Poster **P4-9-004**

Comprehensive care goals in myasthenia gravis: Expert consensus recommendations using the RAND/UCLA appropriateness method

AAN 2026, Chicago, IL, USA; April 18–22, 2026

Pushpa Narayanaswami[1], Renato Mantegazza[2], Carolina Barnett-Tapia[3,4], Elena Cortés Vicente[5], Miriam Freimer[6], Nils Erik Gilhus[7,8], Ali A. Habib[9], James F. Howard, Jr.[10], Anna Kostera-Pruszczyk[11], M. Isabel Leite[12], Andreas Meisel[13], Mamatha Pasnoor[14], Sabrina Sacconi[15], Nicholas J. Silvestri[16]*, Shigeaki Suzuki[17], Akiyuki Uzawa[18], Gil I. Wolfe[16], Kimiaki Utsugisawa[19]

Introduction

While there are several guidelines for the medical management of MG, there is limited guidance to provide comprehensive care goals beyond medical management.

Objective

To develop globally relevant consensus recommendations to provide comprehensive care guidance for patients with MG.

Methods

An international panel was formed and consisted of 17 MG experts from North America, Europe and Asia, and one MG expert methodologist.

A narrative literature review informed the development of consensus recommendations.

Formal consensus was sought using a mathematical formula, as per the RAND/UCLA appropriateness methodology.[1]

Please use this QR code to download a PDF of the poster

Results

Expert consensus was reached on a range of globally relevant recommendations for comprehensive care in MG, with 21 recommendations achieving agreement as appropriate.

The recommendations emphasize the importance of:

- Early symptom control
- Patient engagement and education
- Re-assessing and changing medical management to achieve goals
- Care co-ordination with primary care physicians and other specialists

Summary

We present guidance for comprehensive care to achieve optimal outcomes for patients with MG.

We believe that these recommendations will help guide overall management, treatment and referral decisions throughout the patient journey.

The recommendations will require updates as the treatment landscape evolves.

[1]Department of Neurology, Beth Israel Deaconess Medical Center/Harvard Medical School, Boston, MA, USA; [2]Emeritus and Past Director, Department of Neuroimmunology and Neuromuscular Diseases, Fondazione IRCCS, Istituto Nazionale Neurologico Carlo Besta, Milan, Italy; [3]Ellen and Martin Prosserman Centre for Neuromuscular Diseases, Toronto General Hospital, University of Toronto, Toronto, Ontario, Canada; [4]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada; [5]Neuromuscular Diseases Unit, Hospital de la Santa Creu i Sant Pau, Barcelona, Spain; [6]Department of Neurology, The Ohio State University Wexner Medical Center, Columbus, OH, USA; [7]Department of Clinical Medicine, University of Bergen, Bergen, Norway; [8]Department of Neurology, Haukeland University Hospital, Bergen, Norway; [9]MDA ALS & Neuromuscular Center, Department of Neurology, University of California, Irvine, Orange, CA, USA; [10]Department of Neurology, The University of North Carolina at Chapel Hill, Chapel Hill, NC, USA; [11]Department of Neurology, Medical University of Warsaw, ERN EURO-NMD, Warsaw, Poland; [12]Nuffield Department of Clinical Neurosciences, University of Oxford, Oxford, UK; [13]Department of Neurology and Experimental Neurology, Center for Stroke Research Berlin, Charité – Universitätsmedizin Berlin, Berlin, Germany; [14]Department of Neurology, University of Kansas Medical Center, Kansas City, KS, USA; [15]Université Côte d'Azur, Peripheral Nervous System & Muscle Department, Pasteur 2 Hospital, Centre Hospitalier Universitaire de Nice, Nice, France; [16]Department of Neurology, Jacobs School of Medicine and Biomedical Sciences, University at Buffalo, Buffalo, NY, USA; [17]Department of Neurology, Tokyo Metropolitan Neurological Hospital, Tokyo, Japan; [18]Department of Neurology, Graduate School of Medicine, Chiba University, Chiba, Japan; [19]Department of Neurology, Hanamaki General Hospital, Hanamaki, Japan. *Affiliation at the time of study.

