



Myasthenia Express

Myasthenia Gravis Manitoba Inc. May 2017

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President's Report

By Diane S. Kowaliuk

We have had a very busy year for our support group. Our fundraiser in September was the Grey Cup tickets and it was extremely successful. I would like to send out a big thank you to all the members and their families who sold tickets for our support group.

The support group has members who come and go and it is wonderful to hear from members who have learned how to find the "happy medium" to control the fatigue. Our biggest challenge is listening to our bodies. When you are tired, stop and rest, and when you are feeling better, don't do too much and stay within your limits. Our support group is for the whole family. It is great to see family members attending our meetings to learn what their loved ones are dealing with and how to help them with this illness on a daily basis.

We had a wonderful guest Speaker, Cory Guest, from the Winnipeg Fire Paramedic Service and we are looking forward to having guest speakers from the Winnipeg Police Service in the fall. In September we will hear about personal safety and in November we will hear about fraud and scams. Mark your calendars to attend these meetings as they are extremely informative.

We are going to be distributing our Grey Cup tickets for our one and only fundraiser in September. If you cannot come to the meeting please contact Maureen Silk and she will ensure you get tickets to sell. This is where we ask our family and friend to assist us in selling these tickets.

Have a wonderful summer and stay safe!

Enjoy!

ANNOUNCEMENTS

Myasthenia Gravis Manitoba Inc. Support Group Meeting Dates

The following are the confirmed dates for our meetings for
2017 and 2018

The meetings are held at St. Boniface Hospital
409 Tache Avenue, Wpg, MB
Location Basement South Entrance
Room AG001 & 2 South End of Hospital

September 21, 2017, Thursday	7:00 p.m.
November 16, 2017, Thursday	7:00 p.m.
March 15, 2018, Thursday	7:00 p.m.
May 17, 2018, Thursday	7:00 p.m.

Your attendance and participation at meetings are greatly appreciated.
Invite your family and friends to learn and share your experience with Myasthenia Gravis.

EXECUTIVE OFFICERS 2016/17

President	Diane S. Kowaliuk
Vice President	Verna Kapkey
Secretary	Maureen Silk
Treasurer	Maureen Silk
Telephone & Email Committee Chair	Mary Ross & Leah Roche
Fund Raising Committee Chair	Maureen Silk
Education & Resource Committee Chair	Cheryl & Ray Girard
Hospital Visiting Committee	Diane Kowaliuk
Newsletter Editor & Assistant	Leah Roche & Diane Kowaliuk
Coffee Committee	Liz & Richard Cisaroski
Brochure Distribution	C.J. Emmonds
Website	Grace Hooker

I Am Not MG

By Debbie Norman
June 2016

The message I would like to send out beyond the MG community is a simple one – **I am not MG.**

It is a part of my life. It is not who I am. I want you to know about this disease. I want you to have a glimpse of what our lives are like. Not for pity. But because myself and others like me, need understanding. Understanding is not only critical to our emotional health, but also critical to our physical safety and medical needs.

We need medical staff who are educated enough about MG to stop making mistakes that could cost us our lives. We all need friends and family who understand just enough to hold us up – not push us down.

Stress is a well-established trigger for MG flares. We don't need the stress of someone failing to understand that this disease can fluctuate rapidly in severity and saying things in an accusatory tone like, "Why can't you come to the family reunion today, I saw you in the store yesterday?" or "Why did you show up to the family reunion in a wheelchair, when I saw you walking in Target yesterday?"

Instead, perhaps you could say, "I'm really sorry you couldn't make it to the family reunion. I'm happy you were strong enough to go to the store yesterday." or "I'm sorry that you need your wheelchair today, when you didn't yesterday. But I am so glad that you could be here with us today." Kindhearted expressions of understanding can mean more than you know.

And we certainly don't need anyone to verbally accost us in parking lots because they don't understand why we require a handicapped parking permit. There is a huge lack of understanding about the fact that not everyone with a handicap tag is in a wheelchair. That doesn't mean our need isn't serious and valid.

