Enhancing Health Outcomes in Myasthenia Gravis (MG):

The Role of Community Health Workers

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

Purpose Statement

Significant gaps exist between the myasthenia gravis (MG) community and the healthcare system, affecting the quality of care and support available to those impacted. This training program is designed to bridge these gaps by equipping community health workers (CHWs) with essential knowledge and skills to effectively support individuals living with MG. Through comprehensive education, the program seeks to enhance the capacity of CHWs to deliver accurate information, facilitate access to healthcare services, and promote self-management strategies among patients. By empowering CHWs, we aim to strengthen the connection between the MG community and the healthcare system, ultimately aiming to improve health outcomes and quality of life for individuals with MG.

These slides will be presented to the National Association of Community Health Workers (NACHW) during its June 2025 MG Awareness Webinar by a representative from UCB.

Partnership Acknowledgment

NACHW and UCB partnered to develop this training curriculum.

NACHW staff contributed to the development of this curriculum by providing reviews and feedback from 2 CHWs and 2 allies (non-CHWs).

Through comprehensive education, this training program seeks to enhance the capacity of CHWs to deliver accurate information, facilitate access to healthcare services, and promote self-management strategies among patients. By empowering CHWs, we aim to strengthen the connection between the MG community and the healthcare system, ultimately aiming to improve health outcomes and quality of life for individuals with MG.

NACHW
NATIONAL ASSOCIATION OF COMMUNITY HEALTH WORKERS

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This curriculum will provide educational resources on the following topics:

01 Introduction to Myasthenia Gravis

- Overview
- Treatment Options

02 Understanding Differences in Health Outcomes

- Epidemiology and Demographics
- Barriers to Myasthenia Gravis Care

03 Guidance for Community Health Workers (CHWs)/Promotores (Ps)

04 Myasthenia Gravis Case Studies

05 Advocacy and Policy

Introduction to Myasthenia Gravis

Overview

Myasthenia gravis (MG) (my-us-THEE-nee-uh GRAY-vis) is the most common condition that affects the connection between nerves and muscles, called the neuromuscular junction (NMJ). It causes muscle weakness that comes and goes, often getting worse with activity and improving with rest. MG usually affects muscles that control the eyes, throat, arms, and legs.[1]

Triggers

- Many things can trigger or make MG worse, such as infections, surgery, vaccines, hot weather, stress, pregnancy and certain medications (such as antibiotics, including aminoglycosides and fluoroquinolones, beta-blockers, or drugs that affect the muscles).[1]
- MG often begins with ocular symptoms. About 50% of people with ocular MG will develop generalized myasthenia gravis (gMG) within the first year. About 15% of people with MG will have only ocular MG.[2]

Symptoms

- **Eye Muscles:** Drooping eyelids (ptosis) and double vision (diplopia)[3]
- **Facial Muscle:** Difficulties in speaking (dysarthria), chewing, and swallowing (dysphagia)[3]
- **Respiratory Issues:** Shortness of breath and, in severe cases, respiratory failure[3]
- **Limb Muscle Weakness:** Weakness in the arms, hands and legs, affecting mobility[3]
- **Severe Fatigue and Malaise:** Muscles become weaker with use[4]

Sources: 1. Suresh AB, Asuncion R. (2023, August 8). Myasthenia gravis. StatPearls - NCBI Bookshelf. Retrieved April 7, 2025, from https://www.ncbi.nlm.nih.gov/books/NBK559331/. **2.** Myasthenia-Gravis.com. (2023, November 22). Can I prevent ocular MG from progressing to generalized MG? Myasthenia-Gravis.com. Retrieved April 7, 2025, from https://myasthenia-gravis.com/clinical/ocular-progression. **3.** Kaminski HJ. (2024, October 1). Myasthenia gravis. National Organization of Rare Diseases. Retrieved April 7, 2025, from https://rarediseases.org/rare-diseases/myasthenia-gravis. **4.** Myasthenia gravis (MG). (2025, February 19). Cleveland Clinic. https://my.clevelandclinic.org/health/diseases/17252-myasthenia-gravis-mg.

MG Is Classified Into Several Classes Based on the Severity and Distribution of Muscle Weakness

Class I	Any ocular muscle weakness; all other muscle strength is normal[1]
Class II	Mild weakness affecting muscles other than ocular muscles; may also have ocular muscle weakness of any severity[1]
Class III	Moderate weakness affecting muscles other than ocular muscles; may also have ocular muscle weakness of any severity[1]
Class IV	Severe weakness affecting muscles other than ocular muscles; may also have ocular muscle weakness of any severity[1]
Class V	Requires intubation, with or without mechanical ventilation, except when employed during routine postoperative management[1]

Source: MGFA Clinical Classification. (n.d.). Retrieved April 7, 2025, from https://myasthenia.org/wp-content/uploads/Portals/0/MGFA%20Classification.pdf.

