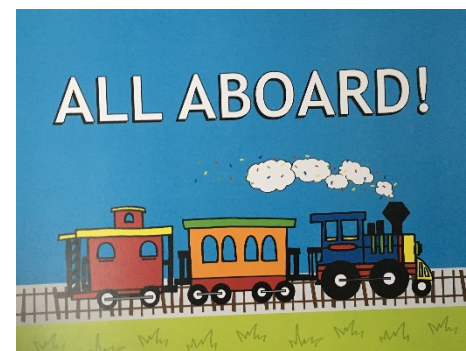




The MG Experience[©]

By Rebecca Molitoris

May 12, 2020





The activities suggested in this packet may be used to simulate what it feels like to have severe muscle weakness. These activities are not meant to be done by MG patients who are already experiencing muscle weakness. Please use adult supervision, caution, and common sense when following the suggested activities.

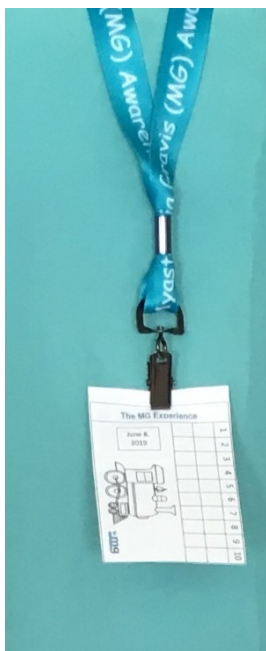
NOTE: Stations were set up on tables placed strategically for social distancing. One Station or activity per table. For Covid-19 safety, use disposable or single use items whenever you can (ie. disposable stacking cups) Clean all surfaces and equipment in between participants.



The pages contained in this MG Experience packet may be duplicated and printed as needed to produce your own MG Experience for the purposes of education and awareness only. This kit shall not be used or duplicated for personal profit or gain. All rights reserved © Rebecca Molitoris 2020

Ticket Booth

At the beginning of the experience, each participant is given a lanyard (optional) with an MG Experience Ticket attached.

This ticket is stamped or punched at each station and the lanyard goes home with each person. (Optional) (see pg. 22 for printable tickets)



MG EXPERIENCE	1	2	3	4	5	6	7	8
	 							

ENERGY STATION

A Pocketful of Nickels




by Beverly Nason (Granny Bev)

- On a good morning we wake with a dollar's worth of invisible nickels in our pocket, or perhaps we fit them after our first dose of Mestinon.
- We must decide how to spend this precious supply. Shall we shower, dress, make the bed, have breakfast, go to a job, and recklessly spend them all at once?
- Perhaps we should use just twenty-five cents, and dress without the shower or shave and leave the bed for later., and spend five to fifteen cents for breakfast. We alone may judge from our recent experience. Having decided, we act, and our precious deposit is made into an invisible slot filled with invisible batteries.
- These batteries kick in slowly and we drain their reserve. When it is close to being gone, we force ourselves to rest.
- As the day progresses, we decide to do a small chore. The shave, shower, shampoo? Five more nickels perhaps? The bed? One nickel perhaps. Cleaning house? Going to work? How many nickels will we have to spend today? For many of us, we can barely afford one nickel at a time today.
- If we have the luxury of time for a rest period or nap, we might waken with a sudden new supply of nickels in our pocket. Probably our next dose of Mestinon will provide us with a fresh supply. For others, we may find we've chosen unwisely and squandered our day's wealth or borrowed from tomorrow's.
- The debt must be repaid and time in bed will be the price. Sometimes, life will surprise us with a pocketful of nickels! We can gamble them all away or spend them gratefully.
- When we awake morning after morning with pockets full of nickels Such an abundance that we no longer have to count them, we have achieved Myasthenia Gravis remission!



The next stop along the MG Experience track is the Energy Station and a poem by “Granny Bev” Nason. Every participant receives their “pocketful of nickels” (about 10) to spend at each station. When a person runs out of nickels, they can rest to receive some more.




