially if symptoms worsen, even if you initially feel stable.
Spotting the early signs of a myasthenic crisis and getting medical help fast can make a big difference. If you feel any symptoms, reach out to a healthcare professional right away.

Why PROs and QoL metrics matter in MG

PROs and QoL assessments offer essential insights into the lived experience of MG. These tools help clinicians capture the fluctuating nature of symptoms and their real-world impact, offering insight into the patient's lived experience that may not be evident during a routine physical exam. There are several PROs and QoL assessments available, with commonly used tools including the Myasthenia Gravis Activities of Daily Living (MG-ADL) scale, Myasthenia Gravis Quality of Life 15-Item Revised (MG-QOL15R) scale, and EQ-5D-5L.[18-21] Providers are encouraged to consider incorporating the MG-ADL or MG-QOL15R disease-specific measures as part of routine clinical assessments to guide treatment decisions. Although additional research is needed to expand the evidence base, incorporating PROs and QoL data already plays a key role in more informed, patient-centered decision-making.

Disease burden of MG	PRO studies show that patients with MG report a significant percentage of persistent symptoms and treatment-related complications that contribute to the overall burden of their disease.[22] A qualitative analysis of lived patient experiences with MG demonstrated five overarching themes related to their burden of disease:[23] ▶ Impact of living with fluctuating and unpredictable symptoms ▶ Feeling in a constant state of adaptation, with continual assessment and trade-offs in all aspects of life ▶ A sense of treatment inertia often resulting in under-treatment ▶ A sense of disconnect with HCPs on satisfactory symptom control and QoL ▶ Feelings of anxiety, frustration, guilt, anger, loneliness, and depression
Recognition of fatigue	▶ Fatigue is a common but often under-recognized symptom in MG, seen in up to **80%** of patients.[24] ▶ Fatigue can occur with fluctuating muscle weakness, but it can also be indicative of many other underlying factors that may need to be addressed, such as brain fog, poor sleep, weight changes, deconditioning, depression, and medication effects.[24,25] ▶ Perception of fatigue can be present even after the MG symptoms are otherwise controlled, and management of fatigue in this situation may not need to involve escalation of MG treatment.
Socioeconomic burden of MG	▶ Providers should recognize that MG may impact patients' ability to perform at work or in educational settings. A significant proportion of individuals with MG may face unemployment due to their condition. Other consequences may include reduced income, difficulty managing long working hours, or the need to modify job responsibilities due to symptom burden, all of which can contribute to financial strain.[26-28] ▶ Providers should advocate for reasonable accommodation in educational and workplace settings to support patients with MG.

HCP=healthcare professional; MG=myasthenia gravis; PRO=patient-reported outcome; QoL=quality of life.

Consultation companion

MG is a chronic neuromuscular condition with a variable clinical course. Counseling patients on disease prognosis and creating individualized treatment plans to manage MG symptoms and improve QoL are important parts of MG care. This set of questions can help HCPs ensure comprehensive and patient-centered care for individuals with MG.

Counseling, communication, and shared decision-making in MG

Establish treatment goals and discuss prognosis	Questions to ask patients
Myasthenia gravis (MG) is a chronic condition that may be characterized by symptom fluctuations and usually requires long-term immunomodulatory treatment. Symptoms tend to be worse in the first few years after diagnosis.	▶ What are your main goals for managing your MG? ▶ How have your symptoms changed since your diagnosis?
Providers should create expectations centered on reasonable goals for long-term treatment and advise patients and carers that it may take time to see a response after initiation of a new therapy.	▶ How have your symptoms changed since your diagnosis? ▶ How have your symptoms changed since you've started treatment? ▶ Have you experienced any side effects from your current medications?
Patients and carers should be familiar with common triggers for MG exacerbation, such as illness or certain medications. It may be helpful to direct patients to resources about medications that should be viewed with caution.[29,30]	▶ Are there any specific triggers you've noticed that worsen your symptoms? ▶ Are you aware of common triggers for MG exacerbation?
Provide patients and carers with education on how to recognize the signs of a myasthenic crisis and what actions to take.	▶ Do you know the signs of a myasthenic crisis and what to do if one occurs?
Implement age-specific monitoring, with particular attention to the management of ocular MG in children under 8 years old, focusing on the prevention and treatment of amblyopia.	▶ How are we managing your child's ocular symptoms?