MG Comes in Many Types with Differing Symptoms

Our immune systems are supposed to create antibodies to fight disease. MG is a rare neuromuscular disease that occurs when some of these antibodies mutate, or change, and become autoantibodies, attacking the body instead of protecting it.[1] The autoantibodies interfere with the communication between nerves and muscles, causing muscle weakness that worsens with activity and improves with rest.[2]

Three Types of Auto Antibodies	Description
Acetylcholine receptor (AChR)	Found in approximately 80% of patients with generalized MG, these antibodies disrupt communication at the neuromuscular junction, causing muscle weakness.[3]
Muscle-specific kinase (MuSK)	Present in a smaller subset of patients, they interfere with neuromuscular signaling and are often linked to more severe disease.[4]
Lipoprotein receptor-related protein 4 (LRP4)	Less common than AChR and MuSK, these antibodies also affect neuromuscular transmission.[3]

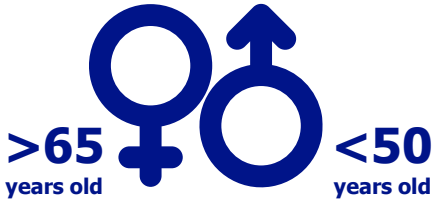
Five Types of MG	Description
Generalized MG	Muscle weakness typically begins in the eye muscles (causing dropping eyelids or double vision) and gradually spreads to other muscle groups. This can include facial weakness of the neck, arms or legs.[5]
Ocular MG	Some people living with MG experience symptoms exclusive to their eye muscles.[1]
Transient neonatal MG	This type of MG affects 10% to 20% of babies born to women with MG. During pregnancy, mothers might pass their autoantibodies to a developing fetus.[1]
Congenital MG	This type of MG can occur anytime from birth through early childhood. Unlike other types of MG, it's not an autoimmune disorder. Instead, it stems from a genetic issue.[1]
Juvenile MG	This rare condition usually begins before age 18 and lasts throughout life. Symptoms might start gradually and could be hard to notice, so the disease may go undiagnosed for a while.[1]

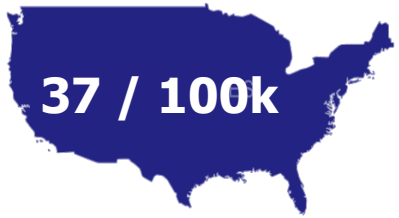
Sources: **1.** *Understanding the six types of Myasthenia gravis | MG United*. (n.d.). MG United US Global. https://www.mg-united.com/disease-and-treatment/the-six-types-of-myasthenia-gravis **2.** Vincent A. Mechanisms in myasthenia gravis. Drug Discovery Today Disease Mechanisms. 2005;2(4):401-408. doi:10.1016/j.ddmec.2005.11.013 **3.** Sun X, Qu M, Rong X, et al. Autoantibodies in myasthenia gravis: cluster analysis and clinical correlations. Frontiers in Neurology. 2025;16. doi:10.3389/fneur.2025.1537783. **4.** Paz ML, Barrantes FJ. Autoimmune attack of the neuromuscular junction in myasthenia gravis: nicotinic acetylcholine receptors and other targets. ACS Chemical Neuroscience. 2019;10(5):2186-2194. doi:10.1021/acschemneuro.9b00041 **5.** Myasthenia Gravis Foundation of America. (2024, October 2). Overview of MG | Myasthenia Gravis Foundation of America.

Epidemiology and Demographics

Demographics

MG can occur at any age but is more common in **women under 50** and **men over 65**. The prevalence also increases with age.[1]





In the U.S., it is estimated that **37 out of every 100,000** people have MG.[2]

The prevalence rate among males aged 65 and older is higher compared to younger populations.[3]

A higher prevalence is observed in certain ethnic groups, indicating potential genetic or environmental factors.[4]

Studies have shown that MG affects different racial and ethnic groups in unique ways.[5-6]

- Scientists believe this could be due to genetics.[5]
- There is a need for more research on how MG affects various populations and why certain groups may experience different symptoms or responses to treatment.[6]

What the Research Tells Us:

African American Women have the highest incidence rates of MG compared to other groups. They are diagnosed with MG more often than others, with a higher number of cases per year.[3]

Hispanic Patients may be more likely to have a specific type of MG-related antibody (blocking antibodies) compared to African American and White patients, but the difference is not statistically confirmed.[5]

African Americans are more likely to have another type of MG-related antibody (MuSK antibodies) compared to Caucasian patients.[6]