How To:

1.	Stack six cups on top of each other and then unstack	
2.	Place 1 weight on each hand	
3.	Stack the same six cups on top of each other and then unstack	
4.	Notice: What happened? Could you feel the difference? How easy was it the second time?	
5.	If you want, place 2 weights on each hand and try to stack again	

See page 20 to make your own hand weights

STATION TWO - LEGS

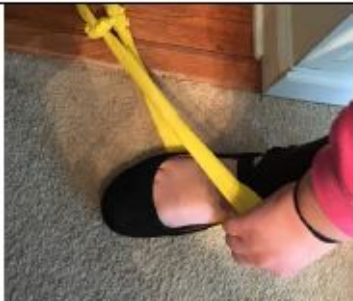

How To:

1.	Step up carefully on the stool one leg at a time and back down again	
2.	Place a weight on each leg	
3.	Now step up and back down again	
4.	Notice: What happened? Could you feel the difference? How easy was it the second time?	

See page 20 for instructions on how to make your own leg weights.

STATION TWO – LEGS PART TWO


LEGS Part Two –

1.	Carefully slip the resistance band over your foot and around your ankle	
2.	Try to walk forward as you normally would do	
3.	<p>Notice:</p> <p>What happened? Could you feel the difference from your normal walk?</p> <p>How easy was it to walk against the band?</p> <p>Did your muscles feel tired?</p>	

IMPORTANT!! Attach the other end of the resistance band to something that will not move like a solid table leg or other solid structure!

STATION THREE - EYES

How To:

<p>1. Place one of the special glasses in front of your eyes. Rest the bridge of the glasses on your nose. With your eyes open, look around you. How much do you see?</p>	
<p>2. Now leaving the special glasses in place, try and read the airline itinerary</p>	
<p>3. Notice: What happened? Were you able to read it? Would it be hard to go through your day seeing just a small amount around you and everything double?</p>	

STATION THREE - EYES

This is a sample of the type of copy that participants were asked to read. You may choose to use only pictures instead.

ABCDEFGHIJKLMNOPQRSTUVWXYZ
ABCDEFGHIJKLMNOPQRSTUVWXYZ

abcdefghijklmnopqrstuvwxyz
abcdefghijklmnopqrstuvwxyz




12345678910

Does this sentence look normal to you?
Does this sentence look normal to you?



STATION FOUR - BREATHING

How To:

1.	Pick a straw Place it in your mouth and breathe through it	
2.	Now take a cotton ball and flatten it somewhat	
3.	Stuff the cotton into one end of the straw and place tape over end to hold cotton in place	

IMPORTANT! Do not forget to place tape over the end of the straw to avoid accidentally sucking in the cotton ball!

STATION FOUR – BREATHING (CONT.)


4. Place the opposite end in your mouth and try to breathe through the straw again.



5. Notice:
 What happened? Was it harder to breathe?
 Where did your muscles feel tired?

**** Please take your straw home with you. It is meant to be reused. ****


STATION FOUR – BREATHING PART TWO

1.	Breathe normally. Notice how your chest feels when you breathe	
2.	Place the vest on and breathe again.	
3.	Notice: What happened? Could you feel the difference from your normal breathing? How easy was it to breathe while wearing the vest? Did your muscles feel tired?	

NOTE: This same effect can be achieved by laying a weighted blanket, or large weighted bean bag over the chest and trying to breathe.

STATION FIVE – CHEWING



How To:

1.	Take one small marshmallow and place it in your mouth and chew	
2.	Now Place one large marshmallow in your mouth and try to chew CAUTION: Choking Hazard! Be Careful and spit it out if you are unable to chew it	
3.	<p>Notice:</p> <p>What happened? Could you feel the difference?</p> <p>How easy was it to chew the second time?</p>	

IMPORTANT!! Please use adult supervision of marshmallows to avoid choking hazard!

