HOPE

For Living a Long Full Life
With
Myasthenia Gravis

Donna Whittaker
HOPE
FOR LIVING A LONG FULL LIFE
WITH MYASTHENIA GRAVIS

NASA engineers, teachers, nurses, counselors, artists, actors, butchers, and many others have productively lived 25, 30, 40, 50, 60 years or more.

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Donna Whittaker, Editor
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A physician has not provided information for this eBook. These are personal experience stories of patients who were diagnosed with myasthenia gravis prior to 1992.
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Amy Whittaker
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Myasthenia Gravis Association of Kansas City
(Danielle Walk and Anne Strader)
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in online myasthenia gravis communities
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Dedication

This work is dedicated to the memory of my parents John and Viola Reeves who encouraged me to live my life to the fullest. When I was diagnosed as a ten-year-old child in 1957, I had myasthenia gravis (MG), a condition no one in our farming community knew. They instilled in me that I could learn and grow and achieve my goals. Whatever I put in my head, no one could take away. I went to school, I learned, I graduated college, I lived independently, I worked, I taught, I married, I parented. I have truly been blessed with a long full life. Yes, it has been a roller coaster ride of healthy times and not so healthy times, but I have been blessed with family and friends and knowledgeable medical professionals.
Introduction

I have been collecting Myasthenia Gravis (MG) friends since 1978. I was originally diagnosed in 1957, but I did not meet another person with myasthenia gravis until 1978. One college roommate had heard of myasthenia gravis (MG). That is a long time 1957 to 1978 to be the only one with a condition.

My family and I have been active in the myasthenia gravis community since 1978 so no other family would have to be alone with MG. As I celebrate my 60th anniversary of living with myasthenia gravis, I decided it was time to collect the stories of my MG friends to share our collective experiences. We are called snowflakes because each one is unique in symptoms and responses to treatment. We are challenges for our medical professionals.

As a newly-diagnosed person with myasthenia gravis, something unknown to you, you are no doubt asking a number of questions and wondering.....
Tomorrow, will I be able to walk?
Tomorrow, will I be able to talk?
Tomorrow, will I be able to hold my eyes open?
Tomorrow, will double vision prevent me from driving?
Tomorrow, will I be able to hold my head upright?
Tomorrow, will I be able to chew my food?
Tomorrow, will I be able to swallow my food?
Tomorrow, will I be able to breathe?
Tomorrow, will I be able to climb stairs or enter my front door with its two steps?
Tomorrow, will I be able to raise my arms to brush my hair or brush my teeth?
Tomorrow, will I be able to hold my cellphone?
Tomorrow, will I be able to enunciate clearly to talk on my cellphone or will I need to text everyone all the time?
Tomorrow, will I be able to work, pursue my dreams, have a family?
What is myasthenia gravis?

As a newly-diagnosed myasthenia gravis patient, you may be experiencing many symptoms that come and go. They may be worse in extremely hot weather or extremely cold weather. Some days you can do what you need to do. Other days you can’t do the same activities. Your friends and family do not understand. This eBook is a tool to help you explain the unexplainable.
The Myasthenia Gravis Association website http://www.mgakc.org has as the official definition of myasthenia gravis: Myasthenia gravis is a relatively rare, chronic autoimmune neuromuscular disease that results in progressive skeletal (voluntary) muscle weakness. MG causes rapid fatigue that increases during periods of activity and improves after periods of rest.

The Myasthenia Gravis Foundation of America’s website http://myasthenia.org lists the following common symptoms:

- A drooping eyelid
- Blurred or double vision
- Slurred speech
- Difficulty chewing and swallowing
- Weakness in the arms and legs
- Chronic muscle fatigue
- Difficulty breathing

We are tenacious active knowledgeable individuals who overcome our challenges to contribute to our families, friends, communities, and countries striving for a world without MG.

The purpose of this collection of myasthenia gravis life stories, websites, and day-to-day living strategies is to give hope to newly-diagnosed patients and those going through tough times.

You are not alone.
Nicole Burns
MG Story
by Nicole Burns

· Will new symptoms arise years later or do you always have the symptoms you started having?

I was born with Myasthenia gravis. I will be 37 years old (October 27, 2017). I am not sure if the current symptoms are similar to what I had as a child. I suppose they are but I am sure that a few new ones have popped up to the aging body. It is really nothing I cannot handle but does cause some frustration.

· What is it? Can I ever be off medications?

I changed my diet to a raw vegan diet and was off my medication (60 mg Mestinon) for 8 months. I was working and going to grad school at the time and only dealt with fatigue. Sometimes chewing was difficult but I did take supplements and was on Huperzine A when I needed it. However, I had to give up the diet when I lost my job and home. Of course, stress causes a lot of problems for people with MG so during this time I had a rough time.

· Did your MG start as ocular only?

No. However, it did for my younger sister. I have three sisters, my little sister has Ocular MG and Lupus, my oldest sister has Lupus and my second oldest sister has reproduction issues as well as a pituitary tumor (same as I).

· What am I in for down the road?

I cannot answer that question for you but for myself, a very exciting life!
I have always been told by doctors, my parents, teachers, family members that I couldn’t do this or that because I was sick. I graduated high school before my two older sisters (graduated at the age of 16), I graduated from my community college with an Associate degree while taking care of my grandma. I graduated with my Bachelor degree in Art with a minor in art education and psychology while commuting and taking care of my grandma and mother. I also graduated with my Masters in Art Therapy and Counseling while working 4 jobs and dealing with ovarian cancer at the time and living away from home in another state. I look back at all of these amazing opportunities that I experienced and none of it was prevented because of MG though MG did give me some challenges in-between it all, I survived it and had a blast.

· What were your best years and worst years since you were diagnosed?

My best years were when I was going to grad school from 2007-2010 because I was living on my own in Santa Fe, New Mexico, and had an amazing growth experience and learned so much. I also dealt with ovarian cancer at that time but survived it and made amazing friends. I also believe that the past three years have been amazing. My worst year was when my grandmother and mother died in 2006 (MG flares and lots of grief and stress). In my experience grief has been a horrible MG trigger.

What seemed to help you most?

What helped me the most was challenging myself. Yes, MG will challenge you but what happens when you challenge yourself in something that you care about? I know that I really wanted to help people through art and horses so I focused on being a better person so that I could help others. An elder tribal member had informed me that I was a healer therefore I was given health issues to learn from, they were gifts. I took this knowledge and explored it. I found that when I shared my story; other people would open up about their stories and felt like they were releasing a burden. With Art Therapy we do the same as telling our story. We create images from our emotions and let them go onto a tangible surface. Sometimes we burn them to let them go, deconstruct them and turn them into another piece of art to transform our story, or we simply say here it is in its purest form … It is no longer my luggage to drag along with me. There is power in telling your story.
With the horses, I always had a connection with them since childhood. A pure understanding that we were not separate, we were related. I rescued an old horse from slaughter and he rescued me from my depression that I experienced in my teens. He knew when I had a difficult time with my breathing (in fact a horse at a local ranch I was at for a workshop informed me that I was in a crisis by breathing into my nose and pressing his nose and head into my chest). I often ignored my symptoms when I was younger just to get on with my day but when the animals interfered I would listen and seek medical help.

· Can I ever have a “normal” life again?

I don’t know what a normal life is but my life is pretty awesome. I volunteer at a Therapeutic ranch for children and adults with special needs and different abilities. I encourage the parents, riders and siblings to create art as therapy and explore or play with different forms of art. I learn a lot from these experiences. The ranch owner has a different disability so on the days that the horses are not working (therapeutic horseback riding) I help the owner feed the horses. She appreciates the help and actually needs the help.

Even though I might have a bad MG day from a flare I still go out to the ranch because I am needed and that alone is what keeps me going. I see the difference in everyone when I am at the ranch, people tell me how important I am to them which means the world to me especially when I felt so alone as a youngster and felt like I was a burden. The children I work with have had similar experiences like I had as a child so I let them know it is okay to feel a certain way and inform them that they are not alone.

I also ride a horse at the ranch. This year (2017) I earned 2nd place in a class of five excellent riders. I am now an independent rider meaning that I do not have a leader (someone leading the horse) or side walkers (people standing next to my horse holding me on). This is a huge achievement especially since my balance had been horrible and I fell or tripped over myself, a lot. I am still improving over time. I ride which I love to brag about because even more the horse knows that I am improving. She loves to test me.
Would you try a natural supplement?

I tried Huperzine A. It was helpful but not something I can take to see quick improvements, plus it stays in the body longer than Mestinon. I am still figuring out the dosage. It cannot be used WITH Mestinon. I only take Mestinon and occasionally Huperzine A for my MG, nothing else. I started Mestinon when I was 28 years old. I took nothing for MG as a child but was hospitalized a lot.

What do I have and how is it going to affect my life?

I do not know how it will affect your life. I have a disease that causes my body to be angry at itself. It doesn’t like stress or too much exercise but does enjoy exercise every day, which must be balanced with rest. My body hates extreme temperatures in the environment but I live in the Mojave Desert and prefer it over living in Houston, Texas, because the humidity there was the very bad for my weak lungs. Everyone is different but since I was born and raised in the desert of Southern California it is what I am used to and I have learned to tolerate it. I use cooling vests in the summer and drink lots of water. I rest a lot more in the summer than I do in winter, but I still remain active. For me being active keeps me healthy and mobile but for many others with MG I hear the opposite, we are all different and we don’t all follow the textbook disease description.

How do you handle medication side effects?

I take Anti-Diarrheal medication for the diarrhea caused by Mestinon and drink lots of water.

How hard is it to get insurance?

I am on disability. It took a few years to get it. I had worked in the past and want to start working again but I have other health issues besides MG that cause many problems. However, the hours I have put in volunteering have given me hope.

How hard was it or is it in the work force?

I am up front and honest about my challenges with MG. Every job I applied to I got hired.
Did MG change your career choices?

MG encouraged me to find a career where I could help others. I was always mindful about standing, lifting and carrying heavy items.

Are companies, businesses, bosses understanding?

All depends where you are and how honest you are with yourself and others.

How much worse is your condition now versus in the beginning?

It varies.

Do you regret doing any specific treatment for MG?

No. I haven’t done anything extreme. I still have my thymus.

Have you developed other illnesses due to MG or the treatments?

I have other illnesses but I am not sure if they are linked to MG except maybe the thyroid issues.

Have you had any periods of remission? No.

Have you had any periods of control of symptoms that were medication dependent? I am not sure.

How do you maintain a fighting spirit or a positive attitude?

I know that I am needed here on earth. I know that art has a healing power to it and that if I am not here to reinforce that belief who will. I know that the connection I have with animals is needed on this earth and even though I may just connect with a few animals it is still important. I know that my story needs to continue and be shared so that people can learn, share and not feel alone.
Connect with people going through similar situations but DO NOT allow their problems to become your own. Support people and be around people who support you. Teach people how you want to be treated, sometimes people just don’t know how to treat you because they don’t understand. Be there for others and help others when you can. Your time is more valuable than money. Have humor (I am very sarcastic and love making other people laugh). Learn and practice gratitude. I am very thankful for having MG and these other health conditions because I can relate to so many people and help guide them through their healing. If I didn’t have MG I would not have been asked to participate in this eBook, how amazing is that? I feel such an honor to be a part of this eBook and helping people I don’t know.

Remember that you are not alone.

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Email Hope4MGLiving@gmail.com for consent to use.