Recommendation 1 defined the ongoing treatment goal in MG:

To work towards, achieve and sustain minimal symptoms and treatment-related adverse events, with a patient-acceptable quality of life (using validated measures)

Subsequent recommendations described how to implement and achieve this goal for patients, across **six topics**:

TOPIC 1

Establishing and sustaining an MG treatment goal

Clinicians should **regularly assess** a patient with MG at **all disease stages** for symptom burden, treatment burden and quality of life, using the same measures to **build an ongoing, overall picture of the disease and its impact**

For full Topic 1 recommendations, go to **Slide 2** →

TOPIC 2

Working towards early symptom control

Clinicians should **consider several factors** when selecting treatment for a patient with newly diagnosed MG, such as **disease-related factors, patient factors, preferences and comorbidities, financial resources and available treatment options**

For full Topic 2 recommendations, go to **Slide 3** →

TOPIC 3

Infection screening and vaccination

Clinicians should **refer** patients with MG to their primary care clinician or appropriate speciality (e.g., infectious disease) to **complete immunization schedules**, per local/national/World Health Organization guidelines and per local prescribing information for MG therapies **as part of immunosuppressive therapy planning**

For full Topic 3 recommendations, go to **Slide 4** →

TOPIC 4

Pregnancy and family planning

Clinicians should **discuss pregnancy** and **pregnancy planning routinely** with all women of reproductive age before initiating treatment for MG and regularly during follow up

For full Topic 4 recommendations, go to **Slide 5** →

TOPIC 5

Fatigue and comorbidity management

Clinicians should **educate patients** with MG on the **difference between neuromuscular fatigability** and **generalized fatigue**

For full Topic 5 recommendations, go to **Slide 6** →

TOPIC 6

Managing impending crisis and crisis

Clinicians should **admit** patients with **impending crisis** to hospital for close assessment of respiratory and bulbar function, evaluate for and **treat precipitating factors**, and **initiate rapid-acting therapy**

For full Topic 6 recommendations, go to **Slide 7** →

Abbreviations: COI, conflict-of-interest disclosures; MG, myasthenia gravis. **Author disclosures:** For full disclosures and acknowledgments, go to **Slide 8 (COI).** **Reference:** 1. RAND. https://www.rand.org/content/dam/rand/pubs/monograph_reports/2011/MR1269.pdf. Accessed March 2026.

Consensus recommendations

TOPIC **1**

Establishing and sustaining an MG treatment goal

1. The ongoing treatment goal in MG is to work towards, achieve and sustain minimal symptoms and treatment-related adverse events, with a patient-acceptable quality of life (using validated measures).
2. Clinicians should **regularly assess** a patient with MG at **all disease stages** for symptom burden, treatment burden and quality of life, using the same measures to **build an ongoing, overall picture of the disease and its impact**.
3. Clinicians should **engage patients with MG and their family/caregivers**, as appropriate, to play an active role in **shared decision making**, so that **patients' personal goals, values and preferences are considered** when discussing treatment plans.
4. Clinicians should **discuss with patients the pros and cons of available treatment options**, including conventional therapies,* available targeted therapies† and thymectomy, before initiation of treatment.
5. In patients receiving glucocorticoids, clinicians should **aim to reduce the glucocorticoid dose** to prednisone equivalent ≤10 mg/day and optimally to ≤5 mg/day, using alternative agents as necessary, and monitor patients closely for MG worsening.
6. In patients with MG, if minimal symptoms, minimal treatment-related adverse events and patient-acceptable quality of life cannot be sustained, clinicians should **re-assess treatment and make changes to achieve treatment goals**.
7. Clinicians should **educate patients** with MG on the **symptoms and potential triggers of exacerbations and crisis, closely monitor** patients who report exacerbating factors, and **take appropriate action** if exacerbations or crisis are suspected.

IVIg, intravenous immunoglobulin; MG, myasthenia gravis.
*Broad-spectrum immunosuppressive/immunomodulatory treatments such as glucocorticoids, non-steroidal immunosuppressants, IVIg and plasma exchange. †Therapies that target specific pathways in MG pathogenesis, such as complement inhibitors and other targeted treatments.

Consensus recommendations

TOPIC **2**

Working towards early symptom control

8 Clinicians should **consider several factors** when selecting treatment for a patient with newly diagnosed MG, such as **disease-related factors, patient factors, preferences and comorbidities, financial resources and available treatment options**.

9 Clinicians should **refer** a patient with MG to (or co-manage with) a **specialist** with expertise in MG management if **there is no sustained clinical improvement within 3–6** months of treatment initiation.

10 Clinicians should seek to **initiate available targeted therapies*** in patients with gMG who have **active symptoms** and for whom **conventional therapy† does not achieve symptom control within 6–12 months or results in excessive treatment-related burden**. Use of available targeted therapies as initial treatment (together with standard therapy where indicated) should be driven by clinician judgment.

(g)MG, (generalized) myasthenia gravis; IVIg, intravenous immunoglobulin.
*Therapies that target specific pathways in MG pathogenesis, such as complement inhibitors and other targeted treatments. †Broad-spectrum immunosuppressive/immunomodulatory treatments such as glucocorticoids, non-steroidal immunosuppressants, IVIg and plasma exchange.

