YOU HAVE JUST BEEN
DIAGNOSED WITH
MYASTHENIA GRAVIS (MG)

NAVIGATING WORK AND TALKING ABOUT YOUR DIAGNOSIS

EuMGA
European Myasthenia Gravis Association

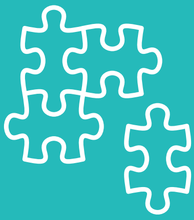
YOUR DIAGNOSIS

It is important to **understand what MG means** and the implications of the treatment you have just been prescribed by your neurologist. **Do not hesitate to read** up on your condition from reliable sources.

Apart from **your neurologist**, **your primary care provider** can help answer your questions and **your local/national MG patient association** is a trustworthy source of information. The more knowledge you have, the stronger you will feel. Furthermore, making contact with **other people living with MG (PLWMG)** means that no one needs to feel alone with their myasthenia. **Family and carers** can also support you.

Whether your diagnosis took years or came as a complete shock, **you will probably experience a complex range of emotions**. People react very differently to their diagnosis, so it's important to remember that there is no right or wrong way to experience your life with MG.

YOU ARE NOT YOUR DIAGNOSIS



Building an identity is a lifelong process, and it can be especially challenging when your body's responses become unpredictable. It's important to understand that **you are not your diagnosis** but MG, like all chronic health conditions, **will become part of you**, along with everything else that contributes to defining who you are.

HOW AND WHEN TO TALK ABOUT YOUR DIAGNOSIS OF MG

It is not always *necessary* to disclose your diagnosis, but at some point, a question PLWMG (People Living With MG) might have to answer is **how and when to talk to friends, classmates, or work colleagues about MG**.

WHEN TO TALK ABOUT IT

If you have **a profession or hobby where your physical condition can directly and negatively impact others**, it is **important to inform these people as soon as possible**.

Otherwise, you are at leisure to decide to whom you tell, when to start the conversation, and how much you want to disclose. Finding the right moment can be difficult, but it’s worth noting that the physical effects of myasthenia gravis are sometimes visible to others earlier than you might think. In order to manage this conversation in the best possible way, it is advisable to **share your diagnosis before your work colleagues, teammates, or fellow students start speculating about your health**, which can lead to misunderstandings.

HOW TO TALK ABOUT IT

No matter how you feel about talking about yourself, MG can bring such significant changes to your life that **conversations about different needs** become necessary. How you talk about your condition **depends on your personality, on your relationship with the person in question** (friend, teacher, classmate, supervisor, or colleague etc.), but also on the culture of understanding around you.

To remain in charge of the conversation and how much or how little you want to say, **some PLWMG have found the automatic responses below helpful** to answer awkward questions:

- “I have a rare muscle condition.”
- “I’ve been diagnosed with an autoimmune disease, and it’s still new to me.”
- “My condition is changing, but I’m managing.”
- “It’s a bit difficult right now, but I’m getting good support from…”

> ***“The people who loved you before or were your friends, will go on, otherwise they were not your friends or lovers. For new relationships, they will have to begin with the whole package!!! Please do not hide your problems, it leads to fake relationships.”***
>
> ***-Marguerite Friconneau, living with MG, France***

HOW TO TALK ABOUT IT: THE WORKPLACE

In the workplace, it is advisable to **inform your supervisor and the management/human resources department** before or at the **same time as your colleagues**, and in all cases, this information should come directly from you.

HOW TO TALK ABOUT IT: ROMANTIC RELATIONSHIPS

If you are getting to know someone, you may have thought about how much or how little you want to disclose about your diagnosis and its implications, and there is no formula for this. If a date becomes more serious, you will have to decide whether you want a relationship to start with omissions.

> ***“Others approach dating differently. I prefer to take things lightly at first and let the connection unfold before getting into heavy conversations. Sometimes I just want to enjoy the moment—and for me, that’s about emotional timing, not hiding anything.”***

-Alisa Matei, living with MG, Romania

HOW TO TALK ABOUT IT: POTENTIAL REACTIONS

For most people the term “Myasthenia Gravis” is either completely unknown or may evoke specific images that don’t necessarily align with how you see yourself or your future needs. It can therefore be helpful to explain the implications of your condition for you personally. **Be prepared for questions** and view them as a natural and friendly sign of interest in who you are and how you live.

