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# Myasthenia Express

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Vol. No.18

Myasthenia Gravis Manitoba Inc.

March 2005

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Meeting on  
January 20,2005  
St.Boniface  
Hospital Room  
AG001&2

Attending Members  
Verna Kapkey  
Diane S. Kowaliuk  
Stan Klos  
Connie & Ken  
Chubaty  
George Sinclair  
Rod & Judie  
Hrappstead  
Maureen Silk  
Sheila Besht  
Bob & Doreen  
Amadatsu  
Gord & Margo  
Mackie  
Roger & Mary  
Ross  
Guest Speaker  
Eleanor Stelmack

## **Chapter Meetings 2005**

**March 10, 7 PM - 9 PM**

**May 12, 7 PM - 9 PM**

**All meetings are held at  
St. Boniface Hospital in  
Room AG001 & 2  
East end dining room.**

Refreshments served  
Please try to attend.

## **Presidents Message by Diane S. Kowaliuk**

Our chapter will be listed  
in the white pages of the

Phone Book as  
Myasthenia  
Gravis and our fax and  
telephone number will be  
582-5456.

In the Yellow pages we  
will be listed under  
Associations as  
Myasthenia Gravis Inc.  
at 582-5456. This is all  
possible due to our grant  
received from the  
Winnipeg Foundation.  
Once again we would  
like to thank the  
Winnipeg Foundation for  
their generosity, enabling  
us to create awareness  
and share information  
and education about MG  
among our members and  
the general public.

At our January 20, 2005  
meeting. Eleanor  
Stelmack, an  
Occupational Therapist  
from the Seniors Health  
Resource Team in River  
East was our speaker.

This wonderful  
presentation was  
regarding the resources  
available to our senior  
members in the  
community.

It was also a great  
information session for  
the members who are  
not quite ready for these  
resources, but have

family members  
who need this  
kind of  
information.

Just a reminder to  
all of our members,  
if you are planning  
a vacation and are  
leaving the province,  
check with the  
Travel Health to see what  
shots you  
require. If you do  
require any shots,  
check with your  
doctor before  
you receive them  
due to your  
Myasthenia Gravis.  
Just a reminder, we  
have a charity  
number and we will  
issue receipts for all  
donations.

Our next meeting  
will be March 10,  
2005 at the St.  
Boniface Hospital,  
at 7 P.M.  
and we will have a  
presentation on the  
Chi Machine.

Get well wishes to  
all members on the  
sick list.

Thank you, for  
your Support and  
dedication.

Diane S. Kowaliuk

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**Living with Myasthenia Gravis by Doreen Amadatsu**

It is now 17 years since I was first diagnosed with Myasthenia Gravis. I had just returned to working full time as a nurse on the Maternity ward and was looking forward to it. Prior to that I had always enjoyed good health and had been in the hospital only to have our son. I worked parttime as a nurse in Labor and Delivery and in the nursery previously.

The first symptoms showed in 1988 after I had been working my seven night shift and I was not used to working long stretches.

It was an adjustment trying to sleep during the day and then staying up all night.

My Myasthenia Gravis started with a droopy left eye and within the year progressed to difficulties carrying babies or holding them. Shortness of breath developed with walking, disqualifying me from doing CPR. How could I breathe for others if stress caused me to become short of breath?

My charting and handwriting became progressively worse to the point I could not read my own handwriting.

I developed fine tremors in my hands and my eye-hand co-ordination became worse. I was unable to do treatments such as intravenous.

My family doctor thought it was Myasthenia Gravis, but he sent me to a neurologist for a more definite diagnosis.

From there I went to a series of doctors and had numerous tests done. The blood work was negative for Myasthenia Gravis antibodies, but a test done by an anaesthetist had a positive result.

I was also diagnosed with Hashimoto's Thyroiditis and Asthma as well, and was soon being treated for that. I had my Thymectomy Operation in 1990, within a few months of my diagnosis. I then applied for Long- term diability. During those years I did much reading about the disease and its complications, which almost sent me into depression. However, I never had to have Plasmapheresis, prednisone or any of the anti-immune

suppressants, so I was fortunate in that way. After two years I attempted to return to work but again had the same problems and this time I applied for permanent long term disability.