Sources: 1. Myasthenia Gravis Foundation of America. Overview of MG | Myasthenia Gravis Foundation of America. Myasthenia Gravis Foundation of America. https://myasthenia.org/Understanding-MG/Overview-of-MG. Published October 2, 2024. Accessed June 4, 2025.**2.** Myasthenia Gravis Foundation of America. (n.d.). Overview of MG. Myasthenia Gravis Foundation of America. Retrieved April 7, 2025, from https://myasthenia.org/understanding-mg/overview-mg/ **3.** Ye Y, Murdock DJ, Chen C, Liedtke W, Knox CA. (2025, April 21). Epidemiology of myasthenia gravis in the United States. Frontiers. Retrieved April 7, 2025, from https://www.frontiersin.org/journals/neurology/articles/ 10.3389/fneur.2024.1339167/full **4.** Kim T, Chaudhari K, MGteam. (2025, February 20). Prevalence of myasthenia gravis in the US and worldwide. MGteam. Retrieved April 7, 2025, from https://www.mgteam.com/resources/ prevalence-of-myasthenia-gravis-in-the-us-and-worldwide **5.** Dresser L, Wlodarski R, Rezania K, Soliven B. Myasthenia Gravis: Epidemiology, Pathophysiology and Clinical Manifestations, Journal of Clinical Medicine, Retrieved April 7, 2025, from https://onlinelibrary.wiley.com/doi/10.1155/2015/197893 **6.** Canadian Pharmacist Last Updated: (n.d.). The impact of ethnicity in myasthenia gravis. Myasthenia. Retrieved April 7, 2025, from https://myasthenia-gravis.com/living/ethnicity-impact.

Treatment Options

There is no cure for MG, but there are effective treatments that help manage symptoms and improve quality of life.[1]

- Treatments include medications such as anticholinesterase drugs, immunosuppressive drugs, monoclonal antibodies, complement inhibitors, a procedure such as plasma exchange, antibody infusions and a surgery for removal of the thymus.[2-3]
- Steroids, specifically corticosteroids, are commonly used to treat MG.[4]
- Intravenous immunoglobulin (IVIG) is a treatment option for MG. IVIG is believed to:
  - Neutralize pathogenic autoantibodies[5]
  - Interfere with the activation and function of immune cells[6]

*Not all treatment options are "on-label" for MG

Surgery

- If the person has a thymoma (tumor in the thymus gland), removing it can help reduce the severity of symptoms and the need for medication.[7]

Lifestyle Adjustments and Supportive Care

MG leads to exertion-dependent muscle weakness, and adversely impacts psychological and social well-being[8]

- **Rest:** Since MG worsens with activity, pacing activities helps[9]
- **Physical Therapy:** Light exercises to maintain muscle strength[10]
- **Avoid Triggers:** Manage infections, heat and stress and avoid certain medications[11]
- **Speech & Swallow Therapy:** Helps those with swallowing and speaking difficulties[12]

Sources: 1. Alhaidar MK, Abumurad S, Soliven B, Rezania K. (2022). Current Treatment of Myasthenia Gravis. Journal of Clinical Medicine, 11(6), 1597. https://doi.org/10.3390/jcm11061597. **2.** Myasthenia Gravis Foundation of America. Myasthenia gravis treatments | Myasthenia Gravis Foundation of America. Myasthenia Gravis Foundation of America. https://myasthenia.org/myasthenia-gravis-treatments/. Published February 11, 2025. Accessed June 4, 2025. **3.** Alhaidar MK, Abumurad S, Soliven B, Rezania K. Current Treatment of Myasthenia Gravis. J Clin Med. 2022 Mar 14;11(6):1597. doi: 10.3390/jcm11061597. PMID: 35329925; PMCID: PMC8950430 **4.** Myasthenia-Gravis.com. (n.d.). Corticosteroids. Retrieved April 22, 2025, from https://myasthenia-gravis.com/corticosteroids **5.** Karnam A, Rambabu N, Das M, et al. Therapeutic normal IgG intravenous immunoglobulin activates Wnt-β-catenin pathway in dendritic cells. Commun Biol 3, 96 (2020). Retrieved April 7, 2025, from https://www.nature.com/articles/s42003-020-0825-4. **6.** Berger M, McCallus DE, Lin CS. (2013). Rapid and reversible responses to IVIG in autoimmune neuromuscular diseases suggest mechanisms of action involving competition with functionally important autoantibodies. Journal of the peripheral nervous system : JPNS, 18(4), 275–296. https://onlinelibrary.wiley.com/doi/10.1111/jns5.12048. **7.** Venuta F, Rendina EA, De Giacomo T, et al. Thymectomy for myasthenia gravis: a 27-year experience1. European Journal of Cardio-Thoracic Surgery. 1999;15(5):621-625. doi:10.1016/s1010-7940(99)00052-4 **8.** Lehnerer S, Jacobi J, Schilling R, et al. (2022). Burden of disease in myasthenia gravis: taking the patient's perspective. Journal of neurology, 269(6), 3050–3063. https://doi.org/10.1007/s00415-021-10891-1. **9.** Myasthenia Gravis Foundation of America. (n.d.). General MG management. Retrieved April 22, 2025, from https://myasthenia.org/Living-With-MG/After-Your-Diagnosis/General-MG-Management/. **10.** Cleveland Clinic. (n.d.). Myasthenia gravis (MG). Retrieved April 22, 2025, from https://my.clevelandclinic.org/health/diseases/17252-myasthenia-gravis-mg. **11.** Suresh AB, Asuncion R. (2023, August 8). Myasthenia gravis. StatPearls - NCBI Bookshelf. https://www.ncbi.nlm. nih.gov/books/NBK559331/ **12.** Healthline. (n.d.). Speech therapy for myasthenia gravis. Retrieved April 22, 2025, from https://www.healthline.com/health/speech-therapy-myasthenia-gravis.

