the MaGazine

MYASTHENIA
GRAVIS
SOCIETY OF CANADA

SOCIÉTÉ CANADIENNE DE LA
MYASTHÉNIE
GRAVE

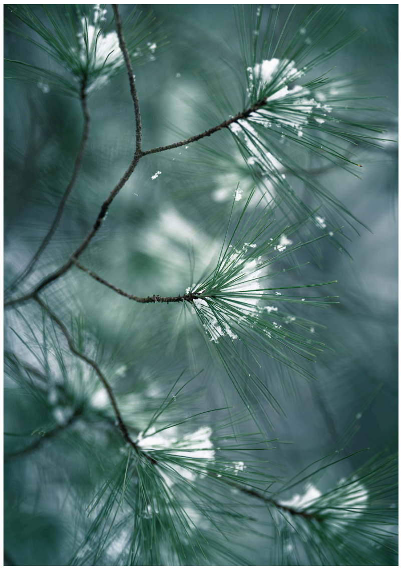
WHAT'S IN THIS EDITION?

Spotlight on MG

Margo Thompson shares her journey with MG and how finding the right treatment has given her new hope.

Caregiver's Corner

In this issue, Claire shares how her experience of being a caregiver to her partner with MG has helped to shape her practice as a doctor.



Holliday season is coming bringing with it both joy and stress. We look at ways to conserve energy and share some MGers favourite tricks.

News and Events

A look at recent, current, and upcoming events.

Our New Website

In case you missed the news, all our hard work has paid off and MGSC's totally new website is live!
You will find:
information and tools for MGers and caregivers, a new calendar with support group meetings, events and webinars with ways to sign up, the latest issue of the newsletter and an archive of past issues.
We also make it easy to donate to MGSC so we can continue our important work. We hope you like it as much as we do!

Spotlight on MG

Margo Thompson shares her journey finding the right treatment for Her MG

Shortly before 2012, I took early retirement from a very toxic work environment. A very brief time after that, I was diagnosed with MG. There were only off label treatment options available to me at that time. Starting on prednisone and Mestinon, we went with that for 6 months before adding Imuran (azathioprine). This was not a drug for my body and I had a very severe adverse reaction to it after only a couple of weeks. This left Cellcept (Micophenolate Mofetil), which for the time I took it, had very little effect on my MG symptoms. These last two medications take about 6-8 months before having a noticeable effect, so the time on them is at least about a year. Needless to say, these treatment choices were not effective in controlling my MG symptoms. Hence, came the final choice of IVIG(IV immune globulins) and changing to SCIG(sub cutaneous immune globulins)after about two years.
I stayed on these treatments for a total of 7 yrs and they seemed to have a very mild effect on controlling my symptoms. We tried adding Cellcept again to see if it would have any different effect along with the immunoglobulins. Again, this was not to be a success story so Cellcept was stopped. As I am musk positive, my neurologist put in an application for Rituximab, which was very quickly denied by the government. Application was also made to my private insurance for coverage which was again denied. When my neurologist was asked to make an appeal of this decision, he declined stating that he didn't think I was "bad enough". My request for a neurologists second opinion was also denied at this time. My only option was to stay on SCIG.
After about another year, my neurologist and I had a rather hot discussion about my treatments and how I was coping. This was around the time of Vyvgart being approved by Health Canada. Even though it was only approved for AchR positive patients, we decided to apply and of course were turned down because I was musk positive. However, the patient support programme for the drug company decided to apply to my personal insurance and it was APPROVED!!!! YEAH!!
It has taken a year to find the correct schedule for administration of this drug and we have settled on alternate weeks. While it has not provided me with remission, it has lowered to my symptoms to a more manageable level and according to the MG ADL, my scores have dropped from 13 or 14 to 7-10. A level I am willing to live with at this time.
One piece of advice to share is to advocate for yourself. Don't be complacent or try to just persevere. If your treatment is not working for you, take that infamous big breath, remember how strong you are, and speak up and talk to your physician to see if there is another option. Maybe if I had "encouraged" my neurologist to appeal the denial of rituxan, I could have seen improvement much earlier.

Conserving Energy Through the Holidays

With Thanksgiving behind us and lots of celebrations like Christmas, Hannukah, Solstice, New Year, and Kwanza on the horizon, it's a great time to discuss how holidays affect us with MG. Not only can they be mentally and emotionally draining, but also simply physically exhausting. Planning ahead helps us to not only survive but enjoy these events.

