

FREE PATIENT-TO-PATIENT GUIDE

I Have Myasthenia Gravis... What Now?

Tame the Dragon

A real, practical and hopeful guide from a patient's perspective — written for the newly diagnosed, the overwhelmed, and the people who love them.

By Lizette Volkwyn

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I HAVE MYASTHENIA GRAVIS... WHAT NOW? ♥

A real, practical and hopeful guide
from a patient's perspective ♥

Tame
the
DRAGON ♥

Inform ♥
Empower ♥
Cope ♥
Adapt ♥
Thrive ♥

You are not alone. ♥

LIZETTE VOLKWYN

PATIENT ♥ ADVOCATE ♥ BELIEVER

Illustrated cover showing Lizette with a friendly sloth holding the teal MG awareness ribbon, with a dragon in the background and the words Tame the Dragon.

A real, practical and hopeful guide from a patient's perspective.

Inform. Empower. Cope. Adapt. Thrive.

You are not alone.

Hi, I'm Lizette Volkwyn

Hi, I'm LIZETTE VOLKWYN My Journey with MG

*Different
days.
Same you.* 

Speaker. Coach. Author. Grandma.
And now, unexpectedly, a woman
learning to live with Myasthenia Gravis.

In April 2026 my world changed.
I went from being the one who did,
fixed, led and pushed through...
to someone learning to measure life
in steps, recovery windows and
medication times.

The last few months have included
hospital stays, PLEX treatments,
trial-and-error medication, **double** vision,
weakness, fatigue and a body I no longer
take for granted.

But this guide is not a pity party.
It's a hand on your shoulder. It's the guide
I wish someone had placed in my hands
at the beginning — honest, practical,
hopeful and real.

If you've just been diagnosed, breathe.
You are still you. We're just learning
how to tame the dragon. 

*All you have to be is
1% better than **YOU** were
Yesterday.* 



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All you have to be is 1% better than YOU were yesterday.

Welcome: the first things I wish someone had told me

I HAVE MYASTHENIA GRAVIS... WHAT NOW?

TAME
THE
DRAGON

A patient-to-patient guide to understanding MG, what to expect, and how to *tame the dragon*.

Welcome

First things first: breathe.

A diagnosis of Myasthenia Gravis can feel frightening, confusing and wildly unfair. But **this is not the end of you**. It is the beginning of learning a new rhythm, a new language for your body, and a new way to measure strength.

"You may have MG. MG does not get to have all of you."

— LIZETTE VOLKWHY

SAME
HUMAN.
BRAVER
YOU.

INSIDE THIS GUIDE



WHAT TO EXPECT

A clear, honest look at MG, how it can affect you, and what the road ahead might look like.

YOU'RE NOT ALONE >



SYMPTOMS & SEVERITY

Common symptoms, how they can fluctuate, and what influences good days and harder days.

KNOW THE SIGNS >



TREATMENT, SUPPORT & DAILY LIFE

Medication options, practical tips, lifestyle adjustments and the power of support and community.

TOOLS FOR A BRIGHTER
TOMORROW >

Different pace. Same dreams.



MORE
GOOD DAYS



REAL
SOLUTIONS



A STRONGER
YOU

Illustrated welcome page with a sloth holding the MG awareness ribbon and a dragon, introducing what to expect, symptoms and severity, and treatment and daily life.

Being told you have Myasthenia Gravis can feel like being handed a medical dictionary in the middle of a thunderstorm. There are new words, new medicines, tests, good days, bad days and days when you wonder whether your body read the same instruction manual as everybody else's.

Here is the bit I want you to hear first: **MG is serious, but a diagnosis is not the end of you.** It is the beginning of learning a new rhythm for your body and a different way of measuring progress.

I call MG **the dragon**. Not because I want to make it dramatic - MG manages that perfectly well on its own - but because a dragon can be unpredictable, demanding and occasionally very loud. The aim is not necessarily to slay it. The aim is to understand it, respect it, treat it and **tame it enough that you get more of your life back.**

What MG actually is

Myasthenia Gravis (MG) is a chronic autoimmune neuromuscular condition. In autoimmune MG, the immune system interferes with the communication between nerves and voluntary muscles. The result is **fatigable muscle weakness**: muscles may work better after rest and become weaker with repeated use.

MG is not contagious, it is not "in your head", and it is not simply being tired. The weakness can affect the eyes, face, jaw, throat, neck, arms, legs and the muscles used for breathing.

The pattern varies wildly from person to person. Two people can both have MG and have journeys that look nothing alike.

