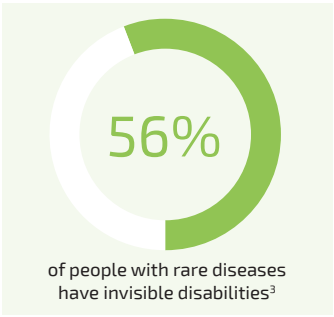
# When your body betrays you, work becomes a battlefield.

**Let's make the invisible visible in healthcare and in the workplace.**

Myasthenia Gravis (MG) and Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) are rare autoimmune diseases that affect mostly working-age adults. Many patients appear fine at first sight but live with physical and emotional exhaustion. The impact on work and autonomy is often misunderstood or ignored.

| Prevalence (Cases per 100,000 people) | 12 MG[1] | 3 CIDP[2] |
|---|---|---|

*When my contract wasn't renewed, it made sense. Who wants to hire someone who's no longer predictable?*
Alejandra, CIDP patient




of people with rare diseases have invisible disabilities[3]

**70%**
of people with MG or CIDP experience limitations in their work and productivity[4,5]

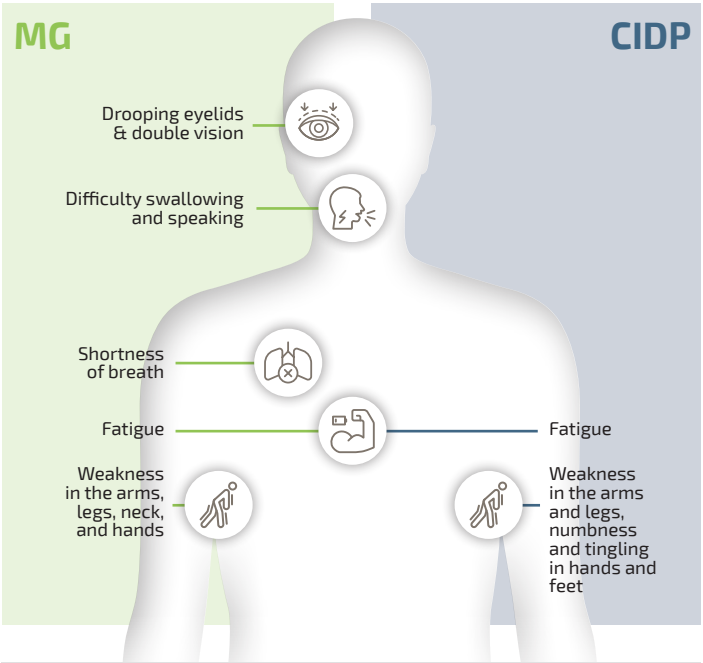
**55%**
of people with MG[6] and 34% of people with CIDP[7] experience difficulty walking

**41%**
of people with MG[9] and 32% of people with CIDP[7] recently missed work

**50%**
of people with CIDP[8] and 48% of people with MG[6] have arm disability

**42%**
of people with CIDP[7] and 11% of people with MG[10] have no full-time employment or had to retire early due to their condition

## MG & CIDP: AUTOIMMUNE DISEASES AFFECTING THE DAILY SOCIAL AND WORK LIFE




*"For me, it's like having muscle aches all the time. When you brush your teeth, it hurts. When you brush your hair, it hurts. When you wash your whole body, it hurts. And that is mentally and physically exhausting."*

Jihane, MG patient

## THE CHALLENGE

- Lack of workplace flexibility
- Insufficient awareness
- Invisibility of symptoms often lead to exclusion from work and care

## WHAT NEEDS TO CHANGE?

- **For physicians:** listen to patients, contribute to early diagnosis, and collaborate with multidisciplinary teams to ensure holistic care.
- **For policymakers:** recognise invisible disability in employment law
- **For employers:** support flexible roles and create inclusive work environments

## LET'S MAKE THE INVISIBLE VISIBLE.

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

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Dare to Care

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1. 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).
2. Lehmann H.C., Burke D., Kuwabara S. (2019), Chronic inflammatory demyelinating polyneuropathy: update on diagnosis, immunopathogenesis and treatment, Journal of Neurology, Neurosurgery & Psychiatry 2019;90:981-987.
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). Data explanation: Among people with rare diseases who have disabilities (80% of all rare disease patients), 70% live with an invisible disability.
4. 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.
5. Adelphi, CIDP DSP (2022-23), PSC, Section A, Q1-6, Section H Q1-6 (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data). Data explanation: According to physician reports, the impact of CIDP on patients' work or productivity was rated as follows: 20% slightly affected, 24% somewhat affected, 19% moderately affected, and 12% extremely affected.
6. 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.
7. Paci, S., Arvin-Berod, C., Brackx, F., Tollenaar, N., Van de Veire, L., Sahar, R., Taylor, Y., Wright, J., deCourcy, J., & Dewilde, S. (2025). Burden of illness and unmet need among patients with CIDP: Results from a real-world survey (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.).
8. Adelphi CIDP DSP (2022-23) PRF, Section E, Q6a/b (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data). Data explanation: 30% of patients reported having symptoms in one or both arms, affecting the following activities: do all zips and buttons, wash and brush hair, use knife and fork together, handle small coins. 16% of patients reported having symptoms in one or both arms, preventing one or two of the above mentioned activities, and 4% of patients reported having symptoms in one or both arms, preventing three or more of the above mentioned activities.
9. 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).
10. 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.)


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