STATION SIX – MUSCLE CONNECTION

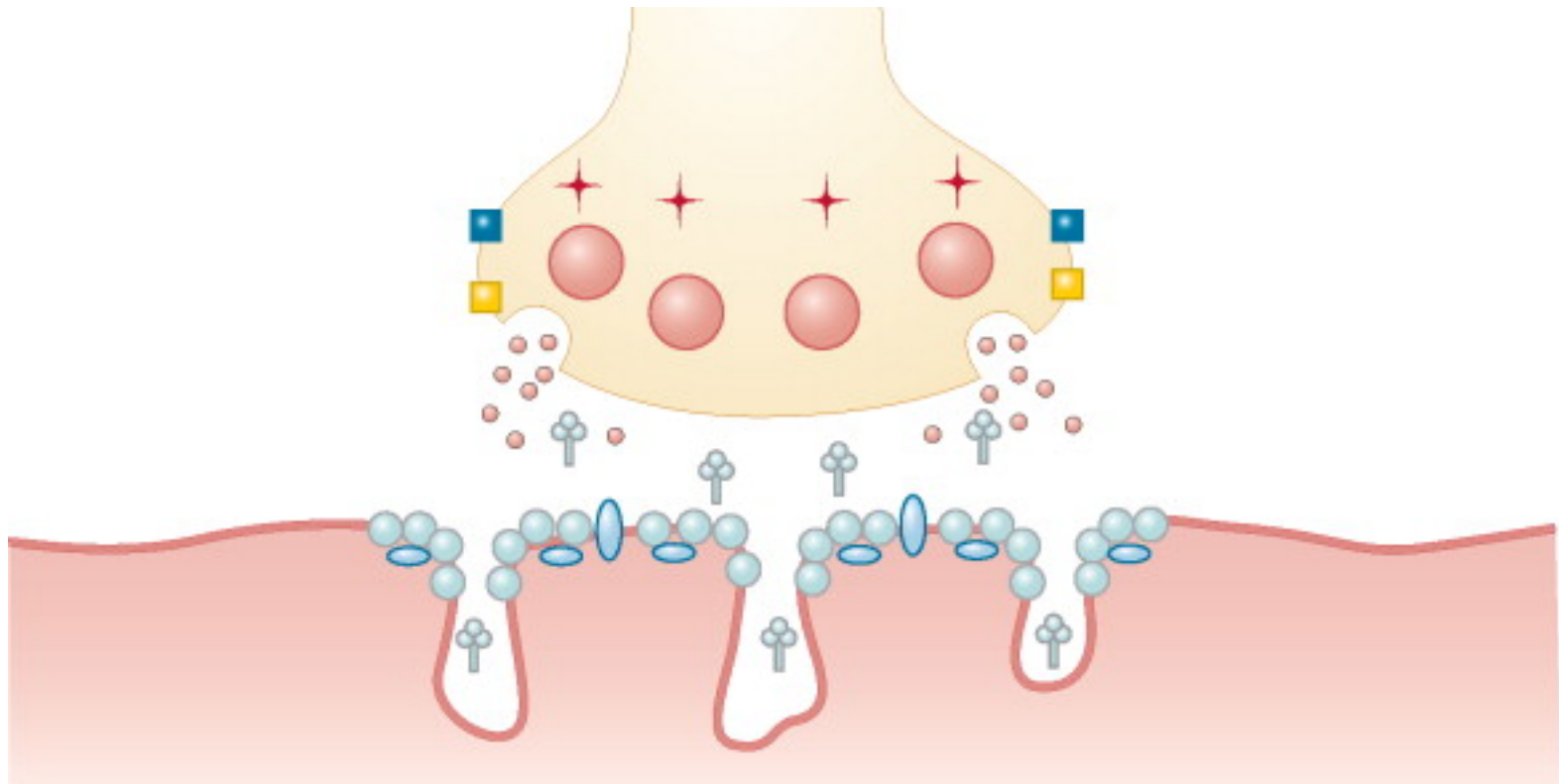
HOW TO:

<p>1. Find a partner. Each one should pick up a mitt marked either NERVE or MUSCLE. Toss the ACh (acetylcholine) bag back and forth between the unblocked mitts.</p>	
<p>2. Now change mitts to the ones which are partially blocked with AChR or MUk antibodies and toss the ACh <i>ball</i> this time.</p>	
<p>3. Notice: What happened? Were you able to catch the bag as well in the partially blocked mitts?</p> <p>This exercise represents the blocked message that occurs between the nerve and muscle causing weakness in someone with MG</p>	







NOTE: This could also be done using four regular baseball mitts and gluing ping pong balls inside of two of the mitts. Play catch with the unaffected mitts first then switch to the ones blocked by the ping pong balls.