Nicole found this website helpful on Save Your Strength:

http://www.myastheniagravis.org/life-with-mg/save-your-strength/

And for working outside in the summer heat, these products help:

https://www.froggtoggsraingear.com/CoolingProducts.shtm

Please consult

with your personal medical care team

before making any changes in your treatment.
Eddie Feinstein
MY MG STORY
by Eddie Feinstein
March 10, 2017

Looking back over the past 42 years since my first symptoms, I know I’ve had a great life in spite of MG. There have been plenty of difficult and frustrating times for me, and of course for my family; still, it could have been much worse, as I know it has been for many others with MG.

I was 26, married about a year to the love of my life, with not a care in the world. I felt physically fit, able to play and work hard. Thoughts of a chronic illness being a part of my life never entered my mind. Without warning, all that changed.

We were on a family vacation in the Grand Canyon. On a hike one day, my legs just gave way and I collapsed to the ground. It was obvious to me I hadn’t tripped; my legs were like rubber. I was too weak to stand and continue the hike. I suggested the group move on. I would catch up if I could or wait until they returned in an hour or so. The rest allowed me to recover sufficiently to make it back to our campsite. I wrote the experience off to the heat or maybe dehydration. No matter, it really took me by surprise as nothing like that had ever happened before.

For the next year or so I experienced episodes of weakness in my arms and legs, my speech would sometimes be slurred and in general I just felt fatigued. Sleep helped restore my strength but eventually I would tire. When the double vision started, I visited with an ophthalmologist thinking I needed new glasses. My glasses were fine. But based upon my recent medical history, he suspected MG. He administered a Tensilon test but the results were inconclusive. He recommended I see a neurologist.

In fact, I saw several. Over the course of the next couple years I had test after test. Finally, after an EMG showed “dive bomber” recordings, a neurologist I was
seeing offered up what turned out to be an incorrect diagnosis: Myotonic Dystrophy. He had no previous experience with the disease. He read the description from one of his medical books, prescribed Dilantin and sent me on my way.

During the next two weeks as I ramped up the dosage of Dilantin, I got progressively worse and my speech became severely impaired. My sister was a friend of the head of neurology at the University of Michigan medical school. She helped make arrangements for me to be seen there soon after I had weaned myself off Dilantin. A neurology resident was assigned to my case; he determined I had MG.

It took a total of three years, but I finally had a diagnosis. I started taking Mestinon and almost immediately showed improvement. Since 1978, I have been well controlled on the same dosage of Mestinon. On a couple of occasions, my double vision was challenging enough that my doctor put me on Prednisone for short periods. I’ve been fortunate to not require any other forms of treatment and have never experienced a crisis.

Slowly but surely, I regained my confidence and resumed a normal life. I took much better care of myself physically, emotionally and spiritually. I still do. And in spite of MG, I consider myself to be in good health.

One of the best things I did after I was diagnosed was to learn as much as I could about MG. I joined the local MG chapter in Milwaukee where we lived at the time - and then in Kansas City. Meeting others living with MG provided support and was encouraging.

Long before I retired, I found value in volunteer work. Now it’s a full-time job! I regularly volunteer with several organizations including Store to Door, Community Warehouse, the Clark Center and Potluck in the Park to name a few. Most signups are through Hand on Portland though the Community Warehouse has its own volunteer signup site. My projects are generally 3 to 4 hours in length and I like to have 3 to 5 projects to do each week.

I also make a real effort to stay fit and eat right. I exercise every day by going to the gym cycling and walking. Our gym, 24 Hour Fitness, is 3 blocks away. Portland is a great place to ride a bike and walk. Daily exercise not only keeps me in good
shape physically but also contributes significantly to my overall mental fitness by reducing stress and allowing me to cope with my disease.

We also like getting together with family and friends often though family always requires air travel which I tend to enjoy less and less. My interests are many. I love the arts and frequent galleries, museums and performances (concerts, plays and such). My wife Gloria and I spend lots of time together - reading, enjoying tea or coffee, hiking and hanging out with friends. It’s important at this stage of life to have a sense of community and stability.

I listen to a wide assortment of podcasts and radio shows from news to comedy like The Daily, Jack Benny, Ezra Klein, Brian Lehrer, Star Talk, WTF with Marc Maron, This American Life and Car Talk. Retirement is a very special time I have found. I have control of my calendar and I don’t freak out when I have nothing “important” on my schedule. Somehow the days fill up with what is most often good stuff.

Dealing with a chronic disability isn’t easy for the patient, family or friends. It became very clear MG was stronger than me. Eventually I got over my embarrassment and learned to ask for help. I needed time to grieve the loss of my good health.

Each of us will move through the psychological stages of dealing with a chronic illness in due time. We’ll get past the feelings of denial, anger and loss on our own terms. We’ll hopefully get to a place where we focus on what we can be and do rather than the things we can’t. It is then that we reach a state of acceptance.

I’ve done this, but I still give myself permission to have a bad day now and then. I also know that even though I’m the patient, having MG is a family affair. I accept that those closest to me will have bad days because of my MG, too.

I’m not happy to have MG but I certainly accept that I do. My life is built around all the things I can do as I avoid the things that I can’t. The scale is definitely tipped in my favor and for this I am extremely grateful.
Websites of the organizations where Eddie volunteers in the Portland, Oregon:

handsonportland.org
communitywarehouse.org
storetodoreforegon.org
potluckinthebark.org
http://www.tprojects.org

Please consult with your personal medical care team before making any changes in your treatment.
1. Who was possibly the richest person to have myasthenia gravis?
Bobette Figler
Bobette Figler

Bobette and Brisk

Bobette is a tireless community activist for healthcare and disability issues. For over 25 years she headed the Myasthenia Gravis Foundation of America, Inc.’s St. Louis Chapter. Her friendly manner and broad smile put patients who called her or met her in person at ease. They opened up to her and she patiently answered their questions about this mysterious disease they were now experiencing.

Bobette not only has myasthenia gravis (MG) but also multiple sclerosis (MS). She was diagnosed with MG in 1979. She had a thymoma which was removed transternally. She was then diagnosed with MS in 1986. Bobette has optic nerve atrophy in both eyes.

She has faced many challenges in her life, but she tirelessly advocates for others. She is a former board member of the Paraquad Independentent Living Center. In the Greater St. Louis area, Paraquad provides information and referrals to help those with any type of
disability achieve their goals of living as independently as they are able. Bobette is very involved in advocating for health care legislation.

For several years, Bobette served on the Missouri Governors Council on Disability. It meets in Jefferson City, Missouri, where they interact with the legislators for legislation that will benefit, not harm those with disabilities.

In 2013, Bobette was named as a Mental Health Champion by the Missouri Health Foundation. Patty Henry, Executive Director of the Missouri Mental Health Foundation, said of Bobette and the two other champions:

“These individuals exemplify courage and commitment and serve as an inspiration to others. They help provide motivation to thousands of Missourians facing the challenges of mental illness, addiction disorders and developmental disabilities. Not only do these Champions demonstrate personal courage through their actions, they encourage others and strengthen their communities.”

Bobette began volunteering for the National Council on Alcoholism and Drug Abuse (NCADA) when she began living a sober life and now she is employed there as a Senior Counselor. The NCADA says “She is incredibly effective in assessing and motivating people to address their addictions and move toward wellness.” Her goal and purpose is to effectively help others.

Bobette has used a service dog for many years. When her first dog, Flint, began helping her, she gained strength and mobility. He helped her with balance so she could walk and didn’t need her wheelchair all the time. Flint was so talented and well trained, he could pick up the back of a pierced earring off the floor for her. When Flint retired, Raja then Brisk became her helpers. Brisk works to keep her safe by his excellent bracing and balancing skills. He helps her identify steps and barriers. He is the strongest dog she has had. He is her guardian – her Hercules. KSDS Assistance Dogs, Inc., in Washington, Kansas, trains her dogs. Bobette
and Brisk enjoy a yearly reunion there. She is pleased to help anyone with questions or referrals who is in need of a service dog. She takes every opportunity to speak about KSDS and the benefits of having a dog like Brisk.

Bobette’s service dogs help her with a variety of tasks. They are trained in Washington, Kansas, by KSDS Assistance Dogs, Inc.

Bobette’s message is “Never give up!”

Senior Counselor

NCADA Staff http://ncada-stl.org

http://fox2now.com/2013/07/03/cdc-more-women-overdosing-on-prescription-drugs/

Bobette’s Thoughts on Recovery - There is hope.

https://www.youtube.com/watch?v=tYLR1q9n3fQ
2013 Mental Health Champion

http://missourimhf.org/bobette-figler.php
https://www.youtube.com/watch?v=XG874_xrq6Y

Bobette served several years on the Missouri Governors Council on Disability advocating for disability issues.
http://disability.mo.gov/

Bobette Figler and Donna Whittaker have both served on the Board of Directors of their local independent living centers. Independent Living Centers are not residential, instead, they provide resources and services to help people have control over their own lives, achieve their own goals, and fully participate in their communities.

Bobette - Paraquad
Http://www.paraquad.org

Donna - MERIL (Midland Empire Resources for Independent Living)
http://www.MERIL.org

To find an independent living center in your area, see
Elaine Huntsinger
At the beginning of 1974, I was a happily married 33-year-old mother of a 12-year-old, working as an RN for a great physician, with hobbies of golf, outings with my family and friends, sewing, reading, etc. In January, I had a serious upper respiratory infection requiring me to miss work for a few days which was very unusual. For a couple of nights, I felt I couldn’t get enough air. My wonderful husband filled our electric skillet to make lots of steam which made it easier for me to breathe. We are the DIY kind. He even stayed up with me to keep the skillet filled with water. I got over the initial infection, but didn’t seem to get my energy back. I still tried to live my normal life. In July, we played golf in a couples scramble when the temperature hit 107. I couldn’t swallow the much-needed cold water or Coke that was provided. But I was determined and finished the game. (You will discover, I am not too smart, but I am hard-headed.) I entered the air-conditioned club house, bathed my face, neck and arms in cool water; and melted ice chips in my mouth until I could swallow some fluids.

I had to admit at this time that I had been having a nasal quality to my voice and difficulty swallowing liquids in the evenings. I always seemed fine in the mornings after a good night’s rest. A couple of days after the golfing incident, I had trouble speaking clearly in the morning. I saw an ENT specialist who was a friend of mine. He had me look into a mirror to see that there was no apparent opening to my throat with my soft palate sagging down onto my tongue. He told me I had a neuromuscular disease and it could very well be myasthenia gravis. He forced me to tell my boss.

I was sent to a hospital in the city for diagnosis. After a week, with all other things ruled out, I was given the Tensilon test which was strongly positive. I was started on Mestinon 4 times a day. I immediately responded well to it. I went back to work, but felt like a drug addict because every week I would report by phone to
my neuro in the city; and he would increase my Mestinon. Each increase was helpful, but soon I would feel I needed more. In September, the neuro had a serious talk with me. He wanted me to continue working, but not do any work at home. My family was to do all shopping, cleaning, laundry and cooking for I was to rest and be waited on at home. This was very devastating to me, but my family, husband and daughter, jumped in and took over without complaints. The doctors reasoning was that my nursing work was more consistent than my housework—making it easier to control my symptoms. I don’t think he had any idea how difficult it was emotionally to surrender my home duties.