Treatment Types

Treatment Type	What It Does	How It's Given
Acetylcholinesterase Inhibitors (AChE inhibitors)[1] (on label)	Work by stopping the breakdown of acetylcholine at the NMJ[1]	Oral, IV or intramuscular injection[1]
Glucocorticoids (GCs)[1] (off-label)	Broadly indicated for neuroinflammatory conditions and immunosuppressive action[1]	Oral[1]
Non-Steroidal Immunosuppressants (NSISTs)[1] (off-label)	Improve muscle strength by suppressing the production of abnormal antibodies[2]	Oral or IV[1]
B-Cell Inhibitors[1] (off-label)	Deplete B-cells through cytotoxicity and induction of cell death[1] Not indicated for the treatment of MG but is commonly used for individuals who don't respond to other NSISTs	IV infusion[1]
Plasma Exchange (PLEX)[1] (off-label)	Plasma exchange filters out abnormal antibodies[3]	IV through a catheter[1]
Intravenous Immunoglobulin (IVIg)[1] (off-label)	Concentrated antibody treatment from healthy donors that temporarily alters immune function; helps by binding to and removing the harmful antibodies that cause MG[2]	IV infusion[1]
FcRn Inhibitors[1] (on label)	Block FcRn, reducing the recycling of IgG, including pathogenic autoantibodies, to prevent impairment of neurotransmission, NMJ damage and muscle weakness[1]	IV or under the skin *(subcutaneous)*[1]
Complement Inhibitors[1] (off-label)	Block complement activation and MAC formation, preventing damage to the NMJ and resultant muscle weakness[1]	IV or under the skin *(subcutaneous)*[1]

Sources: 1. UCB Rare Disease Connect in Neurology. (2025). MG Fast Facts: Summary for HCPS Generalized Myasthenia Gravis (GMG) Treatment In brief. UCB. (US-DC-2500003). **2.** NIH. What is Myasthenia Gravis? https://www.ninds.nih.gov/health-information/disorders/myasthenia-gravis. **3.** Gajdos, Chevret, et. Al. Plasma exchange for generalised myasthenia gravis. https://pmc.ncbi.nlm.nih.gov/articles/PMC8985203/#:~:text=Myasthenia%20gravis%20is%20caused%20by,helps%20to%20treat%20myasthenia%20gravis.

Differences in Diagnosis and Treatment of MG

- A chest computed tomography (CT) scan is often used in the diagnosis of MG.[1]
- Serological test is minimally invasive and used to detect acetylcholine receptor (AChR) and muscle-specific kinase (MuSk) autoantibodies.[2-3]
- A retrospective study of a nationally representative healthcare claims database of privately insured individuals identified that female patients with MG were less likely to receive a chest CT and treatment options such as steroids, IVIG or PLEX compared to males.[4]

Sources: 1. Medscape. (n.d.). Myasthenia gravis workup. Retrieved April 22, 2025, from https://emedicine.medscape.com/article/1171206-workup?form=fpf. **2.** Lazaridis K, Tzartos SJ. Myasthenia gravis: Autoantibody specificities and their role in MG Management. Frontiers in Neurology. 2020;11. doi:10.3389/fneur.2020.596981. **3.** Peeler CE, De Lott LB, Nagia L, Lemos J, Eggenberger ER, Cornblath WT. Clinical utility of acetylcholine receptor antibody testing in ocular myasthenia gravis. JAMA Neurology. 2015;72(10):1170. doi:10.1001/jamaneurol.2015.1444 **4.** Al-Salahat A, Bin Abdul Jabbar A, Sharma R, Chen Y-T, Bernitsas E. (2025). Demographic and geographic trends in myasthenia gravis–related mortality in the United States, 1999–2022. Neurology, 104(8). https://doi.org/10.1212/WNL.0000000000213505.

Guidance for Community Health Workers(CHWs)/Promotores (Ps)

Definitions:

Community Health Workers (CHWs)

A community health worker is a frontline public health worker who is a trusted member of and/or has a unique understanding of the community served. This relationship enables CHWs to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery.[1]

Promotores

A promotora is a lay Hispanic/Latino community member who receives specialized training to provide basic health education within their community.[2] Promotores often serve as liaisons between their community and health professionals, human and social service organizations.[2]

Sources: 1. American Public Health Association. (n.d.). Community health workers. Retrieved April 22, 2025, from https://www.apha.org/apha-communities/member-sections/community-health-workers. **2.** MHP Salud. (n.d.). Who are promotores(as) & CHWs? Retrieved April 22, 2025, from https://mhpsalud.org/programs/who-are-promotoresas-chws/.