Ocular and generalized MG

Ocular MG affects the eye muscles, commonly causing droopy eyelids (ptosis) and double vision (diplopia).

Generalized MG affects muscle groups beyond the eyes. It can involve the face, speech, chewing, swallowing, neck, arms, legs and breathing.

You may also hear **seropositive** and **seronegative**. Seropositive means an MG-associated antibody such as AChR, MuSK or LRP4 has been detected.

Seronegative means standard antibody testing has not detected those antibodies. Seronegative MG is still MG when the clinical picture and other testing support the diagnosis.

MG by the numbers

RARE DOES NOT MEAN INSIGNIFICANT.

Numbers do not tell you what *your* MG will look like, but they can help put this strange diagnosis into perspective. Different studies report different rates because MG is still under-recognised in some places and diagnostic methods vary.

150–200 per million

Globally

MGFA estimates roughly 150–200 people per million live with MG worldwide. A 2024 systematic review found a mean prevalence of about 173 per million across 94 studies.

Any age

MG does not belong to one age group.

It can occur at any age. Women are more commonly affected at younger ages, while later-onset MG becomes more common in men.

~15%

May remain ocular-only.

MGFA notes that about 15% of people with MG have weakness limited to the eye muscles. Others may later develop generalized weakness.

About half

Of people who begin with ocular symptoms may generalize.

MGFA reports that about half of people with ocular MG in the first year develop generalized MG, often within the first two years.

10–20%

Have a thymoma.

The thymus matters in MG. MGFA estimates roughly 1–2 in 10 people with MG have a thymoma, which is why chest imaging is commonly part of the work-up.

15–20%

May experience a myasthenic crisis.

Published reviews commonly estimate crisis in roughly 15–20% of patients. That also means most people with MG will *not* experience one — but everyone should know the warning signs.

My take: statistics describe populations. They do not predict your Tuesday. MG is famously individual, fluctuating and sometimes downright rude about changing the rules without notice.

Sources: Myasthenia Gravis Foundation of America overview and ocular-MG guidance; Sciancalepore et al., 2024 systematic review of worldwide MG epidemiology; published clinical reviews of myasthenic crisis.

Severity: MG is not one straight line

WHAT TO EXPECT

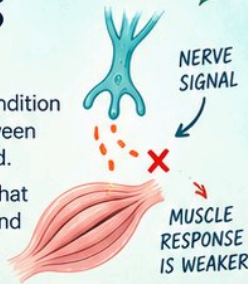
MG is real. MG is unpredictable.
MG is not the same for everyone.

SAME [≠] FIGHTERS.
DIFFERENT JOURNEYS. ♥

WHAT MG IS

Myasthenia Gravis (MG) is an autoimmune neuromuscular condition where the communication between nerves and muscles is disrupted.

This causes muscle weakness that often gets worse with activity and usually improves with rest.



WHAT EARLY DAYS CAN FEEL LIKE

The beginning can feel frightening, confusing, exhausting, and lonely. Symptoms can change from hour to hour and day to day, which can make it hard to plan, hard to explain, and hard not to feel overwhelmed. You are not imagining it, and you are **not alone**. ♥

It can feel like a moving target some days... but it does get easier to navigate. ♥

MG CAN RANGE IN SEVERITY

MG affects everyone differently. Here's a simplified guide based on the MGFA classification.

- | 1 MILD | 2 MILD GENERALIZED WEAKNESS | 3 MODERATE GENERALIZED WEAKNESS | 4 SEVERE GENERALIZED WEAKNESS | 5 CRISIS |
|--|---|--|---|---|
| Mostly eyes involved | | | | Breathing support needed |
| | | | | |
| Symptoms affect only the eye muscles (eg. droopy eyelids and double vision). | Mild weakness in other muscles beyond the eyes (eg. face, swallowing or limbs). | More noticeable weakness in multiple muscle groups that can affect daily activities. | Significant weakness that limits daily activities and may affect breathing, swallowing or mobility. | A life-threatening worsening of symptoms that requires hospital care and breathing support (ventilation). |

Severity can shift. A good day does not mean MG is gone.
A hard day does not mean you have failed. ♥

TREATMENT IS OFTEN TRIAL AND ERROR

Finding the right treatment mix can take time. Everyone responds differently, and what works for one person may not work for another.

It can involve trying different medications, dosages and combinations, while balancing side effects and lifestyle. Stabilisation may take 18 months or more for some people. ♥

"Finding the right treatment mix can take time. Stabilisation may take 18 months or more for some people."