My abilities continued to decline with lots of difficulty swallowing, talking like a duck and extreme fatigue. I could only drink water and tea, since other liquids would go up through my nose when I would try to swallow. By December, I experienced double vision. My neuro (which I now feel was not an expert on MG) decided I was taking all the Mestinon that he was willing to prescribe and I needed a thymectomy and sent me directly to Mayo Clinic from his office. After a few days of testing, it was decided to do the sternal split surgery. I was told I would be on a vent for several days, but surprised all by not needing this.

Being a nurse, I knew it was necessary for me to keep my entire body as physically fit as I could. I ate a well-balanced diet, even with difficulty swallowing. I walked the hospital halls to keep my legs strong. I rested often and slept well at night. I prayed that God would let me live until our daughter was grown. I continued these wellness activities when dismissed.

It was a slow gradual improvement. I lived by an alarm clock for several months, taking Mestinon every 2 hours, with long-acting at bedtime. If I didn’t take it on time, I would not be able to swallow. They taught me at Mayo’s how to test my strength by taking a deep breath and counting (See Single Breath Test for Myasthenia Gravis in the Resources section) to see if I needed more or less Mestinon. Sometimes just adjusting the Mestinon ¼ of a tablet would make a big difference. I was under my own care since there was not a neuro in our rural area. I gradually improved over many months, being able to do more and more of the household chores. The doctors would not allow me to return to work which nearly broke my heart. All the time, I knew I had to do what was best for my
family. (I kept my nursing license active for 15 years before accepting the fact that I would not return to that type of work.)

After a few years, I improved enough to begin going to church and having a little social life. I knew God had something in mind for me to do since he had allowed me to live and recover through the thymectomy. It was good for me to get out and be around people. I am a people person anyway. Eventually, I was able to cut Mestinon to 60 mg 4 times a day, down from 1000-1200/day. I became quite stable, but was not good at extra stressful times. I could not keep up with most friends my age, so I discovered there were many older people in my neighborhood, church and community that were alone, weakened by various conditions, and needed a friend. I also searched and found 3 or 4 other MGers in my county. I could phone, visit, or write notes which fulfilled my need to help others and certainly helped them. I couldn’t do work for them, but I became a great listener and prayer. Not only did this give me a feeling of usefulness, but I was helpful to them. Of course, my nursing education and experience was helpful for my care-receivers. My parents and mother-in-law’s health began deteriorating and I was able to help them also.

I always enjoyed doing handwork and gradually began doing knitting, crocheting, counted cross-stitch and eventually quilting. This helped me develop new friendships. I made many gifts for family and friends. I also continued to take care of myself by eating well, sleeping well, de-stressing when needed, etc.

In 1980, our daughter graduated from high school and I was fairly stable. She lived at home while she attended a nearby college. She worked as many as 3 jobs at a time, so I didn’t have her help with housework, but I could do much of it by myself. God had certainly blessed me. She married a wonderful man when she was a senior. I had lived to see her on her own!!!

My husband was a realtor by this time. He encouraged me to get my real estate sales license and help him with phone calls and bookwork. I eventually obtained my broker’s license. This was in no way comparable to the joy I received by working as a nurse, but it did give me some satisfaction. AND, I was still helping people.

In 1991, I had a severe attack of inflammatory arthritis causing me to be hospitalized twice that summer. As I improved, I started going to the YMCA for
aquasize and soon my husband was going with me. We have been swimming 4-5 days a week for many years now. It is great exercise for arthritic joints.

I was fairly stable until in 2008 I felt that I was not getting enough air. I had a neurologist in a nearby town since I needed him to see me through several surgeries. He ordered 5 days of IVIG which turned things around for me. I had 2 IVIG treatments a few months later to prepare me for knee replacement surgery.

In 2013, I had a thyroidectomy for nodules on my thyroid. A week later, I was having some unusual symptoms. I had been told I might have these due to my body adjusting to living without a thyroid gland. Then a lightbulb went off! These were all symptoms of Mestinon overdose! I called my PCP who suggested I cut my Mestinon in half (I was taking 120 mg 4 times a day.) In the subsequent days, I cut it in half several times until I was taking NONE! I was in drug-free remission!!! Doctors have no answers to why this happened, but I’m one happy gal. I have had no symptoms of MG since.

By this time, I am an old lady. I do have some conditions of old age which limit me. I’m just not what I used to be, as is everyone else my age. I no longer live by the clock and naps. I do volunteer work, spend my days with my retired husband. I enjoy, not only a wonderful granddaughter, but my two great grandchildren!!! Life is good.

Thanks be to God. My wish is that every MGer can experience remission, no matter how much time it takes. Take care, do what you can do, and be patient.

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Elaine enjoys quilting. Another MG Snowflake also is a quilter, Millie Becker. Her biography is at

http://planetpatchwork.com/becker.htm

A chapter is devoted to her in Make Your Quilting Pay for Itself by Sylvia Ann Landman c. 1997
Please consult

with your personal medical care team

before making any changes in your treatment.
Donna Kalisek
I was diagnosed in 1967 at the tender age of 8 ½. At that time the Catholic school system didn’t know what to do with me so they decided to not allow me to attend classes. That meant leaving my friends in grade school to be tutored at home for three years before going back to high school. In and out of the hospital sometimes three times a year, the ICU personnel were getting to know me too well and were not surprised to see me return. But through it all I had a supportive family (parents and four healthy brothers) and wonderful physicians along with the staff at the Myasthenia Gravis Association of WPA to support both my family and me.

I started volunteering at MGA of WPA on fundraising projects and light clerical work. During that time, I also met with and counseled many other patients about my experiences and how to survive them, giving them hope and guidance on how to cope with this life changing, life-limiting illness.

I am now 58 years young and have been part of the staff at MGA of WPA for 25 years as first as a Projects Coordinator and now the Administrative Coordinator. We are a small staff of two full-time and two part-time people and this small organization celebrated “60 Years Strong” last year. We are proud of the work we do to help patients and families with this chronic disease. We try very hard to ensure public awareness of this little known chronic disease.

I wrote the following many years ago during my one semester in college.
The following patient story was reprinted from the News Record, May 1983:

Donna K. of Valencia, a victim of myasthenia gravis since age 8, and an active member of the MG Association said her most difficult memories are not so much of the pain and frustration and long periods of hospitalization, but of the time she was told her school didn’t want her anymore.

That was when she was in the fourth grade. “They kicked me out. They said it wasn’t fair to the other kids for me to get special treatment. No one could understand how I could do something one day and not the next.” Donna then had a tutor for three years, spending two hours two days a week at her kitchen table with a tutor. That was her only contact with the world around her.

When she was 13, her parents were able to enter her into the public school, which was just starting the “open classroom” approach, and they thought Donna would fit in. She went the first day, then had an acute attack of appendicitis and missed the next few weeks. This seemed to be the way it went all through high school. She missed at least 80 days of school a year, was in and out of the hospital, and had days when she just couldn’t move enough to attend school.

Relating to other kids was nearly impossible. “My world was one of doctors and nurses and hospitals. Theirs was a world of sports and activities and friends. I had a few good friends that can be counted on the fingers of one hand. I made it.”

As an adult Donna is “taking each day as it comes, as it is given to me.” Her dream is to go to college. “Perhaps by the time I am 30 I’ll be ready,” she said. But Donna is perhaps more ready than most of us ever were – to understand and to study and to learn.

At present Donna is a volunteer for the Myasthenia Gravis Association. She volunteers herself to do anything which may help her or other myasthenics, including offering herself for testing of drugs and procedures.
She was one of the first patients at Mercy Hospital to receive the plasma exchange. At the time, she was extremely ill with pneumonia and fortunately the plasmapheresis worked on her. She has not been a patient in the hospital now for two years – a record for her.

“What is most important is to get understanding from those around you.” Donna finds this understanding in her family and in her closest friends. She also finds it at the MG Association, where “there is always someone to talk to and always a sense of belonging. It’s a small family,” she said. MGA helped both Donna and her family through some difficult years. She is doing all she can now to help other myasthenics, and to help with the MGA public education program.

She volunteers for pictures, talks to groups and new patients to help them understand that myasthenia gravis is a controlled disease so long as they know their own limitations.

“I’m myself. I don’t care anymore what other people think. I used to be jealous that they could do more than I. Then I learned I could do things they can’t. If others can’t accept me, that is inside of them. That is not me,” she said.

For a child to grow into adulthood through such trying circumstances is quite a wonderful phenomenon, especially when you sense the strength of the person who has come through all that a myasthenic experiences. The knowledge of the value and joy of living, the beauty of close friendships, and the caring people can have for each other is something many of us never achieve, much as we may strive.

Let us not forget Donna: “I take each day as it comes; as it is given to me.”
Donna was interviewed for this news story about the Western Pennsylvania sponsored support group:
http://www.timesonline.com/community/leanonthem/you-re-not-in-this-alone-myasthenia-gravis-patients-support/article_4f5f2e94-4704-11e7-a460-53e2fb59ed86.html

Please consult

with your personal medical care team

before making any changes in your treatment.
2. What connection to myasthenia gravis did actress Ann-Margret have?
Esther Land
December 1959 = Diagnosed. Spring to fall of 1959 symptoms were sporadic drooping eyelids and double vision. A weak cough, trouble sipping through a straw, seeing two balls come at me when playing outfield at softball game. Went to doctor stating fatigue and was initially treated for thyroid condition, but went to ophthalmologist who suggested to my Internal Medicine doctor that it might be Myasthenia Gravis (MG).

A Prostigmin injection was given in that doctor’s office with a positive result. There was only one Neurologist in Grand Rapids who was not interested in MG, so I went to a specialist (Dr. Westerberg) at University of Michigan in Ann Arbor for evaluation and medication adjustment. I was put on anticholinerase meds (Mestinon/Prostigmin) – only treatment available at the time. I had appointments every other week for 2 months, then tapered off to every 6 mos. It was thought radiation of thymus might be beneficial, so treatment was done in the summer of 1961 at U of M. No noticeable positive result and so I just lived life the best I could each day, going to U of M about every 2 years.

Also in 1959, I was employed at Rapistan, a local conveyor manufacturing company, working in the mailroom, then Marketing.
and downs of MG, but was able to do my job. Ended up being there 45 years.

In 1973, I contracted pneumonia and was hospitalized and went into crisis and was put on respirator for 7 days, followed by 12 more days recovering. I went back to work and did pretty well, but slowly felt myself getting worse. At that time, I would fall and not be able to get up on my own. Putting on my winter coat took extra effort. I worked in a building where the copy machine was upstairs – a step was like a mountain and many times co-workers made copies for me. I was constantly fatigued – to bed at 7:30 pm exhausted and got up next morning feeling the same.

**Early 1975** I was put on 10mg Prednisone every other day and by June had I increased to 100mg every other day. I still was not improved by summer so thinking a vacation to the mountains might help, four of us headed to Colorado. We drove in hot un-airconditioned car with temps rising to over 100º - bad for MG patient! We got as far as Kansas City when chewing, swallowing and breathing were not good. During that night in July I went into myasthenic crisis in a small hospital that did not know about MG. Thankfully, I had with me a list of MGFA Medical Advisors. From that list, we located a doctor at Menorah Medical Center who knew about MG and attend me == in ICU, tracheostomy and NG tube inserted. I was at Menorah for 1-1/2 months then sent by air ambulance home to Grand Rapids hospital. Physician team thought perhaps I’d become immune to mestinon, they took me off all meds for 48 hours, and I was on respirator so I had life support during that time. No noticeable improvement, so I went back on meds. What to do next? A thymectomy was performed in September. Improvement came slowly, and in October I was finally released from the hospital after being hospitalized for 3-1/2 months. I went back to work part-time in November and resumed full-time employment in December.