And if someone in a wheelchair stands up, they aren't "faking it". They simply lack the strength and ability to stand and walk all of the time.

Or maybe we just need you to understand that some days we are able to talk on the phone and other days we just aren't, and that is not a reflection of our feelings towards you. It is simply a reflection of our muscle strength in that particular moment.

From a medical standpoint, we need you to understand that things like stress, high temperatures, humidity, physical activity, certain medications, etc. do not impact us in the same ways that they impact others without MG. Something as simple as a power outage could be life-threatening to us.

Four years ago this month, I almost died due to an MG crisis brought on by the effects of a power outage. So few people outside of the MG community understand why storms make me uneasy now. They forget that I almost lost my life to one and that it could easily happen again.

We don't need pity, we need understanding. You don't have to remember how to pronounce "Myasthenia Gravis". You don't have to know all of the complexities of this autoimmune neuromuscular disease.

But you do need to believe us.

We are the experts when it comes to our disease. Not our neighbor, not our friend, and certainly not a judgmental stranger. Those of us living it every day – we are the experts in how this disease impacts our life, in our own personally unique situations.

Sadly, we often know more about this rare disease than 3/4 of the medical personnel we come in contact with on a regular basis.

You need to trust us. You need to respect us. Everyone deserves respect, regardless of their abilities.

I am not MG.

I am not a disease.

It is a part of my life. It is a challenge that I must deal with. Everyone has challenges – everyone.

I refuse to be defined by my struggles. MG is not who I am. Who I am is separate from what I happen to face in life. What I face throughout my life may change me. But I hope that I only allow it to change who I am in the best of ways. The ways that teach me to be a more grateful person, to fight hard, and to not take things for granted.

I happen to live with a disease. I fight a disease every day of my life. I fight it for myself. I fight it for my family. I fight it for my friends. I fight it for those who have lost their battle, may they rest in peace. Most importantly, I fight it for my children.

I go to war every single day with my own body, for every move that I make. I go to war for every single breath that I take. I go to war with antibodies that fight my muscles, including the muscles used just to inhale and exhale – something most people take for granted. At times we may need respiratory assistance to get through a crisis.

We also go to war with the often devastating side effects of the unpleasant treatments that are available to help fight our disease.

Some moments are easier than others. Some moments take everything that I have in me, just to keep fighting. But I do and I will for as long as I can, or until we have a cure.

I prefer not to be labeled.

But if you must label me, label me a warrior.

I am not MG.

~ ~ ~

This article was published with permission from Debbie Norman, Founder and Director of WomenWithMG.org

For more information on MG, visit [MG in the Simplest of Terms](#)

Dental Treatment Considerations

Myasthenia gravis (MG) is an autoimmune neuromuscular disorder that presents challenges for both the dental practitioner and the patient. Facial and masticatory muscles may be involved and complicate dental care and treatment. Exacerbation of muscle weakness and fatigability that characterize this disorder can be precipitated by certain medications used in dentistry. The dental team should be cognizant of the medication precautions in this population, modify dental care to accommodate existing neuromuscular weakness and drug therapy, and be prepared to manage emergent complications occurring in the dental office.

Dental care provision for patients with MG requires special management considerations. These include identifying and managing myasthenic weakness or crisis, avoiding the potential of harmful drug interactions, monitoring oral side effects of drugs and therapies used to treat MG, and modifying dental treatment to accommodate altered muscle strength.

Appointment Scheduling

It is important to realize that oral infections and the psychological stress of anticipating or undergoing dental treatment may precipitate or worsen myasthenic weakness. Short-duration morning appointments will minimize fatigue and take advantage of the typically greater muscle strength during the morning hours. Appointments are best scheduled approximately one to two hours following oral anticholinesterase medication so as to benefit from maximum therapeutic effect and decrease the risk of myasthenic weakness or crisis.