STATION SIX – MUSCLE CONNECTION (CONT.)



Targets for Autoantibodies


-  Voltage-gated calcium channel (VGCC)
-  Voltage-gated potassium channel (VGKC)
-  Acetylcholine receptor (AChR)
-  Muscle specific kinase (MuSK)

Targets for Genetic Defects

-  Choline acetyltransferase (CHAT)
-  Acetylcholinesterase (AChE)
-  Acetylcholine receptor (AChR)
-  Receptor aggregating protein at the synapse (RAPSyn)

STATION SEVEN – NAVIGATION

How To:

1.	Pick a walker and center yourself within it	
2.	<p>Keeping BOTH hands on the walker. Navigate through the obstacle course CAREFULLY. (If you get stuck, ask for help) NOTE: This is NOT a race!</p>	
3.	<p>Notice: What happened? Which surface was the hardest to push through?</p> <p>Why is it important to keep floors and walkways cleared for someone using a walker or wheelchair?</p>	

STATION EIGHT – MEMORY ROCK

How To:

Pick a rock and choose a sharpie or paint marker to decorate it



Carry your rock to let the weight of it remind you how it feels to have weak muscles

****Don't forget to put your name on your rock****

Along the way we placed *MG Myths or Facts* decision boards where each person could guess the answer then lift the cover to reveal the correct answer.

MG Fact
or Myth?

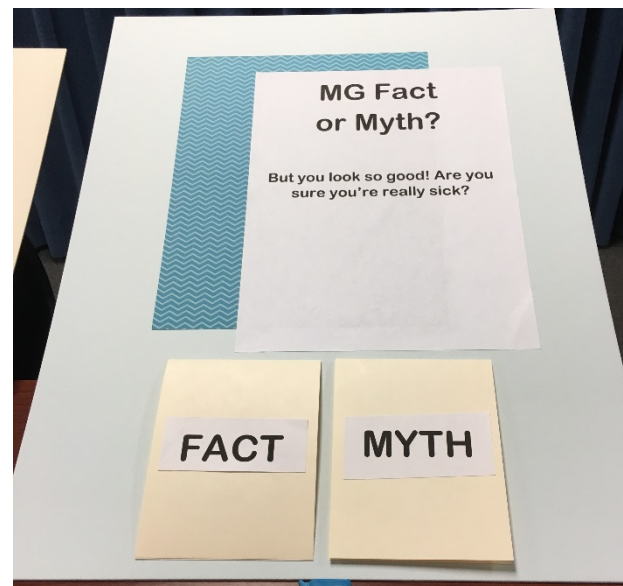
If most of these MG experiences here today involve using extra weight to demonstrate weakness, shouldn't a person with MG just lose weight and they'll get better?

MG Fact
or Myth?

I've heard of people with MG getting cured with vitamins. Is there a simple cure for MG?

MG Fact
or Myth?

Exercise gives you energy, right? So, shouldn't a person with MG exercise more to feel better?





