

Balancing the unseen:

Myasthenia Gravis, energy, and the access to work

When symptoms fluctuate, support and flexibility become essential.

Autoimmune diseases, like Myasthenia Gravis (MG), impact physical health, work, productivity and daily living. These conditions are often invisible, unpredictable and have fluctuating symptoms, creating uncertainty and making it difficult to plan or communicate, leading to social and workplace challenges.

MG is a rare, chronic autoimmune disease characterized by severe muscle weakness¹.

12

Prevalence: 12 cases per 100,000 people²

48%

of MG patients experience difficulties with brushing teeth and combing hair³.

55%

of people with MG experience difficulty walking⁵.

INVISIBLE, UNPREDICTABLE & CHALLENGING

56%

of people with rare diseases have invisible disabilities³.



MG⁴:
- drooping eyelids & double vision



- difficulty swallowing and speaking



- shortness of breath



- fatigue



- weakness in the arms, legs, neck, and hands

"The best way I can describe MG is like having concrete poured over you—covering, wrapping, pressing you down. It's as if gravity were stronger. At the core, there's this deep, persistent fatigue."

Marta, MG patient.

DAILY LIMITATIONS CAN DRIVE SOCIAL ISOLATION: When work feels like a challenge

11%

of people with MG cannot work or had to retire early⁶.

Around
70%

of people with MG experience limitations in their work and productivity due to their condition⁷.

"Being a patient doesn't make you less valuable at work. You might lose some abilities, but you gain new strengths. Focus on what you contribute, not just on what you've lost."

Matthieu, MG Patient.

41%

of people with MG took a sick leave in the past month⁸.

THE CHALLENGE OF WORKING WITH MG

- Fluctuating symptoms and invisible fatigue make daily tasks unpredictable
- Lack of workplace flexibility and awareness leads to exclusion and early retirement
- Emotional burden of constantly justifying one's condition adds to the stress

WHAT NEEDS TO CHANGE

- **For physicians:** Recognize invisible symptoms early and collaborate with occupational specialists to support work-life balance
- **For policymakers:** Acknowledge MG as an invisible disability in employment law and promote inclusive labor policies
- **For employers:** Foster open conversations, offer flexible roles, and adapt work environments to empower people with MG to thrive professionally

INTERESTED IN LEARNING MORE?

Watch the first episode of 'Dare to Care' – the new webinar series by argenx – to hear expert insights, patient stories, and strategies for balancing energy, work and productivity.

<https://argenx.com/events/dare-to-care>



argenx



1. Hehir, M. K., & Silvestri, N. J. (2018). Generalized myasthenia gravis. *Neurologic Clinics*, 36(2), 253–260. <https://doi.org/10.1016/j.ncl.2018.01.002>
2. Salari N, Fatahi B, Bartina Y, et al. (2021), Global prevalence of myasthenia gravis and the effectiveness of common drugs in its treatment: a systematic review and meta-analysis. *J Transl Med*. (1):516. <https://doi.org/10.1186/s12967-021-03185-7> (sample: 63 studies covering ~1.21 billion people for prevalence estimates).
3. EURORDIS (2025). Rare Barometer Survey: Recognising disabilities and barriers. https://download2.eurordis.org/rarebarometer/RB_DailyLife_FS_Europe_EN.pdf (survey sample: 9,591 individuals living with a rare disease or their family members across 43 European countries, representing 1,643 rare diseases).
4. Hehir, M. K., & Silvestri, N. J. (2018). Generalized myasthenia gravis. *Neurologic Clinics*, 36(2), 253–260. <https://doi.org/10.1016/j.ncl.2018.01.002>
5. Dewilde S., Philips G, Paci S, et al (2023), Patient-reported burden of myasthenia gravis: baseline results of the international prospective, observational, longitudinal real-world digital study MyRealWorld-MG, *BMJ Open* 2023;13:e066445. doi: 10.1136/bmjopen-2022-066445 (MyRealWorld-MG study sample: 2,074 adults with myasthenia gravis in 9 countries). In the MyRealWorld-MG study, 29.3% of participants reported needing extra effort but no rest to brush their teeth or comb their hair, 18.1% required rest periods, and 0.9% were unable to perform these activities. Regarding mobility, 45.7% experienced some trouble walking and 9.4% reported severe difficulty.
6. Dewilde S., et al (2025), A cost analysis of reductions in work productivity for MG patients and their caregivers by symptom severity. *Front. Public Health*. 13:1538789. doi: 10.3389/fpubh.2025.1538789 (MyRealWorld-MG study sample: 1,049 participants—including MG patients and caregivers with productivity and MG-ADL data—from 10 countries.)
7. Lehnerer S, et al. (2022), Burden of disease in myasthenia gravis: taking the patient's perspective. *J Neurol*. 2022 Jun;269(6):3050-3063. doi: 10.1007/s00415-021-10891-1. Epub 2021 Nov 20. Erratum in: *J Neurol*. 2022 Oct;269(10):5688-5689. doi: 10.1007/s00415-022-11290-w. PMID: 34800167; PMCID: PMC9120127 (study sample: 1,660 adults with myasthenia gravis, recruited via the German Myasthenia Association). In the study, among the patients who had previously been employed, 72.6% indicated that MG had limited their ability to work or maintain productivity.
8. Jacob, S., Dewilde, S., Qi, C., Saccà, F., Meisel, A., Palace, J., Claeys, K., Mantegazza, R., Paci, S., & Phillips, G. (2022). Productivity losses for MG patients and their caregivers: Association with disease severity (MyRealWorld-MG study sample: 834 participants from 7 countries).