CHWs/Ps Can Play a Role in Bridging the Gap Between Community Members and the Healthcare System, Particularly When Navigating Rare or Misunderstood Conditions Such as MG

Recognize the Red Flags of MG

- Educate clients about the signs and symptoms of MG[1]
  - Drooping eyelids, double vision[1]
  - Weakness that worsens with activity and improves with rest[2]
  - Trouble swallowing, speaking or breathing[1]
  - Fatigue[3]
- Encourage individuals with persistent or unexplained muscle weakness to advocate for further evaluation

Address Medical Mistrust with Cultural Competence

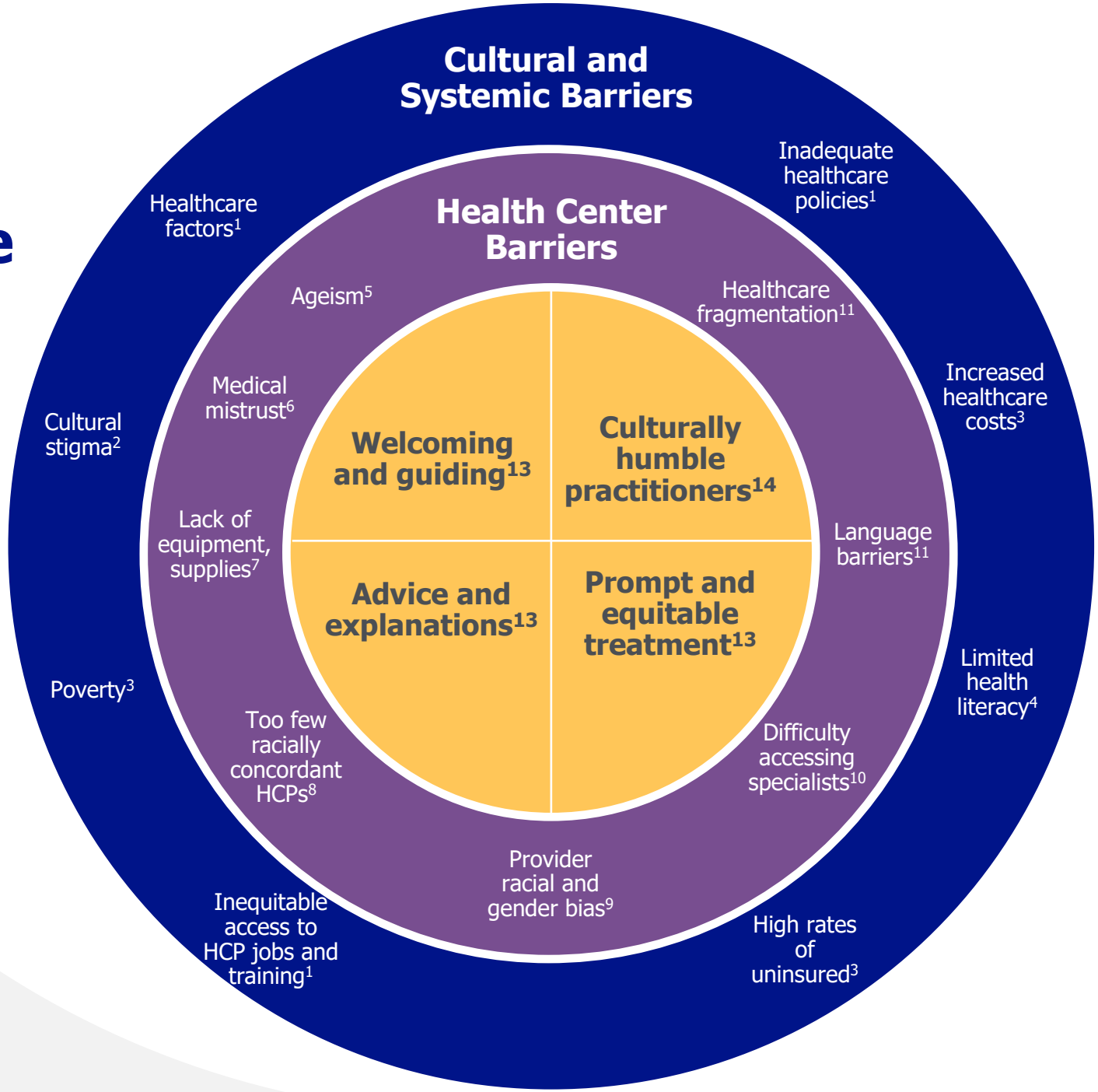
- Acknowledge past negative experiences with the healthcare system, especially in historically less engaged communities
- Encourage and empower patients to ask questions and request second opinions
- Offer to help document their symptoms in writing for provider visits