Supplies Needed:

Small plastic cups for stacking
Hand weights (or make your own (pg. 20)
Small step stool
Resistance bands
Leg weights (or make your own pg. 20)
Smoothie or other disposable straws
Cotton balls
Tape and glue
Card stock or heavy paper for printing
Coins
Mini and Super Large Marshmallows
Popsicle sticks

Hook and Loop Mitt and ball
or baseball mitts and balls
Small rocks
Paint, markers, and or stickers
to decorate rocks
To make weights: cloth 9"x36"
and /or grocery bags beans, corn,
or pea gravel, rubber bands

To make your own hand or leg weights:

If you wish to sew more permanent weights:

1. Cut a strip of cloth approximately 9 " x 36"
2. Fold in half with right sides together so that the cloth is now doubled and measures 9" x 18 "
3. Sew up both side seams on the long edges
4. Turn cloth right side out and fill halfway with heavy beans, corn, or pea gravel
5. Sew closed the last short side
6. Manipulate strip so filling is roughly in the middle
7. Tie a rubber band close to the filling on each side leaving a length of cloth on either side
8. Place weights over hands or ankles and tie or pin weight on



NOTE: This can also be done without sewing by using plastic grocery bags rubber banding the bags after filling and using the handles to tie around hands or ankles.

Ptosis Glasses – Print on card stock or heavy paper, cut out where indicated, and glue popsicle stick on one side





Tickets – (Optional) Print on card stock or heavy paper. These can be stamped at each station or use a hole punch to punch out the number at each station.



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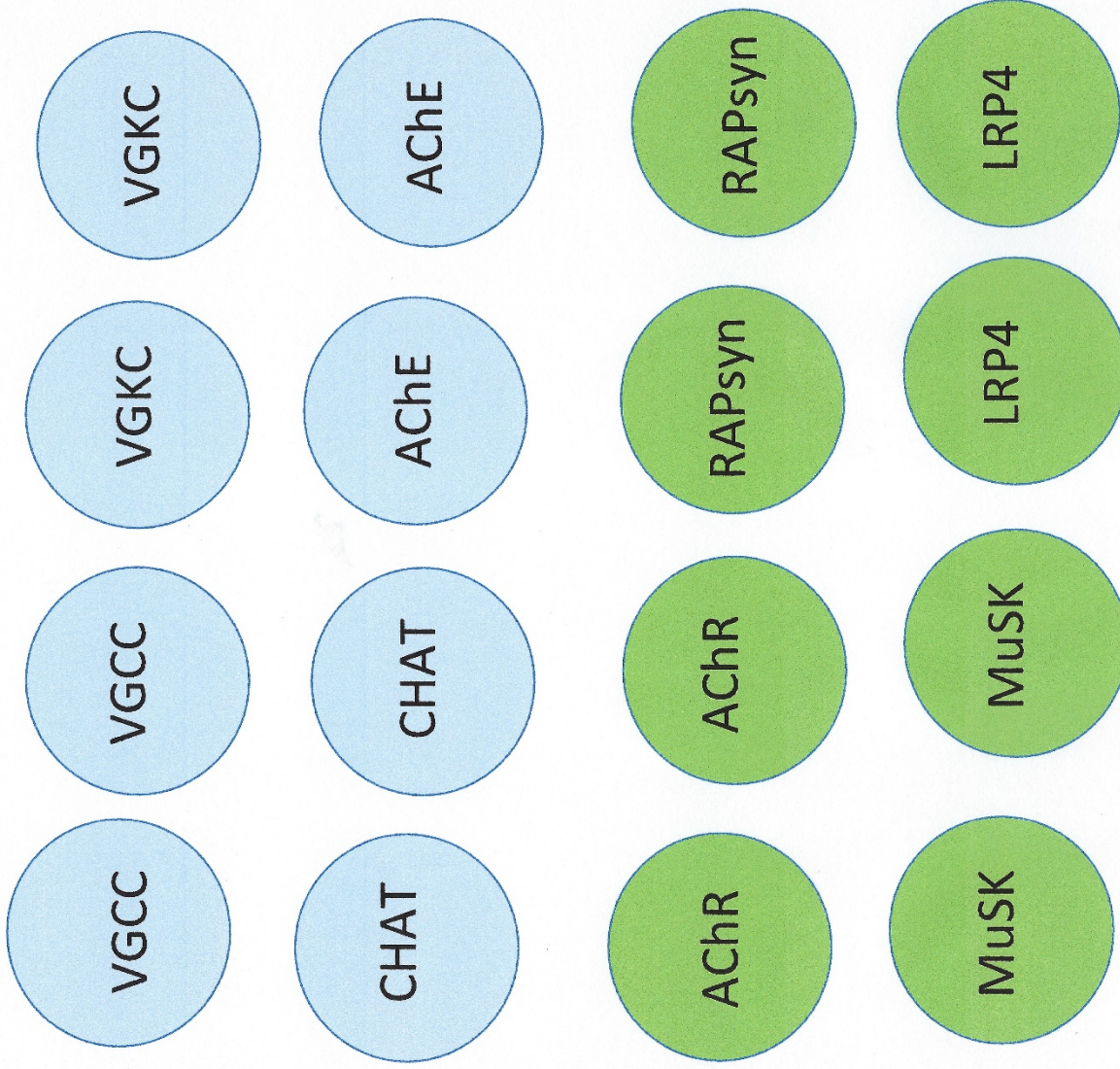
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MG EXPERIENCE	1	2	3	4	5	6	7	8
	 							



