

Myasthenia Gravis

Patient Journey



European Reference Network
for rare or low prevalence complex diseases



Network
Neuromuscular Diseases (ERN EURO-NMD)

STEP 1 Recognizing the first symptoms

They are variable, fluctuating throughout the day or over several days!

Due to their variability, symptoms can be difficult to interpret and link to a known disease. From problems with simple movements such as combing your hair, difficulty walking, chewing or swallowing, as well as articulating words when speaking for long periods, double vision, and drooping eyelids, neck weakness or even shortness of breath to general fatigue, the combination of symptoms can vary from time to time and from person to person. Hot weather tends to make you feel worse, and you usually feel stronger after resting. You may also feel misunderstood, unable to participate in social and everyday activities, anxious, frustrated when faced with events you do not understand.



The diagnosis is a very long process

STEP 2 Getting the right diagnosis

The general practitioner has to ask himself these simple questions:

Could this be a rare disease? Could this be Myasthenia Gravis?

Due to the fluctuating nature of the symptoms, you may not be able to see your doctor at their worst. In this case, it is useful to have someone who can make a short video of what is happening to show your doctor.

Your general practitioner should consider asking for a measurement of the antibodies associated with Myasthenia Gravis (anti-acetylcholine receptor (AChR) and anti-muscle-specific-tyrosine kinase (MuSK) antibodies). These antibodies are the cause of the disease and block communication between nerves and muscles. Another important test is electromyogram (EMG) which involves repetitive stimulation of a nerve and is used to detect fatigability. The symptoms of Myasthenia Gravis may overlap with those of other more common diseases and can occur at any age.

Myasthenia gravis patients should mainly (only) be followed by a specialist.

To care for Myasthenia Gravis patients can be challenging, especially for a general practitioner.

It is important to establish good cooperation/communication between the general practitioner, the specialist and the patient.

General practitioners and patients should find out about neurologists that are specialized in the condition. Neurologists in medical networks may be more aware of new treatments and may be used to manage exacerbations. Finally, patient organizations also have an important role to play in education and sharing good practice.

The best course of action is to get the patient to a specialist as soon as possible, ideally a neurologist or an ophthalmologist if the initial symptoms are ocular. The aim of a prompt diagnosis is to get the patient into remission or near remission as quickly as possible.



- Myasthenia Gravis is not a curable disease BUT effective treatments can reduce the symptoms of the patients to a minimum.
- Patients are faced with an invisible, unpredictable, potentially life-threatening disease.
- Treatments do not cure; they just help for a while. It's a day by day, hour by hour, really a never-ending story.

- Patients need to know how to monitor their symptoms and communicate with healthcare provider and other patients.
- Patients should be aware of the effects and side effects of the treatments.
- Some medications are contraindicated in Myasthenia Gravis and when a new medication is prescribed, the patient should ask their healthcare professional if it is safe or have a list of contraindicated medications.

- Patients must have a card or document that identifies them as having Myasthenia Gravis, especially for emergencies.
- Patients need to be heard and believed.
- Social support such as a psychosocial worker, may be needed to ease the burden on the patient.

STEP 3 Follow-up the disease

Myasthenia Gravis is a never-ending story.

This is a particularly challenging management, as things will change over time, requiring constant readjustment. It includes potential reactions to certain drugs but also to more trivial products (such as quinine in sodas). You may find the right doctor (or treatment) at the moment, but this can easily change over time.

For these reasons, steps 2 and 3 can be seen as cyclical.

STEP 4 Getting the right treatment, including psychosocial support

«What you are entitled to as a patient; what are your rights?»

Patients live with a heavy burden that affects all aspects of their lives

They may have to give up their work, as do their carers, who are usually their partners or close relatives, resulting in a greater financial burden. Social support may be needed, and patients need to be informed about the existing networks available in their country. Patients' organizations have a special and important role to play in lobbying national and international authorities for better living conditions at home and abroad.

Equal rights and conditions of care, at least in Europe, need to be achieved.