— LIZETTE VOLKWYN

BE PATIENT WITH THE PROCESS

- ♥ Keep a symptom diary
- ♥ Communicate openly with your healthcare team
- ♥ Give treatments time
- ♥ Adjust as needed
- ♥ Celebrate small wins
- ♥ You are doing your best and that is enough.

TYPES YOU MAY HEAR ABOUT

MG can present in different ways. Here are some common terms:



OCULAR MG

Affects only the eye muscles. Causes droopy eyelids and/or double vision.



GENERALIZED MG

Affects other muscle groups beyond the eyes. Can impact face, throat, arms, legs and breathing.



SEROPOSITIVE MG

Antibodies (such as AChR, MuSK or LRP4) are detected in the blood.



SERONEGATIVE MG

No antibodies are detected, but symptoms are real. Seronegative MG is still MG, and it can be just as disabling, as seropositive MG. ♥

This is not a straight road.
It is still your road. ♥

DIFFERENT DAYS
DIFFERENT PACE
SAME YOU
AND THAT'S ENOUGH ♥

SLOWER DAYS STILL LEAD TO BRIGHTER TOMORROWS. ♥

Clinicians often use the MGFA clinical classification:

- **Class I:** weakness limited to the eyes.
- **Class II:** mild generalized weakness.
- **Class III:** moderate generalized weakness.
- **Class IV:** severe generalized weakness.
- **Class V:** intubation is required to maintain the airway, apart from routine postoperative ventilation.

Within generalized MG, doctors also pay attention to whether limb/axial weakness or bulbar/respiratory weakness is more prominent.

Your class is a clinical description, not your identity. And your disease can change over time. A good morning does not mean MG has vanished. A hard afternoon does not mean you have failed.

Symptoms can fluctuate - and the mix can change

SYMPTOMS & TREATMENT

MG can show up in many ways – and not all at once.

Everyone's MG journey looks different. Symptoms can change from day to day, and treatment is individualized to your needs.

Different days.
Same you.
Still amazing. ♥

SAME SYMPTOMS.
DIFFERENT DAYS. ♥

SOME DAYS ARE EASIER

SOME DAYS ARE HARDER

ALL DAYS ARE VALID ♥

SYMPTOMS CAN FLUCTUATE ♥

You can have any of these at any given time – and they can change quickly. ♥



EYES

- Droopy eyelids (ptosis)
- Blurred vision
- Double vision (diplopia)
- Eye fatigue



FACE, JAW, THROAT

- Facial weakness (e.g. smile, expression)
- Chewing fatigue
- Slurred speech
- Swallowing difficulty (dysphagia)
- Changes in voice



NECK, BODY & LIMBS

- Heavy head (feels hard to hold up)
- Neck weakness
- Arm weakness
- Leg weakness
- Poor stamina
- Muscle fatigue with activity



BREATHING & CHEST

- Shortness of breath (dyspnoea)
- Shallow breathing
- Trouble lying flat
- Weaker cough
- Chest tightness (in some cases)



WHOLE-BODY EXPERIENCE

- Fatigue (often one of the biggest challenges)
- Weakness that varies throughout the day
- Symptoms that get worse with activity
- Voice changes
- It can affect daily life in different ways

COMMON TREATMENTS

There are several treatment options for MG. ♥



PYRIDOSTIGMINE (MESTINON®)

SYMPTOM RELIEF

- Helps improve communication between nerves and muscles.
- Can reduce weakness and improve function. Often the first treatment used.



CORTICOSTEROIDS (e.g. PREDNISONE)

REDUCE IMMUNE ACTIVITY

- Can be very effective in many people.
- Doses are carefully managed and gradually adjusted to balance benefits and side effects.



STEROID-SPARING MEDICINES

LONG-TERM CONTROL

- Examples: Azathioprine, Mycophenolate Mofetil, Cyclosporine, Tacrolimus.
- Help reduce immune activity and allow lower steroid doses.
- Can take time to work (weeks to months).



RESCUE TREATMENTS (for more severe symptoms or a crisis)

SHORT-TERM SUPPORT

- **IVIG** (Intravenous Immunoglobulin)
- **PLEX** (Plasmapheresis)
- Can provide short-term improvement, especially during severe flares or before surgery.



NEWER TARGETED THERAPIES / BIOLOGICS FOR SELECT PATIENTS

- Examples: Eculizumab (Soliris®), Ravulizumab (Ultomiris®), Efgartigimod (Vyvgart®), Rozanolixizumab (Rystiggo®).
- Target specific parts of the immune system. May be an option for some people with MG.