Connect to Specialists and Resources

- Use patient navigator programs or community health centers to help clients get referred to neurologists and eventually neuro-muscular specialists
- Share resources such as the MGFA Physician Finder

Sources: 1. National Organization for Rare Disorders. (n.d.). Myasthenia gravis. Retrieved April 22, 2025, from https://rarediseases.org/rare-diseases/myasthenia-gravis. **2.** Myasthenia Gravis Foundation of America. (n.d.). General MG management. Retrieved April 22, 2025, from https://myasthenia.org/Living-With-MG/After-Your-Diagnosis/General-MG-Management/. **3.** Cleveland Clinic. (n.d.). Myasthenia gravis (MG). Retrieved April 22, 2025, from https://my.clevelandclinic.org/health/diseases/17252-myasthenia-gravis-mg.

Barriers to Inclusive MG Care



Sources: 1. Hojat LS. (2022). Breaking down the barriers to health equity. Therapeutic Advances in Infectious Disease, 9. https://doi.org/10.1177/20499361221079453. **2.** Stangl AL, Earnshaw VA, Logie CH, Van Brakel W, Simbayi LC, Barré I, Dovidio JF. (2019). The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Medicine, 17(1). https://doi.org/ 10.1186/ s12916-019-1271-3. **3.** Moore B. (2024, May 8). Limited access: Poverty and barriers to accessible health care - National Health Council. National Health Council. Retrieved April 7, 2025, from https://nationalhealthcouncil.org/blog/limited-access-poverty-and-barriers-to-accessible-healthcare/#:~:text=The%202019%20National%20Health%20Interview,5.6%25)%20due%20to%20cost.&text=However%20to%20address%20this%20issue,is%20long%2Dterm%20and%20sustainable. **4.** Allen-Meares P, Lowry B, Estrella ML, Mansuri S. (2019). Health Literacy Barriers in the health care system: Barriers and opportunities for the profession. Health & Social Work, 45(1), 62–64. https://doi.org/10.1093/hsw/hlz034 **5.** World Health Organization. (n.d.). Combatting ageism. Retrieved April 22, 2025, from https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/combatting-ageism#:~:text=Ageism%20affects%20how%20we%20think,'%20health%20and%20well%2Dbeing. **6.** Williamson LD, Bigman CA. (2018). A systematic review of medical mistrust measures. Patient Education and Counseling, 101(10), 1786–1794. https://doi.org/10.1016/j.pec.2018.05.007. **7.** Karpman M, Morris S. (2024, March 14). Barriers to accessing medical equipment and other health services and supports within households of adults with Disabilities | Urban Institute. urban.org. Retrieved April 7, 2025, from https://www.urban.org/research/publication/barriers-accessing-medical-equipment-and-other-health-services-and-supports. **8.** Shen MJ, Peterson E B, Costas-Muñiz R, et al. (2017). The Effects of race and Racial Concordance on Patient-Physician Communication: A Systematic Review of the literature. Journal of Racial and Ethnic Health Disparities, 5(1), 117–140. https://doi.org/10.1007/s40615-017-0350-4. **9.** Vela MB, Erondu AI, Smith NA, Peek ME, Woodruff JN, Chin MH. (2022). Eliminating explicit and implicit biases in health care: evidence and research needs. Annual Review of Public Health, 43(1), 477–501. https://doi.org/10.1146/ annurev-publhealth-052620-103528. **10.** Schuldt R, Jinnett, K. (2024). Barriers accessing specialty care in the United States: a patient perspective. BMC Health Services Research, 24(1). https://doi.org/10.1186/s12913-024-11921-0. **11.** Shamsi HA, Almutairi AG, Mashrafi SA, Kalbani TA. (2020). Implications of Language Barriers for Healthcare: A Systematic review. Oman Medical Journal, 35(2), e122. https://doi.org/ 10.5001/omj.2020.40. **12.** Kern LM, Bynum JPW, Pincus HA. (2024). Care Fragmentation, care Continuity, and care Coordination—How they differ and why it matters. JAMA Internal Medicine, 184(3), 236. https://doi.org/10.1001/ jamainternmed.2023.7628. **13.** Hannawa AF, Wu AW, Kolyada A, Potemkina A, Donaldson LJ. (2021). The aspects of healthcare quality that are important to health professionals and patients: A qualitative study. Patient Education and Counseling, 105(6), 1561–1570. https://doi.org/10.1016/j.pec.2021.10.016. **14.** Stubbe DE. (2020). Practicing cultural competence and cultural humility in the care of diverse patients. FOCUS the Journal of Lifelong Learning in Psychiatry, 18(1), 49–51. https://doi.org/10.1176/appi.focus.20190041.

