Notes:

This pamphlet is for educational purposes only. It is not intended to replace the advice or professional judgment of a health care provider. The information may not apply to all situations. If you have any questions, please ask your health care provider.

Find this pamphlet and all our patient resources here:
https://library.nshealth.ca/Patients-Guides

Connect with a registered nurse in Nova Scotia any time:
Call 811 or visit: https://811.novascotia.ca

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Patient & Family Guide
2025

Myasthenia Gravis (MG)

nova scotia health
www.nshealth.ca

Resources

Community resources and advocacy groups can help to support you and connect you with others who are living with MG.

Myasthenia Gravis Society of Canada

› https://mgcanada.org

Myasthenia Gravis Foundation of America

› https://myasthenia.org

Muscular Dystrophy Canada

› https://muscle.ca

Myasthenia Gravis News™

› https://myastheniagravisnews.com

Myasthenia Gravis Facebook Group (Canada)

› www.facebook.com/groups/MyastheniaGravisCanada/

Myasthenia Gravis Friends

› www.facebook.com/groups/MyastheniaGravisFriends/

- Get enough rest.
- Avoid getting too hot. This may make your symptoms worse.
- Keep your vaccines up to date. People who have MG can have problems if they get influenza (the flu) or pneumonia (lung infection). Ask your primary health care provider which vaccines you need.
- Think about joining a support group for people who have MG. Ask your primary health care provider how to find a support group.

Call your neurologist right away if you have any of these symptoms:

- New weakness in an arm or a leg
- Weakness in an arm or a leg that is getting worse
- Trouble breathing or needing to take breaths in the middle of talking
- Trouble swallowing or choking on food or drinks
- Feeling sick after starting medication for MG
- You cannot lift your head up from a pillow while lying down

Myasthenia Gravis (MG)

What is myasthenia gravis (MG)?

- MG is a chronic (ongoing) neuromuscular disorder. Neuromuscular disorders affect the nerves or muscles, or the communication between them.
- MG causes weakness in your voluntary muscles (muscles you can control). This weakness gets worse with activity, and better with rest.

What causes MG?

- MG is an autoimmune disease. Autoimmune diseases cause your immune system to attack your body by mistake.
- Normally, antibodies (blood proteins) fight foreign (from outside your body) substances and cause an immune response in your body.
- MG causes your immune system to make abnormal antibodies. These abnormal antibodies stop the muscles from reacting to the nerve signals. This causes muscle weakness.
- The cause of MG is not known.

Who is at risk for MG?

- MG can affect anyone, but it is more common in:
  - Females between 20 and 30 years old
  - Males over 50 years old
- MG can develop after certain cancer treatments. This is **not** common.
- MG is **not** contagious (passed from person to person).
- **In rare cases**, MG can be hereditary (passed down from family members, like a parent to their children).

What are the symptoms of MG?

- The first symptom of MG is often weakness of the eye muscles. This can cause droopy eyelids (ptosis) or double vision (diplopia).
- Muscle weakness may happen over a few days or weeks. It may stay the same for a long time or it may come and go.
- Weakness is often worse at the end of the day and usually gets better with rest.

What can I do to help my MG?

- Take your medications as told by your primary health care provider.
  - **Call your primary health care provider if you think you are having a problem caused by your medication.**
  - If you have trouble swallowing your medication, talk to your primary health care provider about other ways to take it.
- Some medications can make MG symptoms worse.
  - If you get a prescription for a new medication, ask your primary health care provider or pharmacist if it is safe to take if you have MG.
  - **If your symptoms get worse after starting a new medication, tell your primary health care provider right away.**
- If you have double vision, talk with your primary health care provider about wearing an eye patch.
- Eat healthy meals. If you get tired while chewing:
  - Rest between bites.
  - Try foods that are chopped, cooked, or softened.
  - Eat smaller meals throughout the day instead of 2 or 3 bigger meals.

How does MG affect pregnancy?

- Pregnancy may cause you to have MG symptoms for the first time. This is rare.

If you have MG:

  - Your symptoms may get worse during the first trimester (first 12 weeks) or right after you give birth.
  - Sometimes, MG symptoms may get better during your pregnancy.
  - You can pass antibodies to your baby. This can cause your baby to have problems with breathing and feeding for up to 1 to 2 months. Talk with your health care team about this while you are pregnant.

- Some treatments for MG are not safe for pregnancy or breastfeeding/chestfeeding. Your primary health care provider or pharmacist will talk with you about this, if needed.