These are examples of treatment options. Treatment is individualized based on your symptoms, medical history, lifestyle and goals. Work with your neurologist or MG specialist to find the right plan for you. ♥

THE TREATMENT TRUTH

MG treatment is not one-size-fits-all.

It is often a journey of trial, response, adjustment and patience.

What works for one person may not work for another. ♥



MEDICATION CAUTION

Always tell all your doctors and pharmacists that you have MG.

- ✓ Check any new medicines, supplements, magnesium products and antibiotics with your treating doctor or pharmacist.
- ✓ Some medicines can worsen MG or trigger a flare.
- ✓ This includes certain antibiotics, heart medicines, beta-blockers, magnesium products and more.

PROGRESS IN MG

IS OFTEN MEASURED IN MICRO-WINS. ♥

- ♥ A little more energy today.
- ♥ An easier conversation.
- ♥ A meal with less fatigue.
- ♥ A longer walk.
- ♥ A better breathing day.
- ♥ A moment of joy.
- ♥ They all count.

SMALL STEPS

REAL PROGRESS

BRIGHTER DAYS ♥

PROGRESS LOOKS DIFFERENT FOR EVERYONE AND THAT'S OKAY. ♥

MG TREATMENT IS A JOURNEY NOT A RACE. ♥

You can experience different combinations of symptoms at different times. Some people have only a few; others have many. They can fluctuate over hours or days and often worsen with repeated activity.

Eyes

- Droopy eyelid or eyelids (ptosis)
- Double vision (diplopia)
- Vision that feels blurred because the eyes are not aligning
- Eye muscles that tire with reading, screens or prolonged focus

Face, jaw, speech and swallowing

- Facial weakness or a smile that becomes weaker
- Difficulty keeping an expression as muscles fatigue
- Jaw fatigue while chewing
- Food becoming harder to chew toward the end of a meal
- Slurred, nasal or fading speech
- Voice changes after talking
- Difficulty swallowing (dysphagia)
- Choking or coughing with food or drink
- Difficulty managing saliva or secretions

Neck and trunk

- Neck weakness
- Head drop or a head that becomes hard to hold upright
- Trunk weakness or difficulty staying upright for long periods

Arms and hands

- Difficulty lifting arms, washing or drying hair, dressing or reaching overhead
- Weakness that increases with repeated movement
- Dropping objects or losing grip as muscles fatigue

Legs

- Difficulty climbing stairs
- Difficulty rising from a chair
- Heavy or weak legs
- Reduced walking endurance or sudden loss of safe mobility

Breathing

- Shortness of breath or a feeling of not getting enough air
- Rapid, shallow breathing
- Difficulty lying flat
- Weak cough
- Difficulty speaking more than a few words without pausing for breath

Breathing or swallowing weakness can become an emergency. Seek urgent medical help for new or rapidly worsening breathing difficulty, choking, inability to handle secretions, severe worsening speech or inability to hold up your head. In MG, a pulse oximeter can look reassuring until respiratory weakness is already advanced, so do not use oxygen saturation alone to decide whether you are safe.

What can make MG worse?

Common triggers can include infection or illness, heat, physical overexertion, poor sleep, emotional or physical stress, surgery, and certain medicines. Hormonal changes can matter for some people too.

The useful skill is not to become frightened of everything. It is to learn **your** patterns.

Treatment: what feels like trial and error

There is no single treatment recipe that fits everybody. Your neurologist may combine medicines that help symptoms now with medicines that try to reduce the underlying immune attack over time.

Some treatments work within hours. Others take weeks. Some long-term immune medicines take several months before their benefit is clear. That is why early MG can feel maddeningly slow.

There is no universal stabilization clock. In real life, finding the right combination can take many months - for some people **12 to 18 months or longer**. That is not a deadline or a prediction; it is permission not to panic when your journey takes time.

Common treatment categories

Pyridostigmine (Mestinon) helps more acetylcholine remain available at the nerve-muscle junction. It treats symptoms and often acts fairly quickly, but it does not switch off the autoimmune process.

Corticosteroids such as prednisone suppress immune activity and can be very effective, but doses need to be managed carefully because of side effects and the possibility of temporary early worsening in some patients.

Steroid-sparing immunosuppressants such as azathioprine, mycophenolate, tacrolimus or cyclosporine may be used for longer-term immune control. They can take months to show their full effect.

IVIg and plasma exchange (PLEX) are faster-acting treatments used when a quicker response is needed, including severe flares, crisis, before some procedures, or as a bridge while slower treatments start working.