Break big tasks or meals into smaller parts. Vanda DesRoches from PEI shared her best holiday tip; break down big tasks like baking and meal preparation into smaller more manageable pieces and then spread those out over days or even weeks. Many things can even be frozen! This way you never have to do too much at once and, when everything is done ahead of time, you can relax and just enjoy celebrations. **Share the load.** Enlist family and friends to help with tasks and delegate jobs. Somebody else can peel potatoes, set the table, or run errands ahead of time. **Make it a potluck!** Consider doing big meals pot luck style. If everyone brings one dish, no one is overwhelmed and you'll get a variety of tasty treats. Make a list of types of dishes, for example: salad, potatoes, stuffing, and buns, and ask guests to bring dishes from the list. **Schedule rest!** Make time to rest or nap between events and spread events out. This allows time to refuel in between so you can fully enjoy visits. **Make extras!** Kathy Baer from Ontario suggests that you make more than you need for the big meal. There are lots of easy ways to enjoy leftovers and being free of having to cook for a while means you have more time for rest and recovery post big events. **(Almost) Everything that can be done standing can be done sitting.** standing at the kitchen counter can use up energyat lightening speed. Try pulling a counter-height stool into the kitchen to sit on or lean against while chopping veggies, stirring pots, or icing cookies. Alternatively, bring your task to the table so that you can sit in a more supportive chair while getting things done. **Gadgets are your friend.** Use stand mixers for baking, electric can openers to save your strength, and food processors to speed up chopping veggies. Using the tools you have at your disposal saves energy for the things that you must do by hand. **Holidays aren't a time of celebration for everyone.** For many, holidays can be hard or lonely time and can emphasize those who are absent from festivities. Be kind and gentle to yourself and others who are having a hard time. Make sure to check in on your friends and family.

CAREGIVERS’ CORNER

Seeing Medicine Through a Caregiver’s Eyes

Dr. Claire Rollans

As a family doctor, I’ve spent years studying, practicing, and teaching care. But nothing transformed my understanding of care as profoundly as becoming a caregiver to my wife, who was diagnosed with generalized Myasthenia Gravis 5 years ago. In medicine, caregiving is often intentionally separated from intimacy. Professional boundaries protect both patient and clinician. At home, however, caregiving is woven into the bonds of our relationship itself. Washing her hair, for instance, isn’t just a task—it can be tender and funny, filled with chatting, shared glances, and moments of quiet closeness. Even cleaning up after an accident can leave us laughing or crying together, completely united in the humanness of it all.

This kind of caregiving has none of the distance that clinical care traditionally dictates. It’s not a “favour” I do for her, and it isn’t a giving-and-receiving dynamic. It’s mutually sustaining—an expression of connection that supports both of us. Being present for her in this intimate, practical way enriches our relationship and shapes me just as much as it helps her. It reminds me daily that care is not a discrete action but a shared experience.

That understanding has profoundly shifted how I practice medicine. Medical training focuses heavily on the intellectual pieces: physiology, diagnostic reasoning, treatment planning. The human part—vulnerability, presence, and connection—can fade into the background during the rush of clinic days and administrative demands. Yet caring for someone always involves vulnerability.

My patients cry in front of me. They trust me with information no one else knows. They find themselves in gowns, on exam tables, or in beds they cannot easily get out of. Their vulnerability is a responsibility and a gift; it’s a doorway to genuine human connection. Removing the human element makes vulnerability feel like exposure. Honouring the human element makes it feel like trust.

Though being a doctor is still my job, when I tell patients I want to be on their team, I mean it in a deeper way now. I understand more clearly what it feels like to be on the other side of that relationship—to rely on others, to feel seen, and to feel cared for without being reduced to the role of “recipient.”

As a teacher of medical students, this is what I most want them to understand. They won’t all have personal caregiving experience, and they don’t need to. But I want them to grasp how profound human care is. It is not a one-way transaction; it is participation in a shared, relational act. No one can be an island in caregiving. One person is never enough for either side of the dynamic. Communities of care function like webs—many people stepping in, supporting, and complementing one another in different ways.