- You may have 1 or more of the following symptoms:
  - Droopy eyelids
  - Blurred or double vision
  - Trouble chewing
  - Trouble swallowing
  - Trouble talking (voice may be soft or hoarse, or you are slurring your words)
  - Trouble breathing
  - Weakness in arms, legs, or neck
  - Trouble walking or climbing stairs
  - Trouble holding your head up
  - Cannot raise your arms over your head
- MG symptoms can range from mild to severe (very bad). Each person's symptoms are different, and symptoms may change at any time.
- Most people being treated for MG live full, active lives and MG does not affect how long you live.

Myasthenic crisis

- Up to 1 in 5 people with MG experience a myasthenic crisis. A myasthenic crisis is when the muscles that control your breathing become weak. This may cause you to have trouble breathing and swallowing. **This is an emergency. Call 911 or go to the nearest Emergency Department right away.**
- You may need:
  - A respirator or other treatments to help you breathe
  - A feeding tube to help you swallow while you recover

How is MG diagnosed?

If your primary health care provider (family doctor or nurse practitioner) thinks you have MG, they may request the following tests:

- **Neurological exam:** This exam tests your muscle strength and how long you can do certain tasks.

- Intravenous immunoglobulin (IVIG) is the most common rapid immunotherapy used for MG. IVIG is antibodies from the plasma (part of the blood) of donors. It is not known how IVIG works in MG, but it is thought to block or lower how many harmful antibodies are made.
- Plasmapheresis (plasma exchange) removes antibodies from your plasma.
  - Some of your blood is taken through an intravenous (I.V.) needle put into a vein in your arm.
  - The blood passes through a machine that filters and separates it into plasma and blood cells.
  - The plasma, including antibodies, is taken out and replaced with a solution called a **plasma substitute**.
  - The blood is then put back into your body through the I.V.

Thymectomy

- This is a surgery that takes out the thymus gland. This can help some people with MG long-term. How much a thymectomy will help is different for each person.

- Other medications that help to lower the making of antibodies long-term include:
  - Azathioprine (Imuran®)
  - Mycophenolate (CellCept®)
  - Cyclophosphamide
  - Rituximab

  Newer medications include:
  - Efgartigimod
  - Eculizimab
  - Ravilizumab

  These medications take longer to be fully effective, so they are often used with prednisone.

Rapid (fast) immunotherapies

- These medications are used:
  - for a short time, if your symptoms suddenly get worse.
  - in people who have not been helped by other medications.
- These medications start working quickly (within days), but they only help for a few weeks.
- They may be used in combination with the treatments listed on pages 6 and 7.

- **Blood tests:** A blood sample is taken to look for antibodies. You most likely have MG if you have the following antibodies:
  - Acetylcholine receptor (AChR)
  - Muscle-specific kinase (MuSK)
  - LRP4

  You may still have MG even if you do not have these antibodies.
- **Nerve conduction studies and electromyogram (EMG):** An EMG uses electricity to check how your nerves and muscles are working. For more information, see pamphlet 0335, *Electromyogram (EMG) – QEII*:
  - Visit: www.nshealth.ca/patient-education-resources/0335

  or

Scan the QR code on your device (open the camera on your device, point the camera at the code, and tap the banner or border that appears)

How does the thymus gland affect MG?

- The thymus gland is a small gland in the chest. It is a part of your body's immune system.
- The thymus gland grows slowly over time until you reach puberty, and then gets smaller as you get older.
  - › In many people with MG, the thymus gland does not get smaller after puberty.
  - › About 10 to 15% of these people will have tumours called thymomas. Thymomas are usually benign (do not cause cancer), but they can become cancer.
- The thymus gland may also cause your body to make acetylcholine receptor antibodies, which can cause MG.

How is MG treated?

There is no cure for MG, but there are treatments to manage your symptoms.

Cholinesterase inhibitors

- **Pyridostigmine** (Mestinon®) is a cholinesterase inhibitor given to help with muscle weakness caused by MG.

Immunosuppressive medications

- Immunosuppressive medications lower the production of abnormal antibodies.
- Steroids are the most used immunosuppressive medications. Prednisone is the main steroid medication used to treat MG.
  - › When you start taking prednisone, there is a small chance that it may briefly cause more weakness before your symptoms start to get better. This is why prednisone is started at a small dose (amount). This is why you will start on only a small dose of prednisone.
  - › The amount of prednisone needed to control MG can change over time. It must be changed by your neurologist.
  - › Prednisone works well for most people with MG, but you may experience side effects. Your neurologist will talk about these with you.