Targeted therapies / biologics now treat specific immune pathways for selected patients. Eligibility depends on the drug, antibody status, disease pattern, previous treatments and local availability.

Tame the Dragon: meds, side effects and the bigger picture

TAME THE DRAGON

Meds, Side Effects & the Bigger Picture

Side effects are real. So is uncontrolled MG. The job is to keep adjusting until the benefit is bigger than the burden.



The goal: fewer dangerous flares, more dependable muscle function, lower steroid exposure where possible, and a body with a better chance to **stabilise**.

Pyridostigmine (Mestinon)

Possible: stomach cramps, diarrhoea, nausea, sweating/salivation, twitching or cramping.

The upside: often works quickly and can improve day-to-day muscle function while longer-term treatment catches up.

Prednisone / steroids

Possible: appetite and weight changes, mood or sleep changes, raised blood pressure or blood sugar, infection risk and bone thinning with longer use. MG can briefly worsen when steroids are started or increased.

The upside: steroids can be very effective at bringing the immune attack under control, often faster than older steroid-sparing medicines.

Azathioprine / mycophenolate

Possible: nausea or gut upset, low blood counts and infection risk; azathioprine can affect liver, pancreas or bone marrow. Regular blood tests matter.

The upside: these can provide longer-term immune control and may allow steroid doses to come down. They are slow workers - think months, not days.

IVIg / PLEX

Possible: IVIg can cause headache, nausea or infusion reactions; PLEX can cause low blood pressure, line-related problems and temporary electrolyte shifts.

The upside: both can act much faster than long-term immune medicines and are important in severe flares, crisis, or when a quicker bridge is needed.

"We are not chasing perfect. We are chasing steadier."

Lizette Volkwyn ♥

TAME THE DRAGON - MEDICATIONS, CONTINUED

The trade-off is **control**, not punishment.

I do not want a newly diagnosed patient to read a side-effect list and panic. These are **possibilities**, not promises. The reason your neurologist keeps balancing dose, timing and combinations is to find the point where you gain more strength, safer breathing and fewer flares without asking your body to carry more treatment burden than it needs.

Targeted / biologic therapies

Possible: depends on the drug; headache, injection or infusion reactions and infection risks are among the possibilities. Some therapies need specific vaccination or screening before treatment.

The upside: for eligible patients, newer therapies target specific parts of the immune system and can provide meaningful control when older approaches are not enough.

How I would track whether treatment is helping

- More usable hours in the day
- Longer conversations before the voice fades
- Eating with less chewing or swallowing fatigue
- More steps, safer transfers or easier stairs
- Fewer or less severe flares
- Less rescue treatment or lower steroid need, when your doctor says it is safe

Questions I want answered

- What is this medicine meant to do?
- When should I expect a benefit?
- Which side effects are annoying, and which are urgent?
- What blood tests, vaccines or monitoring do I need?
- What would make us increase, reduce or change it?
- What is our longer-term target?

Important: Never stop prednisone suddenly or change MG medicines on your own. New or rapidly worsening weakness, breathing difficulty, choking or trouble handling secretions needs urgent medical assessment. Always tell every doctor, dentist and pharmacist that you have MG.

“Side effects are part of the conversation. So are the wins.”

Progress can be tiny and still be real.

1% better than yesterday ♥

I wish every medication discussion started with this sentence: **side effects matter, and so does the disease we are trying to control.**

The aim is not to make you endure anything at any cost. The aim is to find the safest effective combination where the improvement in MG outweighs the burden of treatment.

Pyridostigmine (Mestinon)

Possible side effects include stomach cramps, diarrhoea, nausea, increased sweating or saliva, muscle cramps and twitching.

The upside: it often acts quickly and can improve strength and function while longer-term treatment is still catching up.

Prednisone / corticosteroids

Possible effects include increased appetite, weight gain, mood changes, trouble sleeping, fluid retention, raised blood pressure or blood sugar, infection risk and bone thinning with longer use. Steroids can also temporarily worsen MG when first started or increased, which is one reason they may need careful titration and monitoring.

The upside: steroids can be highly effective at suppressing the immune attack and may improve MG much sooner than slower steroid-sparing medicines.

Azathioprine and mycophenolate

These medicines can cause nausea or gastrointestinal symptoms, lower blood counts and increase infection risk. Azathioprine can affect the liver, pancreas or bone marrow, so regular blood monitoring matters. Each medicine has additional precautions that your prescriber should discuss with you.