It is also worth remembering that the people you share your diagnosis with might be **surprised or deeply affected by your news**, and this may also be reflected in their initial reactions. They, too, might need time to process the new information.

ADAPTING TO LIFE WITH MG

Some individuals with MG gradually become more dependent on others and asking for help can be a challenge to your self-image. Do accept help when offered: having somebody to lighten your load and taking the opportunity for a rest is invaluable.

> ***"In general, no one should feel limited in their career choices: every job should be accessible. However, when living with a disability and experiencing residual symptoms or fluctuations despite treatment, it might be useful to consider roles that allow for flexibility and accommodate your health needs."***

-Maya Uccheddu, Living with MG, Italy

ADAPTING AT SCHOOL

Transitions, such as moving from primary school to secondary education or starting higher education, can be both exciting and challenging. You may experience uncertainty about fitting into new environments and social groups, and the formal and informal support you will receive. You might also wonder how to explain your health condition to new classmates or how to navigate the school's accessibility facilities. It is therefore important to prepare yourself for these moves.

"Some universities or educational institutions provide support and resources for students with different kinds of disabilities or other specific needs via centers for assistance to students with specific needs. These centers aim to ensure that all students, regardless of their disabilities, have equal access to education and can fully participate in university life."

-Marketa Ondrackova, living with MG, Czech Republic

ADAPTING AT WORK

Individuals with a diagnosis of myasthenia gravis can often maintain successful employment, although the impact of the condition on work capabilities may differ significantly among individuals. How the condition affects everyone's job situation varies greatly.

Employees are encouraged to discuss **potential reasonable accommodation**, tailored adjustments with their employer as needed. A reasonable accommodation refers to any necessary and appropriate modification or adjustment, not imposing a disproportionate or undue burden, where needed in a particular case, that enables persons with disabilities to perform their job on an equal basis with others. Possible reasonable accommodation, may include working remotely, flexible scheduling, job restructuring, access to assistive technology, social distancing measures, and reserved parking spaces. These modifications can help employees with myasthenia gravis to better manage their responsibilities in the workplace.

> ***"I think it is important to have in mind a list of career opportunities that are more MG-friendly such as creative or intellectual jobs [...] or the NGO sector who are more understanding with disabilities [...] and allow a better work-health balance."***
>
> ***-Alisa Matei, living with MG, Romania***

If work does become impossible, disability benefits might be an option. If myasthenia gravis significantly impairs your ability to work, you can seek local regulations regarding disability benefits. For those engaged in regular employment, support is generally available if the ability to perform your job is greatly affected. National legislation, such as the Assistance Acts in Employment (where applicable), may offer additional forms of assistance, as may collective agreements between your union and your employer.

Depending on your country of residence, aid might be available through:

- The Act on Compensation for Disabled Persons in Employment
- The Act on Active Employment Initiatives
- The Act on Sickness Benefits

MG might lead you to rethink your career and look for work opportunities that prioritize your comfort and health.

“In my opinion, state care in our country should also be directed at people with rare diseases. Such a legislative framework is currently lacking. Unfortunately, the disease can deprive you of many things.“

-Anita Daneva, Living with MG,
Миастения Гравис-Фондация, Bulgaria

CHALLENGES AND HOW TO OVERCOME THEM

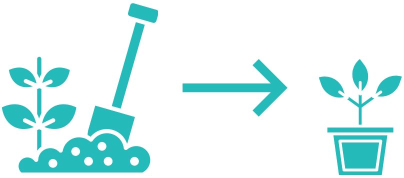
Having MG can also positively influence your identity. You might discover strengths you didn’t know you had and gain a deeper understanding of yourself and who you want to be. You may also develop a new perspective on what truly matters in life.

”Whatever comes into your life, life remains worth living.”

- Lut Allard, living with MG, Belgium

Living with MG presents many challenges and this is also true with continuing hobbies. Many PLWMG have found creative ways to preserve what they love by adapting the activity without losing its benefits.