Perseverance paid off and I was able to apply for both, C.P.P. and long term disability based on my twenty years of working as a nurse. From then on, I worked to rebuild my life, taking into consideration the limits put on me by Myasthenia Gravis. I soon established a pattern of doing active things in the morning like grocery shopping and having the store clerks make sure none of my groceries were more than ten pounds.

Window shopping at the malls became short points of excursions, point A-B and then returning home or resting on the bench while my husband, Bob, did his errands.

In the afternoons I had my rest for one to two hours, depending on how tired I was.

Then because of Bob's previous heart attack we decided that we had to find some physical activity to get us into shape or we would both have not only weight problems but other complications much worse.

We joined Reh-Fit Centre where Bob had a nurse managing his exercise and I had a phys-ed help design a program with my limitations.

Also, there we had our annual stress tests and blood tests done to monitor our blood pressure and cholesterol.

As I gradually built up my strength and endurance, we became interested in ballroom dancing and we joined Westview Dance Club where we danced and served on the executive. I informed the dance instructor of my limitation, so I was able to find a chair to rest between his dance instructions.

We had been doing this for over nine years now, and still going strong. At our social and practice sessions I stop to rest after any strenuous or fast steps, like a "swing" or "cha cha".

I also made sure that on Reh-Fit or dance days I have a rest in the afternoon.

Even the ways I do things at home have been to make changes in my priority-getting, with someone to help with the yard work, snow clearing and house cleaning. It made life easier for both Bob and I.

The other thing I did was to order his and hers "Medical Alert" bracelets for both of us. Wearing this bracelet has saved my life especially when the busy hospital and medical staff are too intimidated to read my medical history. By wearing it, forces the doctors and nurses to talk to me directly and ask about my medical situation. I also carry the drug alert card so that if I see a new prescription I can ask the pharmacist directly if there is any contra-indications.

Through Verna Kapkey and the support group I also gained some insight into my disease and learned that there were others, even though they had different symptoms from mine, we all had the same disease. It is rewarding to talk to new members and let them

know that there is hope, because there comes a time when you do feel better.

Since my diagnosis I feel I have come a long way. Even though the neurologist feels there is no positive signs of Myasthenia Gravis, I know that I am not cured, only in remission. If I do not listen to what my body is telling me, by taking rests my symptoms will return, such as, shortness of breath, blurred vision, irritability and clumsiness.

My handwriting has become eligible. Today I can walk for thirty minutes, take "holidays cruises", and this will be our fourth cruise this year. And we enjoy social dancing.

Sometimes there are reactions to some medications, and my Asthma flares up, but it is fairly well controlled.

My other problems with hypertension and cholesterol problems are complications of age but I try to control it

with diet, exercise and weight control. Each person must learn to adjust to their disease. I am fortunate to have the support and help from my family. Even with a chronic illness you should try to participate in some form of physical activity, walking or just going out for an evening.  
By Doreen Amadatsu

### **Keeping Daily Stress in Check**

While it is impossible to live completely free of stress, it is possible to prevent some distress and minimize its impact. As you begin to understand how stress affects you as an individual you will come up with your own ideas of helping to ease tensions.

#### **Try physical activity.**

When you are nervous, angry or upset, release the pressure through physical activities. Exercise will relieve that tense feeling and turn frowns into smiles.

#### **Share your stress.**

It helps to talk to some one about your concerns and worries. Perhaps a friend or family member can help you see your problem in a different light.

#### **Know your limits.**

If the problem is beyond your control and cannot be changed at the moment, don't fight the situation. Learn to accept what is - until such time when you can change it.

#### **Take care of yourself.**

Get enough rest and eat well. If you are irritable and tense from lack of sleep or if you are not eating properly, you will have less ability to deal with stressful situations.

#### **Make time for fun.**

Play can be just as important to your well being as work, you need a break from your daily routine to just relax and have fun.

#### **Be a participant.**

Offer your services in the neighbourhood or volunteer organizations and get involved. Help yourself by helping other people. Get involved in the area and the people around you and you'll find they will be of interest to you. You will be on your way to making new friends and enjoying new activities.

#### **Check off your tasks.**

Make a list of what tasks you have to do, then do

them one at a time, checking them off as they are completed. Give priority to the most important ones.

#### **Determine you do not always have to be right.**

Try cooperation instead of confrontation. A little give and take on both sides will reduce the strain and make you feel more comfortable.