The upside: they can provide longer-term immune control and may help reduce the amount of steroid needed. Azathioprine, for example, may take around four to six months before improvement becomes noticeable.

IVIg and PLEX

IVIg may cause headache, nausea, infusion reactions and, more rarely, clotting or kidney problems. PLEX can cause low blood pressure, temporary electrolyte changes and problems related to the intravenous access used for treatment.

The upside: these are among the faster tools in the MG toolbox. They can improve strength more quickly during significant worsening and can help bridge the gap while slower treatments take effect.

Newer targeted therapies

Side effects vary by drug and can include headache, infusion or injection reactions and infection risk. Some complement-targeting treatments require particular vaccinations or infection-prevention steps.

The upside: for eligible patients, targeted therapies can provide meaningful disease control by focusing on specific parts of the immune system rather than broadly suppressing it.

My practical rule: ask what the medicine is for, what benefit you are waiting for, how long that benefit may take, what side effects need watching, what blood tests or vaccines are needed, and what would make your doctor change course.

Never stop prednisone suddenly or change MG medication doses on your own. Speak to your treating clinician.

Tame the Dragon: practical ways to make life kinder

TAME THE DRAGON

Practical ways to make life with MG kinder, safer, and more manageable. ♥

SAME HUMAN. BRAVER YOU. ♥

KNOWLEDGE
SMALL STEPS
KINDER DAYS
BRIGHTER TOMORROWS ♥

1 UNDERSTAND YOUR MEDS

Knowledge helps you feel in control and get the best from your treatment.

- ✓ Know what each medicine is for (e.g. symptom relief or long-term control).
- ✓ Take it as prescribed and at the right time.
- ✓ Be aware of possible side effects.
- ✓ Know what changes need a doctor's attention (e.g. new or worsening symptoms, side effects, or if a medicine stops working).

QUESTIONS ARE ALWAYS VALID >

2 FIND THE RIGHT NEUROLOGIST

Work with a neurologist who understands Myasthenia Gravis.

- ✓ Look for a neurologist with MG experience.
- ✓ Ask questions and be open about your symptoms and concerns.
- ✓ You deserve a care team that listens, explains, and partners with you.
- ✓ It's okay to seek a second opinion if you don't feel heard.

THE RIGHT TEAM MAKES A DIFFERENCE >

3 MAKE YOUR ENVIRONMENT KINDER

Small changes can make a big difference in your energy and independence.

- ✓ Pace your days and build in rest spots.
- ✓ Sit for tasks where possible (cooking, showering, getting dressed).
- ✓ Reduce unnecessary stairs.
- ✓ Make meal prep easier (simple meals, pre-chopped veggies, batch cooking).
- ✓ Use mobility aids if needed (e.g. stick, walker).
- ✓ Ask for help sooner — it's strength, not weakness.

LESS STRUGGLE. MORE LIVING. >

4 TRACK THE MICRO-IMPROVEMENTS

Tracking helps you see patterns, celebrate progress, and make better decisions with your care team.

- ✓ Use a simple journal or notes app.
- ✓ Track symptoms, medication response, energy levels, triggers, and wins.
- ✓ It helps you (and your doctor) see the bigger picture — even the small improvements count!

SAMPLE JOURNAL LIST: ♥

- Date
- Symptoms (e.g. eyes, swallowing, energy)
- Meds taken (and time)
- How I felt (energy/mood 1–10)
- Possible triggers (poor sleep, stress, heat, etc.)
- What went well today? (even a small win!)

5 JOIN YOUR PEOPLE

You are not alone. Connecting with others who understand MG can be life-changing.

- ✓ Join MG support groups or online communities.
- ✓ Share experiences, tips, and encouragement.
- ✓ Find people who just get it — no need to over-explain.
- ✓ Understanding reduces isolation and reminds you that there is hope, strength, and humour in this journey.

“In a world that doesn't always understand, it helps to find your people.” ♥

6 WHEN TO GET URGENT HELP

Get medical help immediately if you have:

- ! Breathing difficulty or feeling like you can't get enough air.
- ! Choking or trouble swallowing (especially if it's getting worse).
- ! Rapidly worsening speaking difficulties.
- ! Inability to hold up your head (“dropped head”).
- ! Inability to stand or move safely.

THIS COULD BE A MYASTHENIC CRISIS. GET HELP IMMEDIATELY. ♥

A FINAL NOTE...

You are allowed to grieve.
You are allowed to rest.
You are allowed to rebuild differently.
And even here, you are still you. ♥

MG may have changed your road, but it hasn't stolen your beautiful, meaningful life. With knowledge, support, kindness and a little creativity, you can tame the dragon and find your own version of a good life.