CASE STUDY 1

Delayed Diagnosis in a Black Woman with MG

Overview

CASE STUDY 1

Background

A 34-year-old Black woman enrolled in Medicaid began experiencing symptoms, including drooping eyelids, facial weakness and extreme fatigue. These symptoms worsened throughout the day but improved after periods of rest, which are classic signs of MG.

Initial Healthcare Experience

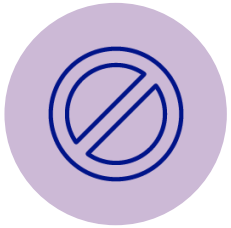
Despite multiple visits to urgent care and her primary care physician, her symptoms were repeatedly dismissed as stress-related or psychosomatic (i.e., "all in her head"). She was prescribed antidepressants and advised to "reduce stress," despite no history of depression or anxiety. Due to being underinsured, she was unable to see a specialist.

Escalation and Diagnosis

After her symptoms progressed to difficulty swallowing and slurred speech, she visited the ER. A neurologist on call recognized the signs and ran tests, including acetylcholine receptor antibody testing and an EMG (electromyography), which confirmed MG. This diagnosis came **over 12 months after** her first symptoms.

Barriers and CHW Roles

CASE STUDY 1



Barriers Identified

- **Racial and gender bias:** Concerns not taken seriously
- **Difficulty accessing a specialist** (neurologist) due to insurance limitations
- **Healthcare fragmentation:** Lack of coordinated follow-up between providers

CHW Roles:

- Help patients document symptoms clearly and consistently
- Encourage second opinions if symptoms are dismissed
- Educate patients on how to describe MG symptoms during visits
- Connect patients to neurologists and MG support resources
- Navigate insurance for specialist referral
- Request medical records to share between providers
- Complete symptom tracker logs

CASE STUDY 2

Hispanic Male Farmworker with Undiagnosed MG

Overview

CASE STUDY 2

Background

A 54-year-old Hispanic man working in agriculture began experiencing generalized fatigue, muscle weakness in his arms and legs, and difficulty chewing his food after long workdays. He attributed his symptoms to aging and hard labor. Over time, he developed slurred speech and shortness of breath.

Healthcare Access Issues

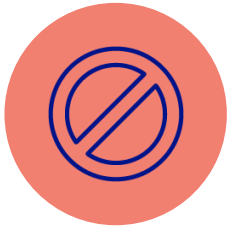
He had no regular physician, no health insurance, and limited English proficiency. He visited a free community clinic, but language barriers made it difficult to fully describe his symptoms. The clinician suspected dehydration or vitamin deficiency and sent him home with general supplements.

Delayed Diagnosis

After collapsing at work due to respiratory distress, he was taken to the ER, where a neurologist recognized possible MG and confirmed it with antibody testing and EMG. He was diagnosed with generalized MG nearly two years after symptom onset.

Barriers and CHW Roles

CASE STUDY 2



Barriers Identified

- Lack of insurance and regular care
- Language barrier
- Cultural normalization of physical exhaustion
- Limited health literacy

CHW Roles:

- Use bilingual resources and interpreters when possible
- Educate community members that persistent weakness and swallowing difficulty are not normal aging signs
- Encourage use of symptom checklists and diaries
- Help connect patients to community health centers that accept uninsured patients
- Promote regular check-ups among un/underinsured
- Educate on where to receive care
- Self-educate on cultural norms and health behaviors/decision making; involve the family (culturally specific guidance)
- Consider root cause of avoiding health-seeking behaviors

CASE STUDY 3

Elderly White Male Veteran with Rapid-Onset MG

Overview

CASE STUDY 3

Background

A 67-year-old White male and retired veteran, living in a rural community, began to notice sudden weakness in his jaw and trouble keeping his eyes open. He had a history of hypertension and was initially told by a VA primary care provider (PCP) that his symptoms were likely medication-related.

Healthcare Access Issues

His condition progressed rapidly, leading to a myasthenic crisis, a severe, life-threatening complication of myasthenia gravis, that required ICU admission. Only after this emergency was a neurologist brought in to assess him, who confirmed the diagnosis of generalized MG.

Barriers and CHW Roles

CASE STUDY 3

Barriers Identified

- Location: Lived in a rural community
- Ageism in symptom interpretation (“you’re just getting older”)
- Delayed specialist referral at VA
- Under-recognition of MG symptoms by PCP

CHW Roles

- Educate seniors and caregivers that sudden muscle weakness and breathing issues are not normal aging
- Advocate for timely referrals to specialists
- Connect veterans with MG to VA neuromuscular programs or external neurologists if needed
- Help keep track of symptoms

Advocacy and Policy

Advocating for Policy Changes to Improve Health Outcomes Across All Communities Involves Several Steps, Including Understanding the Issues, Engaging with Stakeholders, and Effectively Communicating Your Message. Here Are Some Resources and Strategies to Help You Get Started:

Understand the Issues:

- Research: Familiarize yourself with the current policies affecting MG care and the differences in health outcomes that exist. This includes understanding the impact of social, economic, political and environmental factors on health outcomes.[1]
- Data Collection: Gather data and personal stories that highlight differences in MG care.