Being so very thankful to God that I had survived the crisis, I felt the need to share with other MG patients what I had gone through and to encourage
others living with it and that there is hope beyond their present situation. Thus, our local Great Lakes Chapter of the Myasthenia Gravis Foundation of America was organized. We were all volunteers and the operation was run out of my home. Our chapter received our Charter from the National Foundation in 1976, and subsequently I became very active in the organization. In 1985 Rapistan donated a vacant one-room building for our office, finally moving the chapter out of my home. In 1990 the building was torn down and we went to rental properties and hired Rae Green as part-time director.

At the MGFA annual national conferences is where I really learned from others about living with MG, and the cutting-edge treatments that were being administered. Research revealed that MG is both autoimmune as well as a neuromuscular disease, which put a whole new horizon in medications used to treat the condition. Thus, the advent of immunosuppressant meds like Imuran, CellCept and Cytoxan that had previously been used by organ transplant patients.

At the annual national conferences, I saw first-hand the vast improvement in patients taking the immunosuppressant drugs, so in 1985 went to an MG specialist at Mayo Clinic where I was put on Imuran (azathioprine). My doctor said the drug wouldn’t cure my condition but would make it easier to do the things I was currently doing with great difficulty. (I also had an EMG and 2 plasmapheresis exchanges while there). It took 11 months before I even began to feel results of Imuran. It took about 5 years to really feel improvement and to taper off prednisone and Mestinon. Imuran is a miracle drug for me (it is not that for everyone). The past 15 years have been the best of my life. In 1990, I was able to bicycle the 8 miles around Mackinaw Island here in Michigan – amazing! (for 40 years I couldn’t balance on a bike!) I am so very grateful to God for this improvement and for the MGFA. To show my gratitude, in 2009 I completed 9 years of service on the MGFA national board.
I am still on 100mg Imuran/day, but have been off prednisone since 1992 and Mestinon since 2010. Most days I do not remember that I have MG and have stamina to walk in our MG 5K walks. Having had MG for 55+ years, I know the benefit of being involved in the national organization and/or a local MG organization or support group, and I encourage any patient reading this to do become involved. Sharing with and learning from other patients is a lifesaver as together we all learn that MG truly is a disease with hope!

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To find MG walks in Esther’s area or near you, please see
http://www.mgwalk.org/

Please consult
with your personal medical care team
before making any changes in your treatment.
Martin Luther

Martin Luther was diagnosed at age 35 in 1977. He began with ocular symptoms which progressed to generalized weakness. At one point early in dealing with double vision, Martin needed a hay fever shot which was Prednisone in liquid form and it cleared up his double vision. He has now been on a Prednisone regimen for over 30 years. When he went to the Mayo Clinic for a second opinion, he met his wife Shirlee. There are bonuses to having myasthenia gravis!

Martin and his wife, Shirlee, live in a small rural Kansas town, where he ran a beef jerky business for over 30 years. He has now sold that business and is busy giving away “Free Tickets.” The Free Tickets won’t get you anything, but what do you expect for free? Yes, he has a remarkable sense of humor.

For Martin, the therapy that helped him most in dealing with his myasthenia gravis symptoms has been getting his stress under control. He is a fervent believer that stress is a major contributing factor in chronic diseases like myasthenia gravis and must be controlled to alleviate symptoms. In his own case, after dealing with symptoms and medication fixes in the late 70’s and early 80’s, in 1982 he saw a psychologist who helped him learn the underlying causes of his stress and techniques to control them. For 30 straight days for 30 minutes a day
he lay on his back on his couch and listened to a bio-feedback tape, “Relaxation and De-Sensitization.” He was able to take his mind off everything – he focused on his breathing, focused on every part of his body, one by one, starting at the top of his head and working down to his toes. It worked for him. He learned how to control his stress and since then he has been on only a small dose of Prednisone. He walks two miles a day and is careful to watch his stress level, knowing when he needs to back off, and use his relaxation techniques again.

Martin recommends that anyone with myasthenia gravis consider seeing a psychologist for a mental work-up to understand why you do what you do, because understanding yourself will help you learn to deal with your stress and your symptoms. We read a lot these days about the impact stress has on our physical well-being and how it can be a trigger for flare-ups. Because of his first-hand experience, Martin is convinced this is true.

He is also eating healthy avoiding added sugars and eating lots of leaf spinach. He is feeling better and stronger. With a low dose Prednisone, healthy eating, exercise, and relaxation tape as needed, he is doing well.

Martin found the Myasthenia Gravis Association in Kansas City in the early days of his diagnosis and got help from Dr. Ronald Youmans, the Kansas City Myasthenia Gravis expert at that time. He has attended meetings in Kansas City from time to time and has made regular contributions of his delicious beef jerky to their dinner auction fundraisers.
Martin recommends using relaxation techniques.

A free app developed and recommended by the Veterans Administration is Virtual Hope Box. It has tools for coping, relaxation, distraction, and positive thinking. It has guided imagery, controlled breathing, and muscle relaxation. Go to iTunes or Google Play to download to your smartphone or preview it on YouTube.

https://www.youtube.com/watch?v=lJ7pW3luSic

If you do not have a smartphone, a website Calm has sections where you can Meditate, Breathe, Sleep, Relax to reduce anxiety, sleep better, and feel happier. You will need to sign up for the website, but most activities are free. The Calm app is available to download to smartphones on iTunes and Google Play.

http://www.calm.com

Please consult with your personal medical care team before making any changes in your treatment.
Monica Pires
Never Give up!

“The diagnosis is Myasthenia Gravis,” said the neurologist.

As a 14-year-old, my first reaction was to look away. I didn’t know what else to do. What on Earth was Myasthenia Gravis? The office became stifling, my mind went on overload. My parents asked the doctor a lot of questions, I just looked away. That whole conversation didn’t concern me. I was determined to lead a normal life, study, get a degree, become a teacher, have a family. I even knew exactly how many kids I would have, six. I was sure the doctor was wrong. Myasthenia what? Pfft... Nah.

About a year before that day, I noticed the fingers of my right hand felt strange, weaker. I opened my hand, palm down. I couldn’t keep my fingers stretched. I closed my hand, rested, opened it, and the fingers were fine, at least until they got tired. This symptom went away for a few months, and everyone forgot about it, including me.

Then, all hell broke loose. I fell down the stairs at home and seriously hurt myself. I couldn’t remember falling. Head trauma alert... I was rushed off to the ER. Tests, and more tests. An EEG, oh my God, she has epilepsy. Epilepsy?! I had never had any symptoms of epilepsy... “Well, that’s what the test shows. Take this medication for it.”

The weakness reappeared with a vengeance. I could barely walk. I had trouble chewing and swallowing. I couldn’t keep my eyes open and I saw two images. I slurred terribly and my voice would disappear after a minute or two of talking. Breathing wasn’t getting any easier either... Going to school was a nightmare. At gym classes, the teacher thought I was being lazy (I was chubby).
One day, a family friend who was a doctor, out of the blue, said “It looks like Monica has Myasthenia.” He arranged for me to have an appointment with a neurologist and off I went. When my mother mentioned the epilepsy medication, the neuro jolted out of his chair. I shall never forget the look of concern on his face. I was to see a fellow neurologist at another hospital immediately. The urgency was perplexing. Apparently, that epilepsy medication was a big no-no for MG, hence the sudden worsening of my symptoms. “Go, right now.” And off I went to the other hospital. I stayed there for two weeks to run a battery of tests. I did not have epilepsy... “The diagnosis is Myasthenia Gravis.”

The medication helped, but it didn't solve the problem. MG was taking its time to go away, I thought, still clinging on to that naive teenage hope... The wave of initial perplexity and denial turned into anger. The first few years were rough. I went through high school, college, and the teacher training program with a lot of logistic help from my parents and brother, and a considerable amount of stubbornness on my part. I couldn't use public transportation anymore so I had to be driven to and fro. I started working. Oh, boy, that wasn't easy. The students kept me going though. I worked hard, I was well-considered by my peers and I loved being a teacher.

However, I knew. Myasthenia would never go away. Deep inside, I knew that all too well. So, I had two options – pretend I didn't have it, struggle to live a “normal” life, stressing my body beyond its limits OR live with it, understand it, and cope with it. I chose the latter.

I started reading everything I could get my hands on. I read a lot about MG! When the Internet became available to the general public, I found an email mailing list owned by Stan Way. I got in touch with MGers from all over the world. I got involved. I was on the board of two MG organizations, the Portuguese Association of Neuromuscular Diseases and, later on, MGnet, the online Chapter of the Myasthenia Gravis Foundation of American. I met amazing people, some I still keep in touch with after all these years.
Life went on with ups and downs. Sometimes more downs than ups, but now I had the tools to kick back each time MG got worse. I was taking the right medication - Mestinon and Imuran, and IVIGs when in crisis. I was informed. I had a neuro I could talk to. I had a structure around me, family, friends, fellow MGers. And I had my job.

Suddenly, all hell broke loose again. This was at the height of the world financial crisis. Many countries were struggling. New legislation was passed here in Portugal that determined teachers had to work longer hours and teach larger groups of kids. My MG couldn't do it... I was forced to retire at the age of 40.

Teaching gave me a purpose. I never had kids of my own, so, seeing my students thrive, powered my psychological tenacity, even though MG drained my physical stamina. Now, teaching, too, had been taken away from me and I had nothing...

Nothing? I had plenty! That's when the writing started. I love writing. I got more and more involved in writing events. I hosted them online in a virtual world for a number of years. And I met amazing people along the way.

My MG didn't fade away as my 14-year-old self wished for. Today, my 50-year-old self has ptosis, double vision, generalized weakness, chewing and swallowing issues. These symptoms come and go. The medication helps. Rest helps. Being realistic helps. I don't look away anymore.

We have to do everything we can to accept MG. This does not mean giving in. This means understanding it and respecting it. It's difficult. Yes, it is. It's a constant struggle. Yes, it is. But there are a few things you can do!
Be active. Even if that means not moving a single muscle while watching an interesting documentary on TV or chatting an afternoon away with a friend!

Achieve something. Each day that goes by, do something you can look back at and say, I did this today. Was it to finally put away that box that was on the kitchen counter for days? Only that? Well, you did it. You put it away!

Be informed. This doesn't mean to obsess over Myasthenia. No! But knowing what the meds are all about and what new information is out there is a great step forward.

Talk to your neurologist. Doctors are always busy and short on time. Take a few notes and organize your thoughts/questions before the appointment. At the appointment, go straight to the point. And talk to your neurologist openly. He/she is your ally.

Respect your body. Have a nutritious balanced diet, a good hydration, and as much movement as possible, even if it’s only taking a few steps up and down the hall. Take your meds as they were prescribed to you. Beware of over-the-counter meds and natural/herbal products. Everything you eat/drink/take has an impact on your body. It may be fine. Or it may interfere with the MG and the MG medication. Always check with your neuro first. When the symptoms get worse, rest. When breathing is affected, don't wait, go to the ER immediately.
Meet other MGers, face-to-face or online. Some people shy away from this. They say it makes them feel depressed. They don’t want MG to “win” by acknowledging it. But you will never forget the moment when you first realize you’re not alone. That is one of the most empowering moments for a Myasthenic!