All you have ♥ to be is 1% better than you were yesterday. ♥
— LIZETTE VOLKSWYN

PROGRESS LOOKS DIFFERENT FOR EVERYONE. ♥

SMALL STEPS MATTER | KINDER DAYS ARE POSSIBLE | YOU ARE NOT ALONE | REAL PEOPLE REAL PROGRESS | DIFFERENT PACE SAME DREAMS | TAME THE DRAGON

Illustrated Tame the Dragon page with six practical steps: understand medicines, find the right neurologist, make your environment kinder, track micro-improvements, join support communities, and know when to get urgent help.

1. Understand your medicines

Know what each medicine is doing. Is it treating symptoms? Suppressing the immune attack? Acting as rescue treatment? When should it start helping? What needs monitoring?

Keep an up-to-date medication list on your phone and, ideally, a printed copy in your bag.

2. Get a neurologist who genuinely understands MG

MG is uncommon and nuanced. If you can, work with a neurologist who has specific experience in neuromuscular disease or MG. You want someone who listens to patterns, understands fluctuations and is comfortable adjusting treatment when the evidence says it is time.

Questions are not disrespectful. Questions are how you become a useful member of your own healthcare team.

3. Make your environment kinder

I had to stop designing my environment for the woman I used to be on my strongest day and start designing it for the woman I am on a difficult one.

That can mean:

- chairs or stools where you normally stand
- rest points between rooms or tasks
- reducing unnecessary stairs
- simple meals and batch cooking
- keeping regularly used items within easy reach
- cooling strategies in hot weather
- mobility aids when they give you safer access to life
- accepting help *before* you have completely emptied the battery

Making life easier is not surrender. It is intelligent energy management.

4. Track micro-improvements

MG progress can be sneaky. If you only ask, “Am I normal again?” you can miss a hundred small wins.

Try a two-minute daily note:

- Date
- Main symptoms today
- Medication and timing
- Energy/function from 1-10
- Possible triggers
- What was easier today?
- What was harder?
- One small win

Maybe you walked three more steps. Finished a meal without resting. Held your head up longer. Had a clearer hour of vision. Talked for ten minutes without your voice fading. **Count it.**

5. Join your people

MG can be lonely because much of it is invisible. A good support group gives you people who understand why “I showered today” can be a genuine achievement.

Use groups for connection, practical tips and emotional support - but use your medical team for your individual diagnosis and treatment decisions.

6. Know when this is no longer a normal bad day

Get urgent medical help for:

- breathing difficulty or rapidly increasing breathlessness
- choking or rapidly worsening swallowing
- inability to handle saliva or secretions
- rapidly worsening speech or voice weakness
- inability to hold up your head because of new severe weakness
- rapidly worsening weakness that makes standing or moving unsafe

A myasthenic crisis is life-threatening, but it is treatable. Early help matters.

For my partner, carer and family

PLEASE UNDERSTAND THE DIFFERENCE BETWEEN “WON’T” AND “CAN’T TODAY.”

Please don't judge what I can do today by what you saw me do yesterday. MG moves the goalposts without asking permission.

One of the hardest things for the people around us to understand is that MG can be **wildly inconsistent**. I may be able to shower, cook or walk through a shop one day and need help with those exact same things the next. That is not laziness, lack of willpower or giving up. Voluntary muscles simply may not have enough reliable strength at that moment.

Food may suddenly be a big job

I may not have enough strength to stand and prepare food, lift pans, cut ingredients, chew a full meal or finish eating before my jaw tires. Help can mean making something simple, cutting food smaller, bringing the meal to me, or sitting with me while I eat if swallowing is difficult.

Bathing can use the whole battery

A shower is standing, reaching, washing hair, lifting arms, drying, dressing and regulating temperature — all at once. Some days I may need a shower chair, help washing my hair, clothing laid out, or simply someone nearby for safety.

Extreme fatigue can look invisible

MG weakness is fatigable. A small task can drain the same muscles over and over until they stop cooperating. I may need to stop halfway through a conversation, rest after getting dressed, or choose between showering and going out.

Walking may not always be safe

Leg, hip, core or neck weakness can make short distances difficult. A cane, walker, wheelchair or mobility scooter may give me safer access to life and preserve energy. These aids can be used only when needed; using one does not automatically mean the disease is permanently worsening.