#### **Have a good cry.**

This can be healthy way to bring relief to your anxiety, and it might even prevent a headache or other physical consequence.

#### **Create a quiet scene.**

You can't always run away, but you can change the scene by reading a good book or playing beautiful music to create a sense of peace and tranquility.

#### **Avoid self medication.**

Although you can use prescriptions or over the counter medication to relieve stress temporarily, they do not remove the condition that caused stress in the first place.

**Learn how to relax.**

This is the best strategy for avoiding stress. Many people try to relax at the same pace as they lead the rest of their lives. For awhile, tune out your worries about work and responsibilities and just relax. Find activities that give you pleasure and are good for your mental and physical well being.

**Benefits of exercise.**

Although more research is needed, there is evidence that exercise may strengthen your heart and lungs, lower your blood pressure, and protect against the start of adult onset diabetes. Exercise can strengthen your bones, slowing down the progress of osteoporosis, a bone-thinning disorder common in elderly women. It can also strengthen and tone your muscles and help you move about more easily by keeping joint tendons and ligaments more flexible.

Exercise may also give you more energy, help you sleep better and feel less tense, improve your appearance and contribute to good mental health by keeping you socially active. Always begin exercising slowly.

Reprinted from the Carillon.

**Net Wellness  
Consumers Health  
Information: Reprinted**

**Question:**

In your previous two answers you mentioned thyroid disease. What connection does this have with Myasthenia?

**Answer:**

Patients with Myasthenia Gravis have a greater likelihood of having thyroid disease than non-myasthenic patients. Studies have shown that 5% of those with myasthenia gravis will have hyperthyroidism (overactive thyroid), 5% will have hypothyroidism (underactive thyroid) and 2% will have non-toxic goiter. The incidence of thyroid disease in the general population is around 1.5%. Both hyperthyroidism and hypothyroidism can worsen myasthenia gravis or even precipitate a crisis. I routinely check thyroid function once per year on my myasthenic patients with blood work. (TSH, freeT4). Why the association?

Myasthenia Gravis is an autoimmune disease, where the body is attacking

its own tissues, (the acetylcholine receptor). People with autoimmune diseases have a higher rates of other autoimmune diseases, such as antibodies against the thyroid.

**Question:**

Is there any known research on the relationship between MG and MS? Are people who have been diagnosed with MG more likely to develop other diseases like MS?

**Answer:**

I don't know of a significant correlation between MG and MS. MG is more commonly seen in patients with diseases such as lupus, auto-immune thyroid disease, and juvenile diabetes pernicious anemia, and vitiligo (as a group of auto-immune diseases). I have not seen MS included in that group, though it is conceivable that there is a very slight increase in risk.

**Myasthenia Gravis  
Manitoba Inc. Chapter  
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Temporary:

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1-204-586-6784

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**Net Wellness  
Consumers Health  
Information.  
Reprinted:**

**Question:**

I'm a Myasthenia Gravis patient taking mestinon. I was diagnosed with the disease in 1996 and still have problems. I have hypothyroid disease and I had open-heart surgery to remove a thymus in 1997. I have gained too much weight and I am ready to get over these diseases and lose my weight, I don't want to take diet pills, but I need help.

**Answer:**

Weight loss in myasthenia gravis is often difficult. Myasthenics are often on prednisone, which predisposes toward weight gain and increased appetite. Hypothyroidism often makes weight loss difficult, too. A good weight loss regimen involves both exercise and dietary change. Exercising with myasthenia is often difficult, due to fatigue. Graded exercise (increasing from low levels to moderate levels gradually) hopefully can be achieved.

Dietary changes should also be gradual. Calorie counting and gradual decreases of total daily calories are effective strategies. But be gradual. Rapid changes are not good for our bodies, and make weight loss difficult to keep off. As for diet pills, there are often risks with the medications, especially in the context of Myasthenia Gravis.

**Please Note:**

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.

**Myasthenia Gravis  
Manitoba Inc.  
Membership Fees:**

\$10.00 - Family  
\$5.00 - Per Person

Please submit your Fees or donation to:

**Myasthenia Gravis  
Membership  
c/oMaureen Silk  
614 Munroe Avenue  
Winnipeg, Manitoba  
Canada  
R2K 1H8**