If you can, volunteer. Be participant in the MG community.

The golden rule, be active when you can and rest when you must. And never give up!

Monica Pires
Lisbon, Portugal
50 years old
Generalized Myasthenia Gravis since 1979, 38 years and counting.
Alive and kicking, even if slowly at times!

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One of the writing communities that Monica has joined is the
National Novel Writing Month  https://nanowrimo.org/
Writers are challenged to write a novel during the month of November.
She is also involved with Camp NaNoWriMo  https://campnanowrimo.org/ which takes place in April and July.
Please consult with your personal medical care team before making any changes in your treatment.
3. What was Walt Disney’s association with myasthenia gravis?
Gloria Quinones
Gloria Quinones, No Longer an Outsider

Gloria was diagnosed with Myasthenia Gravis (MG) in 1977 at the New York Eye Ear and Throat practice when she was seven years old. As a child, she did not understand what was happening or how much her life would change.

She would cry at the pediatric neurological teaching clinic when she was put through a neurological exam as a roomful of medical students watched. “Look up.” The neurologist would say. “Follow my finger.” He would push down on her arms as she tried to extend them in front of her body. It was frustrating and embarrassing.

As an adolescent with double vision, always feeling tired, and falling frequently became a huge part of her daily life. She dealt with very bad stomach aches from the medicine. She had excess saliva. Lack of concentration made school difficult. These limitations made her angry because she felt like an outsider. No one, not even herself, understood what she was going through.

Gloria has four daughters, a 15-year-old son, and four grandchildren. She cares for her grandchildren as her daughters work. She also cares for her mother and father who live nearby.

Her family recently huddled together in a four-bedroom home with sealed windows as the hurricane passed through Florida. They felt the house shake as the eye of the hurricane traveled over them. Gloria was strong during the actual event, but she was very weak for three days afterward. She wasn’t able to return to her own home for five days because there was no power for electricity. In the Florida heat and humidity, she needs air conditioning. Stress negatively affects MG and Gloria has had a huge amount this year.

She was stronger during her pregnancies and all her children have been healthy. She has had scares with her son. As a three-year-old, he had a
high fever and couldn’t walk. The doctors ruled out MG and he has grown into a strong 15-year-old.

Her ex-husband, the father of her children, had trouble understanding why she could not keep the house perfect, cook full four course meals, and care for the children. He couldn’t understand why driving the children to their various activities was so difficult for her. He had no patience with her need for rest.

She has been showing him videos of others with myasthenia gravis from Facebook and he is beginning to understand it better. She recommends that people have their family members sit in as the neurologist explains the diagnosis of myasthenia gravis. She also has fibromyalgia, thyroid problems, and migraines so she has a full plate of conditions. When she must take prednisone for flares, she has extreme pain in her joints. She takes pyridostigmine bromide, 180 mg time release at night, and Mestinon during the day. The medications have affected her stomach and teeth.

In 2012 she had meningitis and since that time she has had more speech and facial expression difficulties. She has had more symptoms with menopause and must retire to her bed early each night. She feels guilty when she doesn’t feel strong to cook meals for her son. The meat she puts out to thaw often spoils because she lacks the energy to put it back in refrigeration.

Her husband was in the military and they lived many places. When they lived in Yuma, Arizona, Gloria could not find a neurologist who would take Tricare Insurance. She was forced to drive to Mexico to get her prescription medication.

“God is like the wind” to her. He is everywhere and He has kept her out of ER’s and hospitals. She is grateful to God for blessing her with a sense of humor because it has helped her through many tough times.

She recommends patients be especially mindful of the medications given in hospitals. She has had to refuse to take medications that could harm the MG. Nurses have also tried to give her Mestinon too close together which can cause overdose symptoms.

She has worked as a Leasing Agent which is a stressful job because the leasees tend to be quite needy. She recommends that MGrs learn to pace
themselves in working. As long as the MG is under control, they can do what they want. She says, “Adjust your life around the MG. You don’t have to explain yourself.” If it’s possible to have a “work at home” job, that is even better because you can work around your body’s need for rest.

She has taken photography classes and enjoys taking Senior, Sweet 16, and other special occasion pictures. She has enjoyed using her creativity to be a professional party planner in Arizona, California, and New York.

Scrapbooking is her hobby and she’s making them for each child and grandchild. The scrapbooks full of photographs and memories will be her legacy to them. She has started a MG scrapbook with pages of teal and snowflakes.

Crafting is a big part of her life. She sews dresses for her granddaughters by hand. She makes party favors and decorations for baby showers and all types of parties. She has sold crafts at flea markets.

Gloria was diagnosed in 1977, but didn’t meet anyone with MG until recently. She attended an MG Walk in Tampa, Florida, where she saw others who looked like they had MG, but she was uncomfortable talking with them. In 2017, she attended the Myasthenia Gravis Foundation of America, Inc. (MGFA) Annual Meeting in New Orleans, Louisiana, where she became acquainted with others who shared their MG symptoms.

On the MGFA website, Gloria shared her story and said:

It's not easy feeling as if nobody understands or maybe even believes me, but now I know that there are many who actually do. I now know that I am not alone and this gives me more of a reason to want to help others. Just the emotional support itself keeps me strong and going.

She has also began hosting a support group which helps newly-diagnosed patients to learn about their condition and to know they are not alone. Her way of coping through this storm of MG is by always staying positive and looking for the best way to deal with it.
More of Gloria’s story is on the MGFA website:

http://myasthenia.org/LinkClick.aspx?fileticket=l8Equwsms0c%3d&tabid=320

To see the Videos of the 2017 MGFA Annual Meeting in New Orleans,

http://myasthenia.org/CommunitySupport/NationalConference.aspx

To find an MG Support Group in your area:

http://www.myasthenia.org/CommunitySupport/SupportGroupCalendar.aspx

Please consult with your personal medical care team before making any changes in your treatment.
Stanley Way
I was diagnosed about 1982. I know that for sure because prior to my diagnosis I had tried to get in a NASA (National Aeronautics and Space Administration) exercise program at the NASA facility. I had tried that twice and both times the exercise made me feel worse.

Then, I had an experience while driving back from Pennsylvania where I was doing NASA work at General Electric. I stopped to get something to eat which I distinctly recall was macaroni and cheese. I took a bite, chewed it up, but could not swallow it. After a couple of minutes of trying, I managed to swallow. Being an engineer, I decided to try that again. The result was the same.

When I got back to work, I scheduled an appointment with the NASA Health Unit doctor for a physical. During that exam, I mentioned the problem I had swallowing. The doctor listened carefully and then made the suggestion that it might be myasthenia gravis. She recommended that I see a nearby neurologist. I did that and told the neurologist of the NASA doctor's diagnosis. He performed some physical testing and then had a blood sample taken and had it sent to Johns Hopkins Hospital. I then scheduled an appointment at Johns Hopkins Hospital. The neurologist did some physical testing and then commented that he thought it might be myasthenia gravis but he would get the blood test results. After getting those results, he said it clearly showed antibodies that were positive for MG. He prescribed Mestinon and said that would likely work well. I started on Mestinon and immediately felt better.

After a couple of months, I decided I would try the NASA exercise program again. My neurologist approved and I was excited to realize that the Mestinon was working well. As I recall, I was on a dose of 8 Mestinon tablets per day. During my time in the NASA exercise room, I noticed that many others were jogging rather than using the exercise equipment. I decided to jog and after a few weeks of short jogs, I increased my jogging
distance from 1/4 mile to 1/2 mile to 1 mile and finally to 2 miles. I then
noticed that all the NASA Centers conducted 2 mile races twice per year. I
began running those races and was pleased that my times were improving.

Then, in 1985, while working for NASA in Southern California, I saw
an advertisement for a half marathon race. I practiced for longer distances
and then ran a race, called the Valley of Flowers Half Marathon. I amazed
myself by averaging a 9 minute per mile pace. When I returned home, I
noticed the Marine Corps Marathon in downtown Washington, DC. In the
fall of 1985, I ran the Marathon in a time of 4 hours 59 minutes. I
repeated that in 1986 with the same result. I continued to run short races
and during the next 20 years my neurologist lowered my Mestinon daily
dose until he finally told me to stop which I did and I have had no MG
symptoms since then.

I should explain that my MG symptoms began to diminish about
2000. I could tell because I had increased diarrhea. My doctor cut my
dose to 6 tablets, then to 4 tablets, then to 2 tablets, and finally no more
Mestinon. I continued running the whole time. I call it a remission, not a
cure.

I then began to notice a slight tremor at times. My neuro diagnosed
that as Essential Tremor. It wasn’t until 2010 that other symptoms caused
my neuro to think I might have Parkinson’s Disease (PD). He first called it
Benign Tremulous Parkinsonism but after a year or so said it was
Parkinson’s Disease. I was tested with an injection followed by an MRI.
The neuro said it was definite PD. The PD symptoms have continued to
slowly worsen. Near the end of 2014 I could no longer run. Still no signs of
MG.

In my MG days I noticed few patients with similar symptoms. I
realized, however, that all patients are different, both MG and PD.

Stan’s background

Stan is a Penn State graduate in Electronic Engineering (1960). He was
an Electronic Engineer/Instrument Manager at NASA Goddard Space
Flight Center. He also studied Electronic engineering at Carnegie Mellon
University.
He lives in Maryland where he has been a strong supporter of the Myasthenia Gravis Foundation of America and its chapters. He was instrumental in getting myasthenia gravis on the Internet with his MGLinks page on the Prodigy Online Service and as a member of the technology committee which established [http://www.myasthenia.org](http://www.myasthenia.org)

He and his wife Laurie were married 52 years and have four wonderful children.

Modest Stanley Way made numerous trips to Russia and around the world with a locked brief case as a NASA employee. His son shared this article.

**Goddard View** Volume 12 Issue 10 October 2016 picture on page 7

[https://www.nasa.gov/sites/default/files/atoms/files/goddardviewv12i10online.pdf](https://www.nasa.gov/sites/default/files/atoms/files/goddardviewv12i10online.pdf)

September 15, 2017 Stan wrote:

My favorite NASA Project for my 40+ years at the Goddard Space Flight Center is Cassini/Huygens Probe. A good website describing the project can be found at:


He also recommends the movie “Hidden Figures” (2016) which is reviewed at

Stanley Way was not the only person with myasthenia gravis who worked for NASA. Stan was at Goddard on the East Coast. Another MGr was at Ames on the West Coast. Dr. Harold P. “Chuck” Klein (1927 – 2001) was the father of NASA’s life sciences program. He is noted as the “Father of Exobiology” and instrumental in the pursuit of life on Mars. He was also involved in the early days of myasthenia gravis on the Internet.

Coast to coast myasthenia gravis achievers worked as NASA scientists and engineers!
And why was it important to include Stanley Way’s MG journey in this book? He is a modest person who has made a tremendous difference in the lives of thousands of myasthenics, including myself. Here is what I wrote about him and how he has influenced my life for a St Joseph Writers Guild anthology:

Stanley Way

The Person Who Expanded My World

By

Donna Whittaker

Returning from the funeral of one of the first myasthenics I had met, I was feeling lost and drifting. I had had myasthenia gravis (MG) for twenty years when I met Dick Norman and a few others at support group meetings of the Myasthenia Gravis Foundation of America (MGFA) in Kansas City. Now this big burley retired postal worker was gone. Myasthenia Gravis had become too complicated for his body to handle, and he had had reactions to treatments that had saved me the previous year.