Consensus recommendations

TOPIC **3**

Infection screening and vaccination

11 Clinicians should **refer** patients with MG to their primary care clinician or appropriate speciality (e.g., infectious disease) to **complete immunization schedules**, per local/national/World Health Organization guidelines and per local prescribing information for MG therapies **as part of immunosuppressive therapy planning**.

12A Clinicians should **refer** patients with gMG **for whom complement inhibitor therapies may be a future consideration** to their primary care clinician or appropriate specialist **to complete meningococcal vaccination** and other treatment-specific vaccination, per local/national/World Health Organization guidelines and per local drug prescribing information.

12B If complement inhibitors are commenced, clinicians should **ensure maintenance of meningococcal vaccination status**, and of other treatment-specific vaccination status, with recommended boosters throughout the course of treatment.

13 Clinicians should **test all patients** with MG as soon as possible after diagnosis **for underlying infections**, including hepatitis B and C, tuberculosis (in relevant regions) and human immunodeficiency virus (in at-risk populations).

(g)MG, (generalized) myasthenia gravis.

Consensus recommendations

TOPIC **4**

Pregnancy and family planning

14 Clinicians should **discuss pregnancy** and **pregnancy planning routinely** with all women of reproductive age before initiating treatment for MG and regularly during follow up.

15 Clinicians should **advise** women of reproductive age that **well-controlled MG is associated with the best pregnancy outcomes**.

16 When a patient with MG is considering pregnancy or is pregnant, the clinician should **co-ordinate care with obstetrics** proactively before and during pregnancy and in the puerperium.

MG, myasthenia gravis.

Consensus recommendations

TOPIC **5**

Fatigue and comorbidity management

17 Clinicians should **educate patients** with MG on the **difference between neuromuscular fatigability** and **generalized fatigue**.

18 When patients with MG report generalized fatigue, clinicians should **identify and manage** any **factors contributing to fatigue**, including MG itself, and **refer** the patient to the **appropriate specialists** as needed.

19 Clinicians should **screen patients** with MG at diagnosis and during follow up for **physical or psychological comorbidities** that may be associated with MG or its treatment, and **refer** to their **primary care clinician** or **appropriate specialist** for management.

MG, myasthenia gravis.