> ***"For example, if you used to care for a large garden but now find it physically exhausting, you can try container gardening instead."***
>
> ***-Alisa Matei, living with MG, Romania***

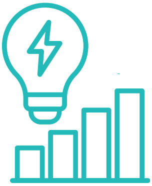


Here are our top tips and considerations for how to live well with MG:

- Understand your stress triggers: identify what causes you stress and where possible, prepare for the circumstance.

- Avoid overcommitting: don't overload yourself with too many activities. While some medication (such as steroids) can provide a temporary sense of energy, your body and muscles need time to recover.

> ***"It is important to plan activities like planning a budget... can we call it 'energy budget'?"***
>
> ***-Matthieu Lusignan, Living with MG, France***



- Implement project management techniques:

“Break down large tasks into smaller more manageable chunks and prioritize activities based on your energy levels throughout the day.”

-Gisele von Buren, caregiver, Switzerland

“There are ergonomic chairs, cushions, footrests and computer mice that help maintain good posture and support to your muscles and joints throughout the day at work.”

- Use Digital Tools such as Voice to Text or others based on AI which can support everyday tasks for PLWMG
- Choose comfort:

“Taking adequate breaks, shortening the workday, and resting the eyes regularly during screen work can all help. Again individual approaches are key. Sleep and rest are extremely important and flexible working hours have been wonderful, and the possibility to work remotely has been invaluable.”

-Niina Lehto, living with MG, Finland

This guide is not comprehensive. If you were recently diagnosed, make sure you get all the necessary information from your patient association, for example:

- contraindicated medications
- myasthenia gravis and diet
- managing myasthenia gravis during temperature changes etc.

AKNOWLEDGEMENTS

We would like to extend our heartfelt thanks to everyone who participated in this project.

Our sincere gratitude also goes to Gloria Felicioli (expert in social security and employment matters), from the Italian Myasthenia Association AIM, for her valuable consultancy in shaping this guide and for developing the section dedicated to employment. Her insights have made this document more practical and accessible for facing the complexities of work and chronic illness.

A special thank you to Alisa Matei, from the Asociatia Nationala Miastenia Gravis Romania, and a member of the EuMGA Young Council, whose input led to the creation of this English version, making it accessible to the entire European MG community.

For coordinating the overall process and for compiling and organizing the contributions from all participants: Maria Bonaria (Maya) Uccheddu, Italian Myasthenia Association AIM.

For contributing to the writing of specific sections:

- Gisele von Büren, caregiver
- Niina Lehto, living with MG, Finnish MG Association, Finland
- Anita Daneva, Living with MG, MG Bulgarian association, Миастения Гравис - Фондация, Bulgaria
- Marguerite Friconneau, living with MG, AFM Telethon, France,
- Matthieu LUSIGNAN, living with MG, AFM Telethon, France
- Lut Allard, EuMGA, Belgium
- Marketa Ondrackova, living with MG Mygra-CZ, Czech Republic

and to the all EuMGA board for providing valuable supervision and guidance throughout the project.

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A Voice for MG

This booklet is part of "A Voice for MG", a campaign by the European Myasthenia Gravis Association (EuMGA) which features the voices of individuals sharing about life with Myasthenia Gravis from people diagnosed with MG, caregivers, healthcare professionals, and individuals impacted by MG.

Learn more about Myasthenia Gravis and employment here:

ALEXION AstraZeneca Rare Disease
AMGEN
argenx
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MERCK
NMDPHARMA NEUROMUSCULAR DISORDERS
NOVARTIS
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EuMGA
European Myasthenia Gravis Association

The roots of EuMGA (European Myasthenia Gravis Association) date back to 1978, when the first European MG contacts were established under EAMDA. Over the years, dedicated volunteers from across Europe worked together to share knowledge, support patient advocacy, and improve treatment awareness—culminating in the publication of the European MG Handbook.

Today, EuMGA is proud to be the leading voice of the myasthenia gravis community in Europe, and our mission is to raise awareness and foster collaboration among European Myasthenia Gravis National Associations across Europe. EuMGA's mission is to raise awareness and foster collaboration among European Myasthenia Gravis National Associations. Our goal is to help individuals and their families affected by myasthenia gravis by offering support and raising awareness about the condition.

Join EuMGA in our efforts to make a positive change in the lives of those impacted by this condition.

Visit eumga.eu to learn more.

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