I was feeling lost and drifting with thoughts of how this condition had challenged my friends and me. I sat at the Windows 3.1 computer and waited as it connected to the Prodigy dial up online service. The phone line crackled. I waited patiently to log on and search. I wasn’t sure what I would find, but I needed to search.

Medical Support Bulletin Board

“Wonder if it has anything about myasthenia gravis? I’ll look under the neurological conditions.” I gasped when I found users discussing myasthenia gravis. Stanley Way lived in Maryland and moderated the bulletin board. Another myasthenic Calvin from the West Coast posted how Imuran had helped him. “Imuran,
"that might help me get off prednisone." That night I read through the posts of Stan and Calvin. It was a relief to know that I was not alone with my myasthenia.

Soon I was posting and commenting on the myasthenia gravis support board of the Prodigy Medical Support Bulletin Board. I met others as well. A special one was a lady named Gingies who had been a teacher like me. Myasthenia Gravis had forced her to retire, but she prayed for others and cardinals came to the yards of those she had in her prayers. She encouraged me to try working part-time at the new Sylvan Learning Center in St. Joseph.

Stan posted a webpage with myasthenia gravis information on the Prodigy Online Service. He encouraged me to share my story about living with myasthenia gravis since childhood. At first, he linked my story "Growing Up and Living with Myasthenia Gravis" to his webpage. Later he coached me to put my story on a webpage of my own on Prodigy.

He hosted a live chat on Prodigy on Saturday evenings, but he felt other chats were needed during the week while he was at work. He was an engineer for NASA at the Goddard Space Flight Center in Maryland. Soon he arranged for me to be the weekday moderator, and I was given free internet service from Prodigy for my volunteering. Later my daughter also moderated a chat for young people affected by myasthenia gravis.

Stan continued to find ways to touch the lives of those with myasthenia gravis. With the cooperation of Prodigy, he established a listserv. Stan, Irv Beck, and I moderated the listserv which had members all over the world.
His online activities had attracted the attention of the national Myasthenia Gravis Foundation of America of which he was a board member. In 1997, he was invited to present a breakout session on “MG on the Internet” at the MGFA Annual Meeting in Indianapolis. Stan was a reluctant speaker so he asked me to share the podium with him. We prepared the PowerPoint presentation online before we met in person. At that meeting, we were met with naysayers who did not believe the possibilities.

A year later at the MGFA Annual Meeting in Chesapeake Bay, Virginia, the online myasthenia gravis community gathered to change the organization and bring it into the internet age. An online chapter, MGnet, was formed with members in Portugal, Israel, and Canada as well as all over the United States. Meetings were held in private chat rooms. MGnet broadcast MGFA annual meeting speakers live on the Internet. Patients all over the world could ask questions of the expert doctors speaking.

At the 1998 MGFA annual meeting in Florida, Stan Way and I were recognized for our worldwide myasthenia gravis awareness activities. Stan Way was the ‘technical’ person who paved the way for patients all over the world to know that they were not alone. He expanded my world beyond my wildest dreams. I gained skills, confidence, and friends. It is still hard for me to believe that a poor shy farm girl with a disease no one knows could grow to have so many skills and connections.

NOTE: For more information on myasthenia gravis, see

http://www.myasthenia.org or http://www.mgakc.org

or #IhaveHeardofMG on Facebook, Twitter, and Instagram
Please consult with your personal medical care team before making any changes in your treatment.
4. Stan Way was not the only NASA employee to have myasthenia gravis. What myasthenic chose the location on Mars where the Rover landed?
Donna Whittaker
My MG journey started at age 10. Hot summer days, I lagged my mother walking to her vegetable garden. When school started, the principal encouraged my mother to take me to a doctor because I had changed so much over the summer. I was falling up steps at school. My smile was a snarl. My speech was soft. I couldn’t enunciate m’s.

At the first doctor’s visit, my dad was upset because the doctor thought I was malnourished. As a farmer, he provided plenty of fresh food – milk, eggs, pork, beef, vegetables – and I ate well. That had been a morning visit.

The second visit was late afternoon after school. The doctor asked me to lie back on the exam table. My muscles let go.... I plopped. “Oh, my goodness girl, I didn’t expect that.” I was admitted to the hospital to test for a brain tumor. After a spinal tap and a trip to Chicago to consult experts, my St. Joseph, Missouri, pediatrician diagnosed myasthenia gravis and started prostigmin.

For that school year, I could barely do two high steps onto the school bus. I took my prostigmin as prescribed. Using my Optican wristwatch, I quietly left the classroom to go to the water fountain to take my pill at the correct time.

My grandparents thought my parents should keep me home because as farmers they didn’t value ‘book learning’ and I had a strange condition no one knew. My mother knew I loved school and sent me.

After a year of struggling with weak muscles, my pediatrician added a pink capsule to my medication regime. My droopy eyes improved, my sardonic smile disappeared, my enunciation improved, I bounced onto the school bus. By the following year, the pediatrician began to slowly decrease my medications.

Three years after diagnosis, I was in drug-free, symptom-free remission. Remission lasted through high school, college, and two years of teaching middle schoolers.
Shortly after marriage in 1972, my world changed. Symptoms returned. My legs gave way, my eyes drooped, the sardonic smile returned, and I couldn’t raise my arms to do my hair. My symptoms were worse on hot summer days. Spring and fall were better. I adapted to my limitations and trudged on. I went from doctor to doctor for four years trying to get rediagnosed. The first doctor was the Kansas City myasthenia expert. He didn’t think I had it as a child.

In college, I had one roommate who had heard of myasthenia gravis. Other than her, no one in our world had heard of myasthenia. My family and I were alone.

In 1978, I met a person who had myasthenia gravis. I was not alone. Through a myasthenia gravis clinic in Kansas City I met others who understood. At support group meetings, my family met other families who faced the challenges we had faced for over 20 years alone.

In the 1990’s, I became active in the myasthenia gravis internet community. Now I have friends who understand MG all over the world. My family’s goal has been that through awareness no other family would have to face MG alone.

At age 70, I do well on four brand name Mestinon, 60 mg, a day and continue working part-time teaching adult literacy. It’s been a roller coaster ride with far more good years than bad years. I have a huge myasthenia gravis family I would not have had without this diagnosis.

My advice to others with MG is to get involved in learning as much as you can about MG, in meeting others in person and online, in continuing your personal education, and in finding activities you can do and enjoy. If there are no myasthenia gravis groups in your area, join multi-disability groups, such as those available through independent living centers.

You can have a long fulfilling life with myasthenia gravis. By connecting with others, I now know that I am not the only one who has lived with MG for 60 years.
Donna’s answers to newly-diagnosed myasthenia gravis patients questions:

- **Will new symptoms arise years later or do you always have the symptoms you started having?**

My symptoms have varied through the years. In the beginning, I had a snarl for a smile, trouble enunciating sounds, and weakness of my extremities. I never was a strong muscular person, but the degree of generalized weakness went up and down. My worst episodes of MG were postpartum after my daughter was born and 15 years later.

After I was stabilized when my daughter was a toddler, I had 15 years of great control on 7 Mestinon 60 mg and 2 ephedrine sulfate, 25 mg a day. I ran a 24-hour insurance policy typing service out of my home before she started school. Then I returned to teaching and completed a certificate in teaching special reading and a Master’s Degree in Reading Education.

Then I had severe symptoms of speaking, breathing, and swallowing and was intubated in ICU several times.

- **Can I ever be off medications?**

Yes, I was off medications from age 13 to 29. From age 13 to 25, I attended high school and college without symptoms. At 25, my legs started giving way with me and generalized weakness took over my body. It took 4 years to get rediagnosed and back on medications.

- **Did your MG start as ocular only?**

No, I had droopy eyelids and my eyes did not focus properly so I had prisms in my eyeglasses as an adolescent. I had brief episodes of double vision – usually early in the mornings. The year I had the most double vision was the year my daughter was 15; just before she turned 15 and ½ to get a driving learner’s permit. Double
vision plagued my driving that summer. I put a towel on the dashboard of the car to help cut the glare. Of course, I had prescription sunglasses, but I had to drive with one eye closed to reduce the double vision.

One 200-mile one-way driving trip from St. Joseph to Carthage in Missouri was particularly frustrating to me. My mother, aunt, cousin, daughter and I were on a special trip to see the Precious Moments Chapel and Museum. Driving down the highway, I had double vision all the way. I did the towel on the dashboard, wore prescription glasses, closed one eye, and took my Mestinon; but nothing seemed to help. We were in my car. My mother was past the age to drive safely, my daughter and cousin were too young, and my stubbornness and persistence didn’t allow me to ask my aunt to drive my car. We had a memorable mini-vacation visiting the Precious Moments Chapel twice, the George Washington Carver boyhood farm in Diamond, Mo, and staying at the Drury Inn in Joplin.

- **What am I in for down the road?**

That is an unanswerable question because everyone is so different. For me, MG has been a roller coaster ride. I was diagnosed at age ten and took medications for three years. My teen and college years I needed no medications. Although I was never a strong person I carried on an active lifestyle of school and extracurricular activities. During my college years I went to school full-time, worked part-time, and did lots of walking around campus and its neighborhood which included the Country Club Plaza in Kansas City.

I forgot all about having MG as a preteen. I did mention my medical history when I went to student health one time for the flu. That was my only visit to student health in four years of college. They informed me the name of the Kansas City myasthenia gravis expert if I ever had symptoms return.

At age 25, symptoms of weakness returned. That is the year I was married. I was teaching language arts and oral communications at a middle school in Excelsior Springs, Missouri. My voice grew softer and softer and I lost my teaching position because my students couldn’t hear me in a classroom of 35.

The first doctor I saw was the Kansas City expert neurologist. He said I couldn’t have had MG as a child and sent me on my way. It took four years to get re-diagnosed. My symptoms would be worse in the summer and winter and I would
do fairly well in the spring and fall. We lived near the Country Club Plaza, but I couldn’t enjoy walking to it because I couldn’t step up and down off the street curbs.

A resident in the office of my primary care doctor rediagnosed me by having me squeeze a blood pressure cuff. When I continued squeezing, the gauge went down until I couldn’t get it to move. He and my doctor started the prostigmin medication I had taken as a child.

• **What were your best years and worst years since you were diagnosed?**

I have had far more best years than worst years. I was in drug-free symptom-free remission during high school and college. It took four years to get rediagnosed partly because my symptoms of generalized weakness were mild and would come and go depending on how hot or cold the weather was. I was beginning treatment with prostigmin when I became pregnant and had my daughter. I was stronger during the first seven months of pregnancy than I had been the previous four years. I was happy I could do Christmas shopping without having to sit and rest in all the shoe departments.

I did have some serious weaknesses during the last couple of months of pregnancy and my doctor referred me to a high-risk pregnancy specialist. My daughter was born by natural birth as the specialist allowed my body to do its job in its own time. Hormonal changes upset my myasthenia and I had several rough months after delivery. I ended up under the care of the Kansas City MG specialist who had said I couldn’t have had MG as a child. He changed my medication from prostigmin to the longer acting Mestinon.