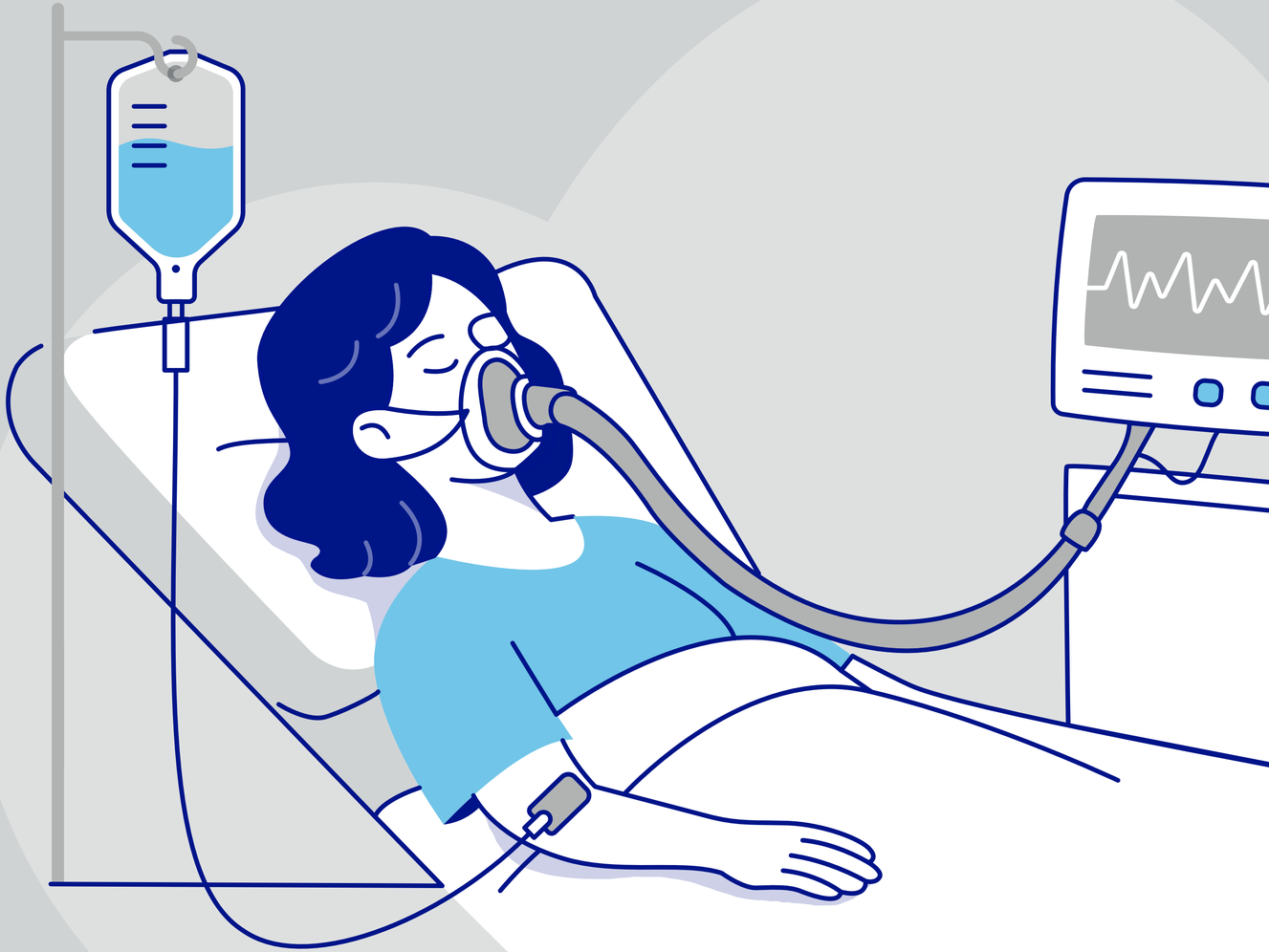
Consensus recommendations

TOPIC **6**

Managing impending crisis and crisis

20 Clinicians should **admit** patients with **impending crisis** to hospital for close assessment of respiratory and bulbar function, evaluate for and **treat precipitating factors**, and **initiate rapid-acting therapy**.

21 Clinicians should **admit** patients with **myasthenic crisis** to an **intensive care** or **step-down unit** (or similar) for appropriate **ventilatory support, treat precipitating factors** and **initiate rapid-acting therapy**.



Disclosures and acknowledgments

Disclosures

P. Narayanaswami has received grant support from the Agency for Healthcare Research and Quality (AHRQ), Alexion Pharmaceuticals, argenx, Cabaletta Bio, Dianthus, National Institutes of Health (NIH), Patient-Centered Outcomes Research Institute (PCORI), and served on advisory boards for Alexion Pharmaceuticals, Amgen, argenx, Cabaletta Bio, Cartesian, Dianthus Therapeutics, ImmunAbs, Immunovant, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine), Merck Serono, Sarepta, UCB, Viridian Therapeutics, and Vor Biopharma; she was a member of the Data and Safety Monitoring Board for Sanofi and is a member of the Data and Safety Monitoring Board for argenx and NMD Pharma. She has received royalties from Springer Nature.

R. Mantegazza has received funding for travel and meeting attendance or advisory board participation from Alexion Pharmaceuticals, argenx, BioMarin, Catalyst, Regeneron Pharmaceuticals, Sanofi and UCB.

C. Barnett-Tapia has served as a paid Consultant for Alexion Pharmaceuticals, argenx, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine), Novartis and UCB. She has received research support from MGNet, Muscular Dystrophy Canada and the US Department of Defense. She is the primary developer of the MGII and may receive royalties for its use.

E. Cortés Vicente receives public speaking honoraria and compensation for advisory boards and/or consultation fees from Alexion Pharmaceuticals, argenx, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine) and UCB.

M. Freimer has served as a paid Consultant for Arcellx, argenx and UCB. She receives research support from Abcuro, Alnylam Pharmaceuticals, argenx, Avidity Biosciences, COUR Pharmaceuticals, Dianthus Therapeutics, Fulcrum Therapeutics, Johnson & Johnson Innovative Medicine, the NIH, RemeGen Biosciences and UCB.

N. E. Gilhus has received consultative or speakers' honoraria from Amgen, argenx, Alexion Pharmaceuticals, Denka, Dianthus Therapeutics, Grifols, Huma, Johnson & Johnson, Lundbeck, Medison, Merck, Novartis, NMD Pharma, Regeneron, Roche, Takeda, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine) and UCB.

A. A. Habib has received research support and/or honoraria from Alexion/AstraZeneca Rare Disease, Amgen, Arcellx, argenx, Cabaletta Bio, Cartesian Therapeutics, COUR Pharmaceuticals, Genentech/Roche, Grifols, Immunovant, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine), Kyverna, Merck, MGNet, Nkarta, NMD Pharma, Novartis, Regeneron Pharmaceuticals and UCB.