Private Office or Hospital

The stable MG patient with limited or mild neuromuscular involvement may be safely treated in the private dental office setting in most instances. However, the patient with frequent exacerbations or significant or pharyngeal, respiratory, or generalized weakness may receive dental care most safely in a hospital dental clinic or other facility with emergency intubation and respiratory support capabilities.

Preoperative Plasma Exchange

Preoperative plasma exchange may be indicated in the patient with frequent severe myasthenic exacerbations or crises who is anticipating significant oral surgery. If an exacerbation is precipitated by the dental care, the

patient should be evaluated for severity of neuromuscular involvement by the patient's neurologist.

Dentures

The patient's ability to manage complete dentures may be compromised by the inability of the weak muscles to assist in retaining the lower denture and to maintain a peripheral seal for the upper denture. Over extended and over contoured maxillary dentures with thick flanges that impinge upon muscle and frenal attachments can lead to muscle fatigue and altered salivation. Improperly fitting dentures may exacerbate symptoms of difficulty in closing the mouth, tongue fatigue, a tight upper lip, dry mouth, impaired phonation, dysphagia, and masticatory problems.

Respiratory Collapse

If respiratory collapse occurs, an open airway and adequate respiratory exchange must be established. Dental staff should be trained in and prepared to do basic life support (CPR) until an ambulance arrives, if needed. Dental suction devices can be used to suction secretions and debris from the oropharynx to prevent aspiration and mechanical blockage of the airway. Manual retraction of the weakened tongue may prevent obstruction of the airway.

Oral Findings

Tongue: Lipomatous atrophy of the tongue may result in a furrowed and flaccid clinical appearance. In severe cases, it can result in a triple longitudinal furrowing of the tongue.

Mouth Drop: Lack of muscle strength in the masseter muscle, especially following a sustained chewing effort, may cause the mouth to hang open, unless the mandible (lower jaw) is held shut by hand.

Chewing/Swallowing: Lack of strength of the muscles of mastication can inhibit proper chewing of food. Eating can be further inhibited by dysphagia (difficulty swallowing), when the tongue and other muscles used for swallowing are involved, and by aberrant passage of food or liquids from the nasopharynx into the nasal cavity, when the palatal and pharyngeal muscles are affected. The consequences of this may include poor nutrition, dehydration and hypokalemia (reduced potassium levels).

To prevent or improve these complications one should instruct patient to

- Take anticholinesterase medication (Mestinon®, Prostigmin®) 1 hour before meals.
- Allow a half-hour rest period before meals and frequent rests while eating.
- Eat the main meal of the day in the morning when muscles are stronger.

Dental Treatment Considerations for the Patient

- Good preventative dental care at home and regular dental follow up office visits for teeth cleaning and inspection will help prevent dental problems, gum infections, and the need for emergency dental care. Open communication with the dentist can reduce the risk of complications during dental treatments.
- Helpful dental care hints include using an electric toothbrush or a manual toothbrush with modified handle that is easy to grasp. This will reduce muscle fatigue.
- Make short duration, morning appointments to reduce stress, minimize fatigue and take advantage of typically greater muscle strength in the morning.
- Schedule appointment approximately 1-2 hours following Mestinon® intake or, if your physician allows, modify your Mestinon® schedule to allow drug intake approximately 1 hour prior to your dental appointment to maximize benefit from the drug's peak effect.
- Mouth props for use during dental treatment may prevent muscle strain of having to hold the mouth open during treatment.
- Dental treatment is usually done in a reclining position. Let your dentist know if you are so far back that you feel like your throat is closing off or you are having difficulty with breathing or handling your secretions.
- Let your dentist know if you will need frequent rest breaks during treatment.
- Tell your dentist how frequently you have weakness and what muscles are usually involved.
- If your MG is stable with limited or mild neuromuscular involvement, you probably can be treated safely in a private dental office.
- If you have frequent exacerbations or significant oropharyngeal, respiratory, or generalized weakness you may receive dental care most safely in a facility with emergency and respiratory support capabilities, such as a hospital or oral surgeon's office. Ask your dentist about his/her emergency equipment.
- If you are anticipating significant oral surgery (wisdom tooth extractions, multiple tooth extractions) and you have frequent severe exacerbations of your weakness, your physician may recommend additional myasthenic

therapy (such as plasma exchange) before your oral surgery.