I continued to be weak the first year of my daughter’s life. I was unable to walk up and down steps to do the laundry in the basement. She was always large for her age so I couldn’t carry her. I used an umbrella stroller to move her inside the house and to the car even though the car was only a few steps from our front door. I rocked her in the rocking chair because I couldn’t walk around to lull her to sleep. I gave her a bath on a large towel in the middle of our bed. I didn’t risk baby bathtubs.
She had been monitored for three days in NICU where she showed no signs of MG. She grew strong and fast. At three months, she was going everywhere using a circular walker. At eight months old, she was walking unaided.

Ephedrine sulfate was added to my medication regime. We were preparing to leave to visit my father-in-law in Wyoming. My mother was leery about my starting a new medication as we were leaving town. I told her “Don’t worry. It’s the little pink capsule I took as a child.” Within a few months, I was not only doing our own laundry and carrying a now heavier daughter around, I was the Regional Manager for an insurance policy typing service using typists in their own homes. I typed hours and hours a day as the policies picked up one morning had to be typed and returned to the companies 24 hours later the next morning. In addition to typing, I hired and trained typists, drove boxes of policies between companies and typists, and carried on with our family responsibilities.

For 15 years, I was well controlled on 7 Mestinon 60 mg and 2 ephedrine sulfate 25 mg a day. I taught Language Arts, Oral Communications, Drama, Reading, and more part-time and/or full-time. I directed plays and held debate tournaments. I finished a certification in Special Reading and my Master’s in Reading Education.

Then came the worst years. I had an abscessed tooth. My dentist did the first stage of a root canal. Then he was killed in a car accident. My MG spiraled as the dental practice had someone come in and finish his work. I had speech, swallowing, and breathing problems. 1992 I spent Easter and Thanksgiving in ICU. I was dragging all summer and sleeping in a recliner in the basement so I could breathe. These were in the ICU at our local hospital. Treatment consisted of high doses of steroids.

September 1993, more dental problems and an antibiotic given for them landed me in ICU again. This time the steroids were even higher doses. When I couldn’t move my legs due to steroid myopathy, I transferred to a Kansas City hospital where as soon as I arrived the 500 mg of solumetrol a day was reduced to 180 mg. I had five plasmapheresis treatments and then five IVIG treatments. I could begin to move my legs again on the first IVIG treatment. Physical and occupational therapy treatments followed so I could relearn to walk and strengthen my body.
I had more plasmapheresis treatments in 1994. Each time we tried to reduce my prednisone my MG crashed. Then my neurologist added Imuran. When it took effect (which takes several months), I was finally able to very slowly wean off the prednisone.

Now over 20 years later at age 70, I only take 4 brand name Mestinon, 60 mg, a day and still work part-time because I want to be active. I have again had a long period of great control and few MG symptoms.

- **What seemed to help you most?**

What seemed to help me the most was ephedrine sulfate that I took both as a child and as an adult. I was able to live many “normal” years before MG got complicated and I needed more aggressive treatments. Prednisone was given when MG got complicated, but I can’t say that it helped me the most. It took an MG expert to wean me off prednisone after an inexperienced local neurologist overdosed me to the point of steroid myopathy. IVIG helped the most to help overcome the myopathy. Then Imuran helped the most to wean completely off prednisone and resume living a very “normal” life.

Other than medications, living a balanced life with lots of interests and proper rest and nutrition along with light exercise has helped me survive many years since MG was diagnosed. Also, fire any doctors not willing to consider your myasthenia gravis as they treat any conditions. It has taken MG experts and doctors willing to learn more about MG to keep me relatively healthy.

- **Can I ever have a “normal” life again?**

During the 1990’s, I wondered if life would ever be “normal” again. I feel I live a “normal” life. I have been married 45 years. We travel wherever we can visiting with friends and relatives, sightseeing, and going to conferences and events. We have been walking regularly with a group of friends for over 20 years. We have a dog and our daughter has two dogs who keep us busy walking between the group walks. We have an MGB car and do activities with our car club. My husband repairs antique clocks and we have booths at an antique mall. I do a lot of volunteering within disability communities, not just myasthenia gravis. And, I’ve been in my present position teaching full or part-time since 2000.
• Would you try a natural supplement?

I do use natural supplements. My primary care doctor who rediagnosed me advised me to take zinc. I do feel better when I take it. My present primary care doctor has me taking Vitamin b12, Vitamin D, and calcium. Whenever I have onset of a cold or other infection, I take Vitamin C.

There is no natural supplement that will cure MG, but there are supplements that can help our bodies stay as healthy as possible.

• How do you handle medication side effects?

Taking lower more frequent doses has been best for me in the long run on most medications. Always take Mestinon or its generic with food. When taking prednisone, avoid using much salt as it adds to water retention and weight gain. When I start a new medication, I take half a dose to see how my body will react to it. Sometimes it is necessary to call the neurologist to help get non-MG medications changed to ones that are more tolerated.

• How hard is it to get insurance?

I have been refused insurance several times. The first time was for mortgage insurance on our first home. It surprised my husband that they wouldn’t insure me. For ten years, my husband worked for a small family business without medical insurance. When the son assumed leadership, he was arranging medical insurance for all the employees except my husband and our family because of my MG. That is when my husband took a full-time position with the Missouri Air National Guard so we would have insurance.

• How hard was it or is it in the work force?

Before the ADA, I lost two teaching positions because of voice problems relating to myasthenia gravis. Since the severe problems I had during the 1990’s, I have been more open about having MG when I apply for jobs. When I returned to work in 1998, the uncle of an owner had MG so they knew a little about it and hired me anyway. In 2000, I applied for my present job after learning about it through the daughter of a person in my local MG support group. From the start, my boss knew I would be active in MG and cross disability groups, and she’s allowed me to have a flexible schedule when necessary.
• **Did MG change your career choices?**

I modified my career due to MG. I began teaching language arts to middle schoolers. I had large classes. In 1990, I achieved a special reading certification which allowed me to teach smaller groups. Presently I teach literacy to adults below a 2nd grade reading level. The classes are even smaller and the students are much more willing learners. Having achieved a Master’s degree in reading education, I do a lot of the testing for our entire program. I have been involved in research projects at the state and national level and attended many conferences.

• **Are companies, businesses, bosses understanding?**

My bosses have been understanding.

• **How much worse is your condition now versus in the beginning?**

My condition is very well controlled presently. My role model is Frankie Wu who was diagnosed in the 1940’s and in an iron lung. When she was in her 80’s, she was in remission and dancing. I am not yet 80, I have 10 more years, but I plan to be dancing when I am 80.

• **Do you regret doing any specific treatment for MG?**

In 1993, I regret not moving from our local hospital to a hospital in Kansas City with more myasthenia gravis experience sooner. But when you are on machines in ICU, you don’t consider moving to another hospital. Yes, it is possible with coordination between medical teams and using an ambulance for the journey.

• **Have you developed other illnesses due to MG or the treatments?**

When I was on high doses of prednisone, I developed sugar diabetes. When I was hospitalized, I was receiving insulin shots. At home, I had to take a diabetes medication until I was able to reduce the prednisone. To this day, I have to watch my diet and exercise to control my blood sugar.

I did have stress fractures in the bones of my feet as a result of the prednisone. I take calcium and try to do weight bearing exercises to stave off osteoporosis.

• **Have you had any periods of remission?**
Yes, I was in drug-free, symptom-free remission from the age of thirteen until the age of twenty-five.

- **Have you had any periods of control of symptoms that were medication dependent?**

I had a fifteen-year period of control of symptoms on 7 Mestinon 60 mg and 2 ephedrine sulfate 25 mg a day. During that time, I did graduate level work at the University of Missouri-Kansas City. I taught language arts, oral communication and reading to all ages. I also was regional manager for an insurance policy typing service with a 24-hour turn around.

After several years of complications, I have regained control of symptoms with 4 Brand Name Mestinon, 60 mg, a day, and I have been teaching full and/or part time for the St. Joseph Adult Education and Literacy program since 2000. At age 70, I am continuing to help with the assessments of English Language Learners and teach a literacy level class.

- **How do you maintain a fighting spirit or a positive attitude?**

I have had a fighting spirit all my life because I didn’t have a choice if I wanted to truly live life.

Long ago, I found that a positive attitude was healthier for me to have than a negative one. Negativity begets negativity. Positivity opens the door for more positivity.

- **How ‘normal’ do you feel your life has been?**

Since myasthenia gravis impacted my life as a child, normal for me is living my life on my own terms to the fullest possible. I feel my life has been ‘normal’ as I have attended school, married, had a child, worked, volunteered, and been active within my community.

- **What is the wisest step a new patient can make?**

The wisest step a new patient can make is to find a doctor who truly understands myasthenia gravis. Listen to your body and discuss what is happening with that MG expert.

- **What is one thing you wish you had known when you were diagnosed?**
I was diagnosed long before the internet and long before patients had access to the names of their medications. When I began researching myasthenia gravis as an adult, I found very brief paragraphs describing it so I still had very little knowledge. It would have been nice to have known others with it to compare symptoms and treatments.

- **When you face a setback, what do you do?**

I research my options. I find the most knowledgeable medical professional. I am not afraid to move on to another medical professional to get the best treatment. I try to live a healthy lifestyle. Then I ‘let go and let God’ as there are situations over which I have no control.

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Email Hope4MGLiving@gmail.com for consent to use.
Our family hobby as written for the Kansas City MG Car Club newsletter:

The Whittaker Bumblebee and Blue Belle, too

By

Donna Whittaker

“Mom, Tracy and I saw a cute little yellow car for sale on the Belt!” Amy informed me and that began our MG car adventure.

A day or two later, we stopped to look at it, a yellow 1978 MGB, at the St. Joseph Toyota dealership. Amy did the test driving as my legs were too short to reach the pedals. We cruised I-29 for a few miles and everything seemed to be in working order. “Mom, you need this car. You have MG and it’s an MG! It’s even yellow, your favorite color.”

Back at the dealership, the salesman was determined to make a sale. I told him I needed to talk to my husband. He expected me to call Roy right then and there. I said “You don’t understand. He is deployed in Qatar. We talk once or
twice a week. It will be a day or two before he calls home.” Amy was outside on her phone typing an email to her dad telling him what I was doing.

The price came down. Amy is standing there drooling. Roy was checking into getting me a new Mustang through the military plans. I love Mustangs, but we’d recently paid off the loan on my car. I didn’t want another payment.

“I really need to talk with my husband.”

The dollars continued to fall off the sticker price. “We need to move the MGB. A local dentist traded it in on a Toyota Spyder.

I was taking deep breaths, but I wasn’t ready to buy it without talking to Roy.

More dollars fell off the sticker price.

I took a deep breath and pulled out the checkbook. At least we wouldn’t have any car payments. Amy was astonished. A few minutes later we owned a yellow with black trim 1978 MGB, and new adventures were ahead of us.

That night I emailed Roy that he didn’t have to buy a Mustang; I’d bought an MGB and we had no car payments, the B was ours free and clear. When he read the email, he said “Guys, you won’t believe what my wife bought – an MGB! An electrical nightmare!”

Amy, the dogs, and I enjoyed regular trips to the local Sonic and the dogs were spoiled with treats there until Roy returned home. We only ventured the twenty-mile trip to my mother’s home in Gower a few times since we didn’t know much about MGB’s.

The first trip to Kansas City was to celebrate Roy’s and a friend’s birthdays. After dinner at the Corner Café, the electrical problems started. Amy learned to pop the clutch as Roy pushed. We came back to St. Joseph 169N through Gower. I dropped by mother at her home. Amy managed to keep the MGB going, and Roy and Amy kept rolling on to St. Joseph.