J. F. Howard Jr. has received research funding (paid to his institution) from Ad Scientiam, Alexion/AstraZeneca Rare Disease, argenx, Cartesian Therapeutics, Centers for Disease Control and Prevention, Merck EMD Serono, MGFA, Muscular Dystrophy Association, NIH, NMD Pharma, and UCB; honoraria/consulting fees from AcademicCME, Alexion/AstraZeneca Rare Disease, Amgen, argenx, Biohaven Ltd, Cartesian Therapeutics, CheckRare CME, CorEvitas, Curie.Bio, H. Lundbeck A/S, Japan Tobacco Company, Kyverna Therapeutics, Merck EMD Serono, NMD Pharma, Novartis, PeerView CME, Physicians' Education Resource (PER, MJH) CME, Regeneron Pharmaceuticals, Seismic Therapeutics, Toleranzia AB, UCB and Vor Biopharma; non-financial support from Alexion/AstraZeneca Rare Disease, argenx, Biohaven Ltd, Cartesian Therapeutics, Toleranzia AB, UCB and Vor Biopharma.

A. Kostera-Pruszczyk has received consultative or speakers' honoraria from argenx, AstraZeneca, Baxter/Shire/Takeda, CSL Behring, Kedrion, Medison Pharma, Medscape CME, Merck, Novartis, Roche, Sanofi, UCB, and has received non-financial support from Biogen, Kedrion and Sanofi. A. Kostera-Pruszczyk is a member of the European Reference Network for Neuromuscular Diseases – Project ID number 101156434.

M. Isabel Leite is funded by the NHS (Myasthenia and Related Disorders Service and National Specialised Commissioning Group for Neuromyelitis Optica, UK) and by the University of Oxford, UK. She has been awarded research grants from UK associations for patients with myasthenia and with muscular disorders (Myaware and Muscular Dystrophy UK, respectively) and the University of Oxford. She has received speaker honoraria or travel grants from Biogen, the Guthy-Jackson Charitable Foundation, Novartis and UCB. She serves on scientific or educational advisory boards for argenx, Horizon Therapeutics (now Amgen) and UCB.

A. Meisel is an advisor, Consultant, speaker and/or investigator and has received research grants (paid to his institution) and honoraria from Alexion/AstraZeneca Rare Disease, argenx, Axunio, Grifols, Hormosan, Immunovant, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine), Merck, Novartis, Octapharma, Regeneron Pharmaceuticals, Sanofi and UCB. He served as a member of the medical advisory board of the German Myasthenia Gravis Society (DMG e.V.) and Chairman of the Association for Research in Myasthenic Syndromes in Germany (VEMSID e.V.).

M. Pasnoor has served as a Consultant or medical advisor for Alexion, argenx, Catalyst Pharmaceuticals, CSL Behring, Immunovant, Janssen, Momenta (Johnson & Johnson), Takeda Pharmaceuticals Ltd, Terumo BCT, and UCB.

S. Sacconi has nothing to disclose.

N. J. Silvestri is a Consultant/Advisor for Alexion Pharmaceuticals, Amgen, Annexon Biosciences, argenx, Immunovant, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine) and UCB; he is a speaker for Alexion Pharmaceuticals, argenx, Takeda Pharmaceuticals and UCB.

S. Suzuki received personal fees from Alexion Pharmaceuticals, Asahi Kasei Medical and the Japan Blood Products Organization.

A. Uzawa has received honoraria from Alexion Pharmaceuticals, argenx and UCB.

G.I. Wolfe has served as a member of advisory boards or provided paid consultations to Alexion Pharmaceuticals, argenx, Cartesian, Janssen, and UCB; is on speaker bureaus for Alexion Pharmaceuticals and UCB; and has received research support from Alexion Pharmaceuticals, argenx, Immunovant, the MG Foundation of America, Roche and UCB.

K. Utsugisawa has served as a paid Consultant for argenx, Chugai Pharmaceutical, HanAll Biopharma, Janssen Pharmaceuticals (now Johnson & Johnson Innovative Medicine), Merck, Mitsubishi Tanabe Pharma, UCB and Viela Bio (now Amgen); he has received speaker honoraria from Alexion Pharmaceuticals, argenx, the Japan Blood Products Organization and UCB.

Acknowledgments

This study was funded by UCB. The authors acknowledge Julia Stevens, PhD, of Ogilvy Health, London, UK, for editorial assistance, which was funded by UCB. The authors thank Veronica Porkess, PhD, of UCB for publication and editorial support.