Being a caregiver to my wife has reaffirmed that care is not something I “give.” It’s something we inhabit together—an ongoing expression of connection, love, and partnership. And it has made me a different kind of doctor: one who can truly relate to the position of my patients and fully engage in the very human act of care.

15 Positive Tips for Living with MG

By Cheryl Girard

15 tips that I have gleaned through research and experience:

1. Eat well. Eat a healthy, well-rounded diet with vegetables, fruit, and protein. Eating low sodium and low cholesterol may be recommended if you are on treatments like prednisone. A Dietician can help plan the right diet. always consult with your doctor before making changes to your diet.

2. Rest. Making time for rest is crucial. Nap. Schedule breaks while doing demanding tasks, and periodically resting your eyes when reading or on screens helps with fatigue and ptosis or double vision.

3. Pace yourself. Decide which are the most important things for you to do and do them when you're at your best- often mornings for many people with MG. Cook extra meals on days you feel the best and freeze them for hard days.

4. Be positive. Some days are harder than others but try to be positive. Look for good things and people. "When it rains, look for rainbows. When it's dark, look for stars,"-Oscar Wilde

5. Avoid stress. Easy to say and hard to do. Stress comes into all our lives, but since stress can often worsen our MG, it is important that we try to find ways to reduce it, de-stress, and build relaxation techniques into our daily lives. Meditation, yoga, and tai-chi can relax muscles and ease stress.

6. Keep a diary. Make notes on how your MG is doing. Keep track of reactions to new medications, changing symptoms, etc. These will be a great help when you see your general practitioner or your neurologist. This is also a good place to write down any questions you may have which are easy to forget.

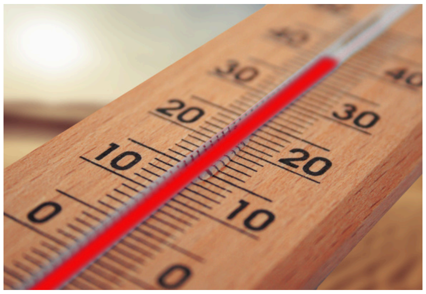
7. Stay in touch with others with MG. Join a support group or reach out to others on social media. Friends with MG can be extremely helpful with experience and tips that have made their lives better. Those without MG may not always understand what you're going through, so it's nice to have people that do.

8. Knowledge is power. Read as much as you can about MG on sites like mgcanada.org or other reliable sources. The more you understand, the better you will be able to deal with your condition.

9. Accept help. When you feel weak, unsteady, or tired, accept help when family offers it. Don't push yourself beyond your limits.

10. Baby steps. You will have bad days, and you will have better days. It is best to take small steady steps to manage your MG. Don't expect enormous or rapid improvement. One day at a time.

15 Positive Tips for Living with MG continued



11. Watch the weather. Extreme weather, in particular extreme temperatures, can affect muscle weakness for those with MG. Avoid the weather that worsens your MG by planning ahead, and being prepared with the right clothing

12. Avoid triggers. We are all affected differently by MG; Fatigue, weather, all sorts of stress, and illness can all trigger MG symptoms. Learn what triggers your MG and then avoid it as much as possible.

13. Carry a card. Carrying a card (or medical alert jewelry and card) with you that identifies your MG, and medications can be helpful in an emergency. You can also carry the list of medications to avoid in MG.

14. Exercise. Exercise within your limits and follow the advice of your doctors as to when you can and what or how much you can do. Exercise not only helps strength but also makes you feel better.

15. Don't give up on the things you love. Sometimes we may have to take temporary breaks from the things that bring us joy. Try to do what you love in small doses whether it is gardening, walking, travelling or whatever you enjoy. You may need to make adjustments, and always discuss it with your doctor.

Sources: www.myaware.org, www.myasthenigravis.org- Conquer MG

Volunteers Wanted

Do you have time, energy and skills that you would like to volunteer? There are opportunities to volunteer in a number of areas and time commitments so you can find the position that's right for you. As we are a non-profit organization, we are run by volunteers just like you! Interested? Email us at: **volunteers@mgcanada.org**

Currently MGSC is seeking volunteers with experience in working on newsletters or other types of written communication. Position Requirements:

- Able to work with other volunteers both independently and as a team member.
- Interested in donating time and energy to a non-profit organization.
- Must have access to a good working computer and reliable internet.
- Experience and education and around writing and editing a bonus.