A few months later, we discovered the KCMGCC in the Kansas City Star cars section. We joined it and the real adventures began: slim runs, fat runs, Guy
Fawkes, drive-ins, car shows, crystal digs, Christmas parties, a 90th birthday surprise, and more.

Another 1978 MGB joined our family in 2002. Yes, as we’d been told families rarely have one MGB – they multiply. Blue Belle joined Bumblebee.

And KCMGCC has helped in the awareness of my other MG – myasthenia gravis – members have made donations to fundraising events. They even showed their cars at the St. Joseph antique mall Hunterland to help promote MG awareness in June.

Roy likes to say that MG - the cars -and MG - the chronic health condition are alike – sometimes they run well, sometimes they don’t move.

I am grateful for all the wonderful friends our family has from that spontaneous car purchase. We are looking forward to many more adventures.

NOTE: For more information on my other MG, see http://www.myasthenia.org or in the Kansas City area http://www.mgakc.org

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Websites featuring Donna Whittaker:

The Motivational Editor Debra L. Butterfield’s interview:

Please consult with your personal medical care team before making any changes in your treatment.
More Myasthenia Gravis Stories On the Internet
Myasthenia Gravis: 25 Years and More

Lisa Gigiliotti
http://myasthenia.org/LinkClick.aspx?fileticket=yH8CWNkJFA4%3d&tabid=320
Telling her story for MGFA
https://www.youtube.com/watch?v=YpUH_G22z8w
34-minute presentation at MGFA Annual Meeting
https://www.youtube.com/watch?v=NgBZBCQ1pFU

Ingrid Grice
http://myasthenia.org/LinkClick.aspx?fileticket=P1sRFSEeVWM%3dR&tabid=320

Betty Johnston – “PACE not PUSH” – diagnosed 1990
http://myasthenia.org/LinkClick.aspx?fileticket=G38sR2hdLO4%3d&tabid=320

Suzanne Rogers of “Days of Our Lives”, diagnosed in 1984
https://en.m.wikipedia.org/wiki/Suzanne_Rogers

Tommy Santora – diagnosed at age 12
http://myasthenia.org/LinkClick.aspx?fileticket=JoJRB7wqTMT%3d&tabid=320
Roger Smith
Husband of Ann-Margret and actor, diagnosed in 1980, died 2017
https://en.m.wikipedia.org/wiki/Roger_Smith_(actor)

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Richard Whitney diagnosed 1954
http://myasthenia.org/LinkClick.aspx?fileticket=H43aD1ebEtE%3d&tabid=32

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For more myasthenia gravis patient stories, see
http://myasthenia.org/CommunitySupport/PatientStories.aspx


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Please consult
with your personal medical care team
before making any changes in your treatment.
5. What pro football coach won championships in both the NFL and AFL?
Resources
Resources for myasthenia gravis information

Clinical Overview of MG

MYASTHENIA GRAVIS - A SUMMARY
James F. Howard, Jr., M.D.
Department of Neurology
The University of North Carolina at Chapel Hill

http://www.myasthenia.org/HealthProfessionals/ClinicalOverviewofMG.aspx

- Emergency Management of Myasthenia Gravis
  Emergency Care by First Responders


- Emergency Card to print and carry

http://myasthenia.org/LinkClick.aspx?fileticket=EGx2awFeoKo%3d&tabid=82

- myMG app to track meds and symptoms

http://mymg.myasthenia.org/home
• Drugs to Avoid
http://www.myasthenia.org/LivingwithMG/DrugstoAvoid.aspx

• What makes myasthenia gravis worse
http://www.myastheniagravis.org/about-mg/what-makes-mg-worse/

• Single Breath Test for Myasthenia Gravis
https://www.youtube.com/watch?v=r-MeOiCMTAQ

by

Alice White Kaminski
with contributions by Christy Lier
Published on Nov 18, 2014

This is a video I made to help my friends stay safe when having difficulty breathing with Myasthenia Gravis(MG). MG is a neuromuscular disease that causes muscle weakness. All patients are unique and are affected differently, so they are sometimes referred to as Snowflakes. Some of the more common symptoms of myasthenia gravis are droopy eye lid(s), double vision, slurred speech, difficulty chewing and swallowing, shortness of breath and limb and muscle weakness.

The Single Breath Test: The best way to test your own lung function when you have MG weakness is the Single Breath Test. To do a Single Breath Test you take a deep breath. As you count out loud, count from 1 to 50. If you can get 35+ your breathing is really good. From 25 to 35…it is time to start thinking about a nap or possibly a booster of mestinon if you use it that way per your doctor. 20-25...Call your doctor because you are in need
of some further treatment. Under 20 is the danger zone...go to the ER or Urgent Care. You are at risk!!

Other aspects of your condition to observe during this test are:

1) VOLUME OF VOICE: The volume of your voice needs to be audible at what would be considered "one on one conversation level". Because MG can affect the volume of our voice even on a good day, it is important to consider your "normal" volume level. If it is much softer, then it should be a warning sign of a decline as well.

2) SPEECH ARTICULATION: MG often affects the clarity of our speech articulation. When doing the breath test, if your speech is "Slurred" more than usual, this too needs to be considered a warning sign.

3) VOCAL QUALITY: This is different from the volume of our speech. Vocal quality takes into consideration the tone/pitch and resonation. Here are some things to listen for:

   A]: Deeper or Lower Tone. When MG exacerbates it is common to hear a change in vocal tone. Typically, the vocal tone will become deeper/lower, but it can also become higher pitched.

   B]: Raspy, breathy, harsh or strained sound of the voice

   C]: Nasality....Typically, MG causes "Hyper-Nasality" due to weakness of the soft palate. The voice will sound like it is resonating in nasal cavity, with air escaping through the nose vs your mouth.

   This is my 'layman's explanation' of the test. You can do an internet search for it also for a more technical, medical explanation. Be safe and consult your doctor about using this tool!!

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Email Hope4MGLiving@gmail.com for consent to use.

NOTE: The pulse ox readings do NOT show the degree of breathing problems a myasthenic is having. The reading may be within normal ranges and the myasthenic’s muscles are not working properly to breathe adequately.
The prayer Donna Whittaker silently says over and over when she is having a breathing crisis is

**Prayer for Protection**

The light of God surrounds us;
The love of God enfolds us;
The power of God protects us;
The presence of God watches over us;
Wherever we are, God is!

She has had several crises and believes that God has saved her to spread hope to all who have been diagnosed with myasthenia gravis.

- **Videos on a variety of topics from reliable sources**
  
  [http://www.mgakc.org/videos.html](http://www.mgakc.org/videos.html)

- **Podcasts**
  
  [http://myasthenia.org/LivingwithMG/PodcastEducationalSeries.aspx](http://myasthenia.org/LivingwithMG/PodcastEducationalSeries.aspx)

- **Practical Living With MG Tips**
  
  [http://www.mgakc.org/living-with-mg.html](http://www.mgakc.org/living-with-mg.html)
  
• Become a part of the solution, register as a myasthenia gravis patient in the United States:
  https://mgregistry.soph.uab.edu/MGRegistry/PortalLogin.aspx

  Please consult with your personal medical care team before making any changes in your treatment.
6. Why are snowflakes scattered throughout this eBook?
1. Aristotle Onassis – he wore big sunglasses to shield his droopy eyelids
2. Her husband manager Roger Smith was diagnosed with myasthenia gravis in 1965. He died at age 84 in 2017. She has been a long-term spokesperson for the Muscular Dystrophy Association.
3. Sleepy the Dwarf was modeled on a friend of Walt’s who had droopy eyelids due to myasthenia gravis.
4. Harold P. (Chuck) Klein
5. Weeb Ewbank who attended the Myasthenia Gravis Foundation of America Annual Meeting in Kansas City, Missouri, in 1980 as he had myasthenia gravis.
6. Years ago, the snowflake was chosen as a symbol for myasthenia gravis by a group of myasthenics on the Internet because each person is so different and reacts differently to treatments. It has no political meaning. Snowflakes were often crocheted and sent to fellow myasthenics who were going through tough times by the “Snowflake ladies”.
In conclusion, words of wisdom and hope for the newly diagnosed:

https://www.youtube.com/watch?v=ekkMTGp0TQ&feature=youtu.be

from Atlanta, Georgia

My hope is that this eBook has brought understanding and hope to those reading it. Many live long productive lives after being diagnosed with myasthenia gravis. Twenty-five years was chosen as a random number that seemed significant; however, many of us have lived – really lived – 40, 50, 60 years or more with myasthenia.

Get involved with the organizations linked to this eBook. Join groups on the Internet.

You will never need to be alone with your myasthenia.
PAY IT FORWARD

If you know someone newly diagnosed with myasthenia gravis and struggling to come to terms with what is happening to their body, please have them email Hope4MGLiving@gmail.com to have a free copy of this eBook sent to them.

If you have a family member who needs to read this information, please have them email Hope4MGLiving@gmail.com for a free copy of this eBook.

If you know a student in a medical program or a medical professional, please have them email Hope4MGLiving@gmail.com for a free copy.

Together we can spread the understanding of our condition.

This eBook is free; however, readers may make a tax-free donation to organizations that serve those with myasthenia gravis.

Myasthenia Gravis Association (MGA)
www.mgakc.org/

Myasthenia Gravis Association of Western Pennsylvania
www.mgawpa.org/

Myasthenia Gravis Foundation of America (MGFA)
www.myasthenia.org/
DONNA L. WHITTAKER

ABOUT THE AUTHOR

Donna L. Whittaker is a lifelong reader and writer. Her senior year in high school she was the Editor of the school yearbook. Writing has been an important part of her employment and volunteering throughout her life. She was the editor of the Myasthenia Gravis Foundation of America newsletter for several years. She has written numerous articles on aspects of living with myasthenia gravis and was one of the first myasthenics to share her experiences by having a website devoted to living with this condition beginning in 1996. She is the author of W. T. Rawleigh, His Life, His Company and Collectibles 1889-1989 and several contributions to “Young at Heart”, “Capper’s”, and St. Joseph Writers Guild anthologies.

Her latest work is an eBook for those diagnosed with myasthenia gravis to give them hope for living a long life with this chronic condition. She herself was diagnosed as a child in 1957. She has had a complete remission and several crises where she was on life support. She is the first college graduate in her family. She
has a Master's Degree in Reading Education from the University of Missouri-Kansas City. She has been a teacher with the St. Joseph Adult Education and Literacy since 2000.

She has a supportive family, her husband of 45 years, one daughter, and canine companions. Her volunteer activities have included not only being on the Board of Directors and various committees of myasthenia gravis organizations, but also being a Board Director of the Midland Empire Resources for Independent Living for ten years. She has been a speaker at local, state, and national disability conventions.

Contact

Email: Hope4MGLiving@gmail.com

As a newly diagnosed myasthenia gravis patient, you may be experiencing many symptoms that come and go. They may be worse in extremely hot weather or extremely cold weather. Some days you can do what you need to do. Other days you can’t do the same activities. Your friends and family do not understand. This eBook is a tool to help you explain the unexplainable.

The purpose of this collection of myasthenia gravis life stories, websites, and day-to-day living strategies is to give hope to newly diagnosed patients and those going through tough times that they can live life to the fullest.