

The Unseen Experience of Living with **Myasthenia Gravis (MG)**

Myasthenia gravis (MG) is a rare, chronic, autoimmune, neuromuscular condition where the body's immune system mistakenly targets the connections between nerves and muscles, leaving patients with unpredictable, fluctuating symptoms such as fatigue, muscle weakness and difficulty breathing and swallowing.¹⁻⁴

A 2018 survey* showed that 50% of MG patients feel their disease prevents them from living a full life, while 39% do not feel in control of their condition on most days.⁵

Unpromoted reporting on social media+ sheds some additional light on the experiences of people living with MG, who currently feel somewhat invisible.⁶

A Failure To Be Recognized

People living with MG report frequent misdiagnoses and confusion related to their condition, reflecting the broad and often unpredictable symptoms experienced



14 is the number of different conditions that MG can be misdiagnosed as, including stress, fibromyalgia, and diabetes⁶

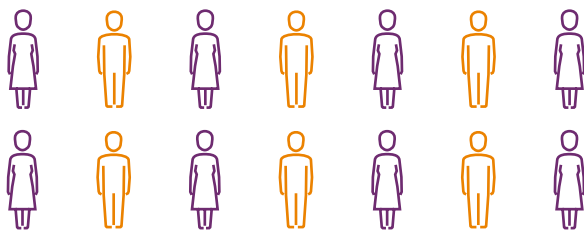
49% of these misdiagnoses are made up of mental health conditions⁶

3% Yet, just 3% of online discussion is attributed to mental health-related symptoms in relation to MG⁶

Patients are left feeling **exasperated** and **misunderstood** – their physical symptoms are being **overlooked**, leading to misdiagnoses focused on mental health.

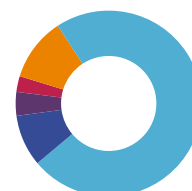
A Lack Of Adequate Support

Patient confusion is compounded by a complex specialist landscape, with no clear support system to rely on



MG patients reported contacting over **14 different specialists** at some point in their care pathway⁶

Whilst **73%** of patients mention being referred to neurologists, **1 in 10** are referred to less relevant specialists such as rheumatologists (2%), psychologists (2%), ENT specialists (1%), pulmonologists (1%), psychiatrists (1%) and paediatricians (1%)⁶



Neurologists	73%
Primary Care Physicians	9%
Ophthalmologists	4%
Emergency Carers	3%
Other	11%

Specialists mentioned (% of total)

MG patients often traverse a complex pathway through the healthcare system, making it **more difficult for patients and clinicians to interact consistently and productively.**

High self-sufficiency



Patients living with MG have learnt to cope with their condition, with many self-educating and adapting their everyday life rather than relying on professional support

Patients describe deploying nearly **30 different coping mechanisms** to manage the physical and psychological burden of disease⁶



Self-education (**34%**) was the most frequently mentioned coping mechanism⁶

Patients make **practical adaptations** every day to cope with the muscle weakness and overall fatigue associated with MG

These include:



hygiene



dressing



activity



mobility,
working



finances



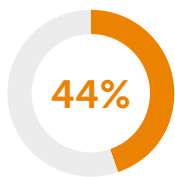
caring
duties

Support from within the MG patient community is strong, but patients may nevertheless feel **isolated and alone**, struggling to cope with the unpredictable impact of their disease.

A Need To Feel Truly 'Seen'



Patients are driven by hope for greater recognition from others and a sense of personal acceptance of their disease.



The number one driver of patient happiness is recognition of MG as a significant condition⁶



Although there is potential in the development of new treatments, patients are twice as likely to focus on **recognition** and **acceptance** as they are to have hope for a better future

There is a clear need for patients living with MG to be **recognized, understood, and taken seriously**, for them to feel adequately supported in their everyday life.

Helping Patients Feel Truly 'Seen'

More needs to be done to help MG patients feel **acknowledged, understood and supported**.

This MG Awareness Month, **join the conversation** to share your experience, raise awareness and **drive action to help accelerate progress**.

Research methodology: Social listening was conducted in the US, UK, France, Germany, Spain and Italy. Relevant unprompted patient / caregiver comments were identified and analyzed in local language from public platforms and forums.



References:

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3. Conquer Myasthenia Gravis. What is MG? <https://www.myastheniagravis.org/about-mg/what-is-mg/> (Last accessed: 29th June 2021).
4. British Medical Journal (BMJ). Best Practice Myasthenia gravis. <https://bestpractice.bmj.com/topics/en-gb/238> (Last accessed: 29 June 2021)
5. UCB Data on file - Ra Pharma market research 2020 see the true impact of gMG. Poster.
6. UCB Data on file - Real Chemistry 2021 the MG patient experience.

*Completed by UCB in partnership with the Myasthenia Gravis Foundation of America (MGFA)
+ Identification and analysis of social media reporting of people living with MG across the United States (US), France, Germany, Italy, Spain and the United Kingdom (UK)