Cut out and glue onto hook and loop mitts or label ping pong balls if using regular softball mitts.

Blue = Nerve side

Green – Muscle receptor side

Current Treatment Options

While there is no known cure for myasthenia gravis (MG), there are many effective treatments. Spontaneous improvement and even remission, although uncommon, may occur without any specific therapy.

Treatment Options

Medications:

- Anti-acetylcholinesterase agents – Mestinon[®] (pyridostigmine bromide)– allows acetylcholine to remain at the neuromuscular junction for a longer period, which in turn allows activation of more receptor sites, resulting in increased conductivity and muscle engagement.
- Corticosteroids and immunosuppressant agents – Corticosteroids, such as Prednisone or an immunosuppressant agent such as Imuran[®], Cellcept[®], or Cyclosporin[®], may be prescribed as a stand-alone medication or in combination. These medications suppress the production of antibodies that may be blocking or binding onto acetylcholine receptors. This blocking or binding of the acetylcholine receptors causes weakness.
- Monoclonal antibodies – Monoclonal antibodies such as Soliris[®], generic name Eculizumab or Rituximab, are the newest classification of infusible drugs to be FDA-approved for MG treatment. These drugs work as complement inhibitors, to reduce immune system attacks that may contribute to MG symptoms.

Other Treatment Strategies

- Intravenous immune globulins (IVIg) – During IVIG, a line is placed into a vein to receive delivery of immune globulins (IgG). A typical IVIG infusion may take from 4- 8 hours and is typically in a hospital setting. This influx of IgG is thought to override antibody production. Results are often temporary, so repeated treatments are required.
- IgG Sub-cutaneous Hizentra– A less invasive method of delivering immune globulins (IgG) is known as IgG sub-cutaneous, which means subcutaneous or “under the skin”. In this method of IgG delivery, a series of 4-6 short needles are placed into the subcutaneous layer of skin and can be done at home.
- Therapeutic Plasma Exchange, or Plasmapheresis – Also known as TPE or PLEX. This is a filtration procedure whereby abnormal antibodies are removed from blood plasma. This procedure requires two intravenous (IV) lines or a port placed before undergoing PLEX. Because the body continually produces antibodies, repeated PLEX treatments may be required.
- Thymectomy – This is the surgical removal of the thymus gland. The thymus gland lies over your heart. This gland plays a role in the production of antibodies. While it is most active in early childhood, the thymus gland usually shrinks over time and by early adulthood is believed to no longer function. Sometimes, the thymus gland remains large and continues to be active in antibody production. Some MG patients may develop a tumor in the thymus gland known as a thymoma.

NOTE: Pictures shown are pre-covid-19 the tables were still spaced out allowing for social distancing and flow of participants.



For More Information

For more information about myasthenia gravis and /or to find a support group near you, go to www.myasthenia.org

To connect with the Northeast Ohio MGFA Support Groups, go to www.clevelandmggroup.org

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