Myasthenia Gravis in daily life:

Finding strength beyond the symptoms

Redefining independence, managing energy and preserving connections

Living with a rare neuromuscular autoimmune disease like Myasthenia Gravis (MG) means facing daily challenges that affect both body and mind. **MG weakens muscles and drains energy, reshaping independence, hobbies and relationships, often in ways invisible to others.** This infographic combines scientific insights and patient voices to highlight how people with MG adapt, preserve their identity, and reclaim quality of life.

DAILY CHALLENGES & LOSS OF INDEPENDENCE

Invisible & variable: MG symptoms often fluctuate daily, making routines difficult to maintain.

59% of people with MG report loss of personal independence[1].

34% of people with MG have difficulty with grooming and selfcare[2].

"I can meet my friends for an afternoon but it's all structured. I have to rest whether I like it or not." Lutgarde, MG Patient.

ENERGY & LEISURE: WHEN FUN BECOMES A LUXURY

Fatigue is a defining feature of MG, limiting hobbies, social life and travel.

80% of people with MG experience limitations in leisure activities and hobbies[1].

84% of people with MG must structure social plans[1].

"Planning vacations is always quite demanding because I always prepare backup plans, given the unpredictability of MG. But I don't let that discourage me and still try to go on the vacation of my dreams." Marta, MG Patient.

EMOTIONAL TOLL & MENTAL HEALTH

Living with MG impacts mental health as much as physical health:

- Cycles of anxiety, grief, frustration.
- Shame, self-isolation and identity loss.
- Emotional highs and lows tied to energy levels.

54% of people with MG feel depressed or overwhelmed[1].

77% of people with MG feel frustrated[1].

Even after 7 years I sometimes feel like I'm still on day one, emotionally speaking. I can still get mixed up in this storm of feelings and still feel anxious and frustrated." Alisa, MG Patient.

RELATIONSHIPS & ROLES: NAVIGATING SOCIAL IMPACT

MG can reshape dynamics in families, friendships and romantic relationships.

Honest conversations, setting boundaries, and peer support help maintain emotional connection.

70% of people with MG limit their social activities due to their condition[1].

60% of people with MG struggle to meet family needs[1].

KEY TAKEAWAYS

- **FOR THE PATIENT:** Accept help, but fight to retain independence & plan energy, not just time, to enjoy life.
- **FOR THE CAREGIVER:** Encourage independence while offering support.
- **FOR HCPS:** Offer emotional support alongside medical care & collaborate on life-oriented treatment plans.

WANT TO DIVE DEEPER?

Watch the second episode of the Dare to Care webinar series to hear patients stories and expert insights on living fully with autoimmune diseases.

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

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1. Dewilde S., Philips G., Paci S. et al. (2023), The Burden Patients with Myasthenia Gravis Experience in Terms of Breathing, Fatigue, Sleep, Mental Health, Discomfort and Usual Activities in Comparison to the General Population Adv Ther 41, 271–291 (2024). (MyRealWorld-MG Study sample: 2,074 adults with myasthenia gravis in 9 countries). Data explanation: 35.7% of people with MG report having 'somewhat' lost their personal independence and 23.9% reports having lost it 'very much' (those two put together makes 59.8%); 46.4% of people with MG report being 'somewhat' limited in their ability to enjoy hobbies and fun activities and 33.7% report it to be 'very much' (those two put together makes 80.1%); 44.3% of people with MG report to 'somewhat' have to plan around their condition and 40% reports 'very much' (those two put together makes 84.3%); 52.3% of people with MG report feeling 'somewhat' frustrated and 24.2% reports 'very much' (those two put together makes 76.5%), 45% of people with MG report feeling 'somewhat' depressed and 11.3% reports 'very much' (those two put together makes 56.3%), 42.3% of people with MG report feeling 'somewhat' overwhelmed and 13.3% reports 'very much' (those two put together makes 55.6%); 41.6% of people with MG report to 'somewhat' have to limit their social activity and 28.3% reports 'very much' (those two put together makes 69.9%); 39.5% of people with MG report to 'somewhat' struggle to meet their family needs and 20.6% reports 'very much' (those two put together makes 60.1%) DOI: https://doi.org/10.1007/s12325-023-02704-w

2. Dewilde S., Philips G., Paci S. et al. (2022), Patient-reported burden of myasthenia gravis: baseline results of the international prospective, observational, longitudinal real-world digital study MyRealWorld-MG (Study sample: Baseline results of 841 adult patients with MG from seven countries: USA, Japan, Germany, UK, Italy, Spain and Canada) Data explanation: 66.4% of people with MG report having 'no problems' with performing their personal grooming needs and self-care, this leaves about 34% of people living with MG that report having 'mild' to 'extreme' problems. DOI: https://doi.org/10.1136/bmjopen-2022-066445