- If an exacerbation is precipitated, your treating physician should evaluate you for severity of neuromuscular involvement.
- If respiratory collapse occurs, an open airway and adequate respiratory exchange must be established. Ask your dentist if the staff are trained in and prepared to do basic life support (CPR) until the ambulance arrives, if needed.

Compromised ability to manage complete dentures

- Your ability to manage complete dentures may be compromised by the inability of the weak muscles to assist in retaining the lower denture and to maintain a peripheral seal for the upper denture.
- Overextended and over contoured maxillary dentures with thick flanges that impinge upon muscle and frenal attachments can lead to muscle fatigue and altered salivation.
- Ill-fitting dentures may exacerbate symptoms of difficulty in closing the mouth, tongue fatigue, a tight upper lip, dry mouth, impaired phonation, dysphagia, and masticatory problems.

Drug interactions

Many common drugs used in dentistry may have potential complications for MG patients by exacerbating their muscle weakness or interfering with breathing. The following table may be of help to the myasthenic patient and the treating dentist. Please remember that this list can not cover all potentially dangerous medications and one should consult with their treating physician if there are any questions.

Monitoring for Oral Side Effects or Drug Interactions of Therapies Used to Treat MG

1. Cyclosporine

- May cause gingival hyperplasia (fibrous gum overgrowth). This may begin as early as the first month of drug use and seems to be dependent upon the presence of dental plaque or other local irritants individual susceptibility, and the dose of cyclosporine used.
- May cause interactions with medications your dentist might prescribe. These include enhanced kidney toxicity or elevated drug levels of cyclosporine:
 - Nephrotoxic interaction: gentamicin, vancomycin, ketoconazole, and the nonsteroidal anti-inflammatory drugs (NSAIDS e.g. ibuprofen, Advil, Aleve, Motrin).
 - Cyclosporine levels increase to possibly toxic levels: erythromycin, ketoconazole, fluconazole, and itraconazole.

2. Azathioprine (Imuran®)

- Suppresses immune system.
- May predispose to oral/wound infection.
- May delay wound healing.
- Consider need for antibiotic treatment after oral surgery.

3. Prednisone

- Suppresses immune system.
- May predispose to oral/wound infection.
- May delay wound healing.
- Consider need for antibiotic after oral surgery.
- May cause adrenal gland suppression, depending on dose taken.
- Patient should discuss with physician and dentist whether there is a need to increase steroid dose before stressful or complicated dental procedures (e.g. multiple extractions or general anesthesia) particularly if the patient has been on daily prednisone of medium to high dose.

4. Mestinon®/Prostigmine®

- May cause your saliva flow to increase.
- Dentist can use a low speed saliva ejector to collect the saliva during dental treatment.
- Dentist can use high-speed evacuation, suction to collect debris and saliva in patient's mouth during treatment.
- When having restorations (fillings) done, a rubber dam can be used to isolate teeth and keep the dentist's water and restorative materials from getting near the throat. If an impression for a crown or bridge prosthesis

is being done, the patient may need to ask for an appointment at a time when they have not been having these symptoms or a physician may suggest other medications to dry up secretions temporarily.

5. Plasma Exchange (Plasmapheresis)

- If the patient's exchange protocol involves the use of anticoagulants (blood thinners), including heparin or acid-citrate-dextrose solutions, dental treatment should be arranged for a non-exchange day in the treatment sequence.

