



**University
Hospitals Sussex**
NHS Foundation Trust

Myasthenia Gravis

Orthoptic Department

Patient information

What is this information about?

This information is about myasthenia gravis (MG).

It explains:

- what myasthenia gravis is
- the things that can cause MG
- the symptoms that MG can cause in the eyes and other parts of the body
- how MG may be diagnosed and treated
- how your MG may change and affect you over time (your prognosis if you have MG).

Why have I been given this information?

You have been given this information because you, a family member, or someone you are a carer for has been diagnosed with MG. Reading this information can help you to know what to expect from the condition and any treatment you may have for it.

What is myasthenia gravis?

MG is an 'autoimmune' condition that affects nerves and muscles (a neuromuscular condition). It causes weakness of the muscles which control some movements.

Autoimmune conditions are caused by the body's immune system mistakenly attacking healthy body tissue instead of fighting infections.

In MG the body produces antibodies that block the messages that pass from the nerve endings to the muscles. When this happens, your muscles do not contract (tighten-up) as well and become weak.

This weakness happens in the muscles that you must make a deliberate choice and effort to move. These are called the 'voluntary' muscles. These are different to muscles such as your heart muscles or muscles that you use for breathing that work without you having to think about moving them.

The weakness gets worse the more you use the muscle.

MG can cause different symptoms throughout the body or for many people only in their eyes.

What are the symptoms of MG that people may get throughout the body?

MG can cause difficulty with things such as:

- speech
- swallowing
- breathing
- facial expressions (such as smiling or frowning)
- moving your arms and legs. For example, raising your arms above your shoulders or walking more than a short distance.
- holding your head upright.

What are the symptoms of MG that people most often get in their eyes?

The symptoms of MG that people most often get in their eyes are:

- double vision (diplopia)
- drooping eyelids (ptosis).

What might trigger my symptoms of MG or make them worse?

People may find that their symptoms are worse when:

- they are tired (fatigued). For example, at the end of the day.
- they use an affected muscle for longer periods or work it harder.

Hot weather, infections, stress, or menstrual periods may also trigger symptoms.

How many people are affected by MG?

Myasthenia gravis affects about one person in every 10,000 in the UK.

It can develop at any age, but is more common:

- in women under the age of 40
- in men over the age of 60.

There has been an increase in the number of people over 60 years old who develop MG in recent years.

How is MG diagnosed?

If you visit the orthoptist because you have double vision or droopy eyelids caused by muscle weakness that:

- gets worse when you are tired
- comes and goes or gets better and worse (is variable)

there is a chance that MG is the cause.

The ophthalmologist will arrange for you to have blood tests which can tell if MG is causing your symptoms. You may also need to have a scan of your chest. This is to check your thymus gland or for other problems which can give you similar symptoms to MG. MG can be related to issues with the thymus gland.

What treatment for MG might I get?

The usual treatment for MG is taking a type of medicine called an 'acetylcholinesterase inhibitor'. These improve the connections between nerve endings and muscles. The doctor who prescribes them can tell you more about how they work. Do ask if you have any questions about them.

If you have a tumour in your thymus gland you may have an operation to remove it. You may also need medical treatment afterwards.

Before you can have these treatments, you will need to be sent (referred) for an appointment with a neurologist (specialist in brain and nervous system conditions) or endocrinologist (specialist in hormone and gland conditions). They can assess your condition and decide what treatment is right for you.

What treatment might I get for the eye symptoms of MG?

The eye symptoms in MG are different for everyone. A person's symptoms and how bad they are may differ at different times. This can make them difficult to relieve.

Double vision may be relieved by:

- the eyelid drooping and covering the eye so that you do not notice that you have double vision
- using a prism (a special lens in your glasses) to 'join up' the double vision. As the symptoms of MG vary from time to time this may not always work well.
- using a patch over one eye. This may work better for longer-term relief than using a prism
- taping eyelids open. We may need do this for a time if you are unable to open one or both eyes at all. If your eyelids are taped open, you may need to use a gel or drops in your eye to protect its surface.

What might happen to my MG and symptoms in the future (what is the prognosis for people with MG?)

There is not a cure for MG, but people:

- often find that their symptoms are better once they are taking medicine to treat it or have had an operation to remove their thymus gland
- may have long periods of time when their symptoms do not get worse
- may find their symptoms get better or even go away (they go into long-lasting remission).

Who can I contact if I have other questions about MG and its treatment or would like further information or support?

Please contact your orthoptist:

St Richard's Hospital

01243 831499

Southlands Hospital

01273 446077

Sussex Eye Hospital Orthoptists

01273 664872

Princess Royal Hospital Orthoptists

01444 441881 Ext. 68305

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**This leaflet is intended for patients receiving care
in St Richard's, Southlands, Sussex Eye Hospital**

Ref. number: 2231.2 ORT16
Publication date: 03/2026
Review date: 03/2029

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