I may need to stop driving

Double vision, droopy eyelids, neck weakness, limb weakness or severe fatigue can make driving unsafe. MG does not automatically mean giving up driving forever, but I should not drive when symptoms could interfere with seeing, steering, braking, reacting or holding my head comfortably. My neurologist can help me decide when it is safe to return.

Personal care can become personal help

Buttons, bras, shoes, hair drying, brushing teeth, getting in and out of bed, using stairs or even holding a hairdryer can become difficult. Ask before helping, protect my dignity, and remember that needing assistance today does not erase my independence.

A better question than “What’s wrong?”

Try: “What would save you the most energy right now — food, a shower setup, a lift somewhere, your meds, or just company?”

Mobility aids are tools, not defeat

A walking stick, rollator, wheelchair or mobility scooter can reduce falls, preserve muscle reserve and make it possible to participate in family life, appointments and outings. The best aid depends on which muscles are weak, so where possible get advice from a physiotherapist, occupational therapist or rehabilitation professional. If arm or shoulder weakness is significant, for example, a walking stick may not be the best choice.

Sometimes the smartest thing I can do with limited strength is **not spend all of it proving I can walk.**

What I need from you

- **Believe the fluctuation.** A good hour does not cancel a bad afternoon.
- **Ask, don't assume.** Help me keep as much independence as is safely possible.
- **Plan rest into the plan.** Do not wait until I crash before we make space for recovery.
- **Learn my medicines and emergency information.** Know where the list is and who my neurologist is.
- **Watch swallowing and breathing changes.** Rapid deterioration here needs urgent medical attention.
- **Remember I am still me.** Talk to me, not just about me. Include me. Laugh with me. Let me have normal conversations that are not about MG.

To the carer: caring can be exhausting too. You are allowed to need sleep, backup, information and support. This disease affects a household, not just a set of muscles.

A note about medicines that can worsen MG

Tell every doctor, dentist and pharmacist that you have MG. Some medicines have been associated with worsening weakness, including IV magnesium, certain antibiotics, some heart/rhythm or blood-pressure medicines, botulinum toxin and some anaesthetic drugs.

This does **not** mean every medication on a caution list is absolutely forbidden for every person with MG. Sometimes the medicine is necessary and can be used with appropriate clinical judgment and monitoring. The important thing is that MG is part of the decision.

My tiny journal for taming the dragon

You do not need a perfect planner. A notes app is enough.

Today:

Sleep:

Eyes / speech / swallowing / breathing / arms / legs:

Medication times:

Energy or function 1-10:

Possible trigger:

What went well:

One micro-win:

Progress often hides in the small stuff.

From me to you

I do not know exactly what your MG journey will look like. Nobody does. That uncertainty can be one of the hardest pieces.

But I do know this: you do not have to solve the rest of your life today.

Learn the condition. Find the right medical team. Understand the medicines. Make your home kinder. Track the tiny changes. Find people who understand. Get help quickly when breathing or swallowing changes.

Then take the next piece. And the next.

Different pace. Same human. Same dreams.

Tame the dragon - one day, and sometimes one hour, at a time.

All you have to be is 1% better than YOU were yesterday.

— Lizette Volkwyn

Medical note and sources

This is a patient-to-patient education guide and does not replace medical advice, diagnosis or emergency care. Treatment choices depend on your MG subtype, antibody status, symptoms, other health conditions and local availability. Do not start, stop or change prescription medicines without your treating clinician.

Medical information in this edition was checked against:

- Myasthenia Gravis Foundation of America (MGFA), *Myasthenia Gravis Treatments*: <https://myasthenia.org/myasthenia-gravis-treatments/>
- MGFA, *Cautionary Drugs*: <https://myasthenia.org/understanding-mg/learn-more-about-mg-treatments/mg-brochures/cautionary-drugs/>
- MGFA, *MG Emergencies*: <https://myasthenia.org/living-with-mg/mg-emergency-preparedness/mg-emergencies/>
- NHS, *Myasthenia gravis - Treatment*: <https://www.nhs.uk/conditions/myasthenia-gravis/treatment/>
- MGFA, *Overview of MG*: <https://myasthenia.org/understanding-mg/overview-mg/>
- MGFA, *Ocular MG*: <https://myasthenia.org/?p=23166>
- Sciancalepore F, et al. *Prevalence, Incidence, and Mortality of Myasthenia Gravis and Myasthenic Syndromes: A Systematic Review*. *Neuroepidemiology*. 2025;59(5):579-592. PMID 39380477.

Emergency: if you are struggling to breathe or swallow, seek urgent local medical care immediately.

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