Local Anesthetics

General comments concerning local anesthetics:

- Amide type rather than ester type local anesthetics should be used.
- Care should be observed in avoiding intravascular injection of local anesthetic.
- Use of a vasoconstrictor, such as 1:100,000 epinephrine in combination with lidocaine is beneficial in maximizing anesthesia efficacy at the oral site, while minimizing total anesthetic dose.
- The periodontal ligament injection and intrapulpal injection techniques should be considered if the dental procedure warrants their use.
- Nitrous oxide sedation may be helpful in allaying apprehension.
- Intravenous sedation techniques and narcotic analgesics should be used with caution to avoid respiratory depression.

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Become a Member

For \$5 a person or \$10 per family you can become a member of the Manitoba MG Support Group.

Members are entitled to vote at the annual meeting or at any special meetings of the corporation. Members receive a copy of the newsletter, Myasthenia Express. Membership fees are for the year starting October 1st and ending September 30th.

Please complete the form below and return it with your annual membership fee to:

Myasthenia Gravis Membership
c/o Maureen Silk
614 Munroe Avenue
Winnipeg, Manitoba
R2K 1H8

MYASTHENIA GRAVIS MANITOBA INC. MEMBERSHIP APPLICATION

Last Name: _____ First Name: _____

Street: _____

City: _____ Province: _____

Home/Cell Phone: _____ Postal Code: _____

E-mail Address: _____

Relation/friend with MG: _____

Family Member names if family membership: _____

Membership fee enclosed: _____

Myasthenia Gravis Manitoba Inc. is a non-profit, charitable organization. Donations are graciously accepted and provides us with the means to educate our member and the community regarding Myasthenia Gravis.

A charitable tax receipt is provided with all donations over \$10. Thank you.

Donation enclosed: _____

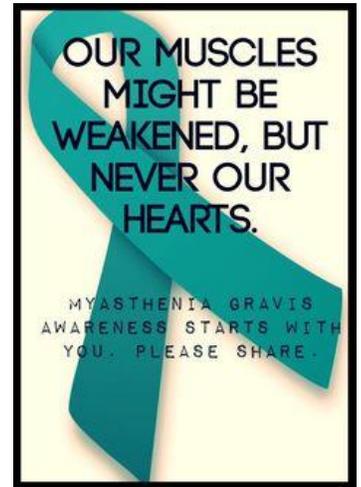
JUNE is Myasthenia Gravis Awareness Month

June has been identified as Myasthenia Awareness month in Canada and the US and many organizations are promoting awareness with activities such as Walks and disseminating information about MG.

To learn more about this disease you can visit these websites

Myasthenia Gravis Coalition of Canada website: www.mgcc-ccmg.org

MG Manitoba Inc. Website: <http://www.mginc.mb.ca>



Together we are stronger

Charitable Donations

Myasthenia Gravis Manitoba Inc. is a non-profit, charitable organization. Donations are graciously accepted and provides us with the means to educate our members and the community regarding Myasthenia Gravis.

If you are considering a donation there are some choices that are available. Payroll deductions are convenient and you can add Myasthenia Gravis Manitoba, Inc. to the United Way list of charities. Also, when someone passes away, the family quite often requests charitable donations be sent in lieu of flowers to a charity of your choice. Myasthenia Gravis Manitoba, Inc. could be that charity of choice. A charitable tax receipt is provided with all donations over \$10.

We **thank you** for your continued support and we would like to acknowledge our donators since our last newsletter.

The Estate of Edith Kathleen Crowston

Diane Kowaliuk

Wanted: your stories, feedback and comments

If you would like to share your story and experiences, suggest topics for future newsletters or just to provide feedback, please contact me at leahroche@shaw.ca. Everyone's MG experience is different, and we can all learn so much from each other

*Thank you
Leah Roche, Editor*

Please note:



This newsletter is intended to provide the reader with general information to be used solely for educational purposes, and that any medical views expressed in this newsletter are those of the individual author and do not reflect any official position of the Myasthenia Gravis Manitoba Inc. Chapter. Always consult your physician or health care professional for medical advice.