Does this sound like you? Please email us at:volunteers@mgcanada.org

News and Events

Health Fair in Toronto

Aug 28th 2025 saw us host our first MG Health conference in cooperation with the Myasthenia Gravis Foundation of America (MGFA). Tasha Duncan from MGFA and Melissa Kennedy from MGSC were the coordinating volunteers. There were approximately 60 attendees who enjoyed our three speakers. Dr. Katzburg, Dr Wilma Koopman, and Dr Matilda Nowakowski. We are all looking forward to our next conference.

MDC Camp Ontario

On Sept 19-21, members of MGSC in Ontario took part in a weekend camp put on by Muscular Dystrophy Canada (MDC). MDC runs camps that provide not only information and support for individuals and their families, but also recreation and fun in a welcoming and inclusive environment. Below from left to right are Kathy Baer, Lindsay Peets and Laura Reynolds.

CREATING SELF-CARE

This 6 week hands-on webinar explores the idea of making art as an act of self care, something that is so important for our wellness. While the group is underway, there is still time to join. email us! events@mgcanada.org

No art experience necessary

CREATING SELF-CARE

To register email: events@mgcanada.org

Join us for 2-hours of creating lead by student art psychotherapists. Group sessions will offer participants directives aimed to increase personal self-care practices, increase self-compassion and improve self-talk.

Bring your favorite art materials-markers, colored pencils, paints, brushes and paper whatever you want to use.

Come to all sessions or just one!

**group is not a substitute for personal therapy; if you feel you would benefit from individual therapy, do not hesitate to reach out to one of the faciliators.*

FRIDAYS @ 11AM PST

NOV 14
NOV 21
NOV 28
DEC 5
DEC 12
DEC 19

Virtual art therapy link will be emailed to you after registration

MYASTHENIA GRAVIS SOCIETY OF CANADA

Spaces are limited, sign up now!

UP COMING WEBINAR

Reprogramming the Immune System to Halt Myasthenia Gravis

December 13, 2025 10amPST 1pm EST, 2pm AST

Dr. Paul Peloso, Chief Medical Officer at COUR Pharma, is leading the development of a new kind of treatment that uses nanoparticles to safely retrain the immune system. Join us to learn more about these exciting new treatments.

To attend please email us:
events@mgcanada.ca

Note from the Chair

MGSC has been busy all summer and fall. With lots of hard work from our wonderful volunteers, we have totally redone our website to better support our Canadian MG community. We are excited to share it with you, Please check it out! Not only have we been busy with the website, but we have also redesigned our newsletter. It now comes out twice a year with articles and information that we hope you will find interesting, entertaining, and helpful. To receive it via email, please sign up on the website where you can also find the current and past issues.

We need you, and here are some great ways to get involved:

- We are trying to organize a webinar each month. If you have any topics that you would like covered, or know of someone who would like to present, please email us at mginfo@mgcanada.org.
- We are planning a support group for caregivers and parents of children with MG. If this might be of interest to you, please email us at mginfo@mgcanada.org
- Volunteers are the heart of our organization. Do you have a particular skill or experience that you would like to volunteer for MGSC? Do you have no experience but really want to help? We need you too! We are searching for volunteers to fill a variety of positions. Please email us at mginfo@mgcanada.org

Finally, please check out all the different new ways to engage with us:

- On YouTube - https://www.youtube.com/@MyastheniaGravisCanada
- On Facebook - Myasthenia Gravis Facebook Group (Canada)
- On the web- https://www.mgcanada.org

I hope you like our changes as much as we do!

- Linda MacMullen

Note from the Editor

It has been a great year volunteering for MGSC. I have gotten to watch and be a part of some big changes to the organization from the launch of the all new website, forging new partnerships with other organizations, to great webinars, and the new newsletter. I have gotten to meet so many wonderful people in our community. It has been an amazing experience and I am looking forward to seeing MGSC continue to grow in the New Year.

Happy Holidays and a healthy New Year ahead!

- Sovay Desmarais

Linda & Sovay

MG Canada will be out of the office from Dec 17 to Jan 12, 2026

During this time we will not be reading or replying to emails. If you do leave us mail during this time, rest assured we will respond when we return in the New Year. We wish you all the best this holiday season and look forward to serving our MG community in the New Year!