Treatment of MG

Treatment options for MG include acetylcholinesterase inhibitors, corticosteroids or other immunosuppressants, and steroid-sparing immunosuppressants. Additionally, numerous targeted immunomodulatory therapies, which act via mechanisms such as neonatal Fc receptor (FcRn) antagonism, complement inhibition, or B-cell depletion, are now available. Intravenous immunoglobulin (IVIG) and plasma exchange are typically used to manage MG exacerbation and myasthenic crisis but are also sometimes used for long-term management of symptoms.[28-30]

Management options	How to explain them
Acetylcholinesterase inhibitors (e.g., pyridostigmine)	This medication helps to improve communication between nerves and muscles, which may improve symptoms.
Corticosteroids or other immunosuppressants (e.g., prednisone, prednisolone) and other, nonsteroidal immunosuppressants (e.g., azathioprine, mycophenolate mofetil, cyclosporine)	These treatments work to prevent your immune system from creating antibodies that attack your muscles.
Intravenous immunoglobulin (IVIG)	IVIG filters all antibodies, including those that cause myasthenia gravis (MG), and gives you healthy antibodies to help control exacerbations or severe symptoms.
Plasma exchange	This procedure filters all antibodies, including those that cause MG, from your blood. We often use it for serious symptoms or exacerbations, and it is administered through a peripheral intravenous (IV) site or, more commonly, a port.
Thymectomy	This is surgery to remove the thymus gland. For some patients, it can help improve symptoms over time.
Targeted therapies	
Complement inhibitors (e.g., eculizumab, ravulizumab-cwvz, zilucoplan)	This treatment blocks part of the immune system that is activated in MG, resulting in damage to the muscles. It can help improve strength and reduce symptoms.
Neonatal Fc receptor (FcRn) inhibitors (e.g., efgartigimod, rozanolixizumab, nipocalimab)	This therapy lowers antibody levels, including disease-causing MG antibodies, in your blood by stopping your body from recycling them. That can ease symptoms and help your muscles work better.
B-cell-directed treatments (e.g., rituximab)	This treatment targets immune cells that make healthy and disease-causing MG antibodies. By lowering these antibodies, it may reduce symptoms.

Medication side effects

Discuss medication side effect profiles	Questions to ask patients
▶ Myasthenia gravis (MG) medications can have numerous side effects specific to each treatment, and a detailed discussion with the patient and carers is a key part of counseling. ▶ Medication side effects, such as weight gain, acne, and Cushingoid appearance from steroid use, may also impact patient adherence.	▶ Have you experienced any side effects from your current medications? ▶ How are you coping with the side effects of your treatment?

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Discuss medication side effect profiles	Questions to ask patients
▶ Important age-related side effects to consider include growth suppression and delayed puberty associated with steroid use. ▶ Additionally, avoid initiating teratogenic medications in individuals of childbearing potential.	▶ Are you concerned about any potential side effects of your medications? ▶ Are you planning to start a family soon?
▶ Counseling on MG in pregnancy is imperative for patients of childbearing age. This is ideally discussed prior to pregnancy in any patient of childbearing potential, as there are differences in the clinical course and treatment options and special considerations for delivery and the postpartum period.[31]	▶ Have you discussed your treatment plan for pregnancy?
▶ Cost and accessibility concerns (eg, time off work or education for an infusion therapy, access to an infusion center) should be considered prior to initiation of therapy.	▶ Do you have any concerns about the cost or accessibility of your treatment?
▶ Other important factors in treatment selection include the patient's antibody status, disease severity and rate of progression of MG, concomitant medications, prior treatment history, time since thymectomy, medical comorbidities, and patient preferences and values.	▶ What are your preferences and values regarding your treatment options?

Mental health impact

Patients with MG commonly experience anxiety and depression, which may impact symptom perception, treatment adherence, and overall QoL.[22] Early involvement of psychological support services, where appropriate, can be beneficial and should be considered as part of a comprehensive, multidisciplinary care approach.

Psychological support strategies	Some questions to ask patients to get you started
Proactively screen for signs and symptoms of emotional distress by asking targeted, empathetic questions during consultations.	▶ How are you feeling emotionally about managing your myasthenia gravis (MG)? ▶ Have you been limiting social activities or hobbies due to your symptoms? ▶ Are you experiencing any anxiety related to the unpredictable nature of MG symptoms or progression?
Encouraging patients to advocate for their needs helps foster trust and ensures that care plans reflect both physical and emotional needs.[32]	▶ Do you feel comfortable advocating for your needs with family and healthcare providers?

Exercise

Patients with MG can be encouraged to pursue physical activity, as tolerated, once their MG is stable. Although more data is needed in this area, avoiding high temperatures, starting slow, selecting an activity that lends itself easily to modification, and allowing for periods of rest are likely to be helpful in MG. Exercise may help patients with MG increase their endurance and improve psychological well-being.[33]

Some questions to learn more about patients' physical activities
▶ What types of physical activities do you enjoy?
▶ Have you noticed any changes in your symptoms with exercise?
▶ How does exercise impact your overall well-being?

Abbreviations

ACh: acetylcholine
AChR: acetylcholine receptor
Ca: calcium
gMG: generalized myasthenia gravis
HCP: healthcare professional
IVIG: intravenous immunoglobulin
LRP4: low-density lipoprotein receptor-related protein 4
MG: myasthenia gravis
MG-ADL: Myasthenia Gravis Activities of Daily Living
MG-QOL15R: Myasthenia Gravis Quality of Life 15-Item Revised
MuSK: muscle-specific receptor tyrosine kinase
PRO: patient-reported outcome
QoL: quality of life
RNS: repetitive nerve stimulation
SFEMG: single-fiber electromyography

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