Engage with Stakeholders:

- Join Advocacy Groups: Organizations such as the Myasthenia Gravis Foundation of America (MGFA), Myasthenia Gravis Holistic Society (MGHS), and the Myasthenia Gravis Association (MGA) offer advocacy programs and resources to help you get involved. Seek out local support groups; virtual may be the best option. Several groups are available on social media (Facebook) and/or meet virtually.
- Network: Connect with other advocates, healthcare professionals, and policymakers who are interested in improving MG care.

Communicate Effectively:

- Develop Your Message: Clearly articulate the changes you want to see and why they are important. Use data and personal stories to support your message.
- Public Speaking: Improve your public speaking skills to communicate your message at meetings, conferences and public forums.
- Writing: Learn how to write persuasive letters, emails and social media posts to reach a wider audience.

Source: Myasthenia Gravis Foundation of America. (n.d.). Advocate for patients. Myasthenia Gravis Foundation of America. Retrieved April 7, 2025, from https://myasthenia.org/Support-the-MG-Community/Advocate-for-Patients/.

How to Take Action

By following these steps and utilizing available resources, you can advocate for policy changes that could improve equity in MG care.

Contact Legislators

Write to your local, state and federal representatives to advocate for policy changes. Provide them with data and personal stories to support your case.

Public Awareness Campaigns

Use social media, blogs and other platforms to raise awareness about the disparities in MG care and the need for policy changes.

Participate in Advocacy Events

Attend rallies, conferences and other events to show your support and connect with other advocates.

Resources*

Myasthenia Gravis Foundation of America (MGFA): Offers advocacy training and resources to help you get involved

Myasthenia Gravis Association (MGA): Works diligently to ensure individuals with MG are being supported and cared for through awareness efforts, education,
member services and supporting research

Myasthenia Gravis Holistic Society (MGHS): Dedicated to empowering individuals affected by MG through advocacy, connection, engagement and education

Rare Disease Diversity Coalition: An initiative launched by the Black Women's Health Imperative to address the unique challenges faced by underserved populations with rare diseases

National Organization for Rare Disorders (NORD): Provides advocacy, education, research support and patient services to improve the lives of those affected by rare diseases

Muscular Dystrophy Association: Has MG-specific resources

Caregiver Action Network: Has rare-specific resources

*This is not an exhaustive list. There may be local MG support groups or advocacy groups in your state. Consider virtual options for areas with limited support.

Potential Strategies to Reduce Barriers to Care

Support Health Literacy

- Explain the condition using clear, simple terms (e.g., "This is a condition where the nerves have trouble talking to the muscles.")
- Help patients understand the importance of diagnosis and the names of key tests (e.g., EMG, blood tests for antibodies)
- Offer printed materials or videos in the patient's preferred language

Document and Validate Patient Experiences

- Encourage clients to keep a symptom diary (time of day, what they're doing, what symptoms appear)
- Role-play conversations with providers so patients feel more prepared

Be an Ally in Advocacy

- If appropriate, offer to attend doctor's appointments
- Ensure that the patient's full history is heard, not dismissed
- Reinforce that their voice matters, and early diagnosis improves outcomes[1]

Source: Marlet IR, Andersen RK, Axelsen KH, Andersen LK, Vissing J, Witting N. (2024). Factors affecting the diagnostic delay of myasthenia gravis. Journal of neurology, 272(1), 29. https://doi.org/10.1007/s00415-024-12807-1.

Appendix

Community Engagement Resources and Links

*Resources for connecting patients with local services:

Feeding America

Offers resources to identify local food banks, food pantries, soup kitchens and meal programs in your local community

USA.gov

Provides information about rental, home buying and home repair assistance programs; you can also learn how to find emergency housing and avoid foreclosure and eviction

Healthcare.gov

Helps you find low-cost healthcare in your community

MGFA Caregiver Resources
https://myasthenia.org/living-with-mg/find-support/for-caregivers
Offers practical tools, tips, and emotional support for individuals caring for someone with Myasthenia Gravis.

National Alliance on Mental Illness (NAMI)
https://nami.org
Provides education, peer support groups, and a helpline for those navigating mental health challenges.

Benefits.gov
https://www.benefits.gov
A comprehensive tool to help patients determine eligibility for disability, housing, food, and healthcare assistance.

U.S. Department of Labor
https://www.dol.gov
Find information on employee protections, including the Family and Medical Leave Act (FMLA), disability discrimination laws, and workplace accommodations.

ADA.gov
https://www.ada.gov
Learn about your rights under the Americans with Disabilities Act, including how to request workplace and public access accommodations.

*This is not an exhaustive list.