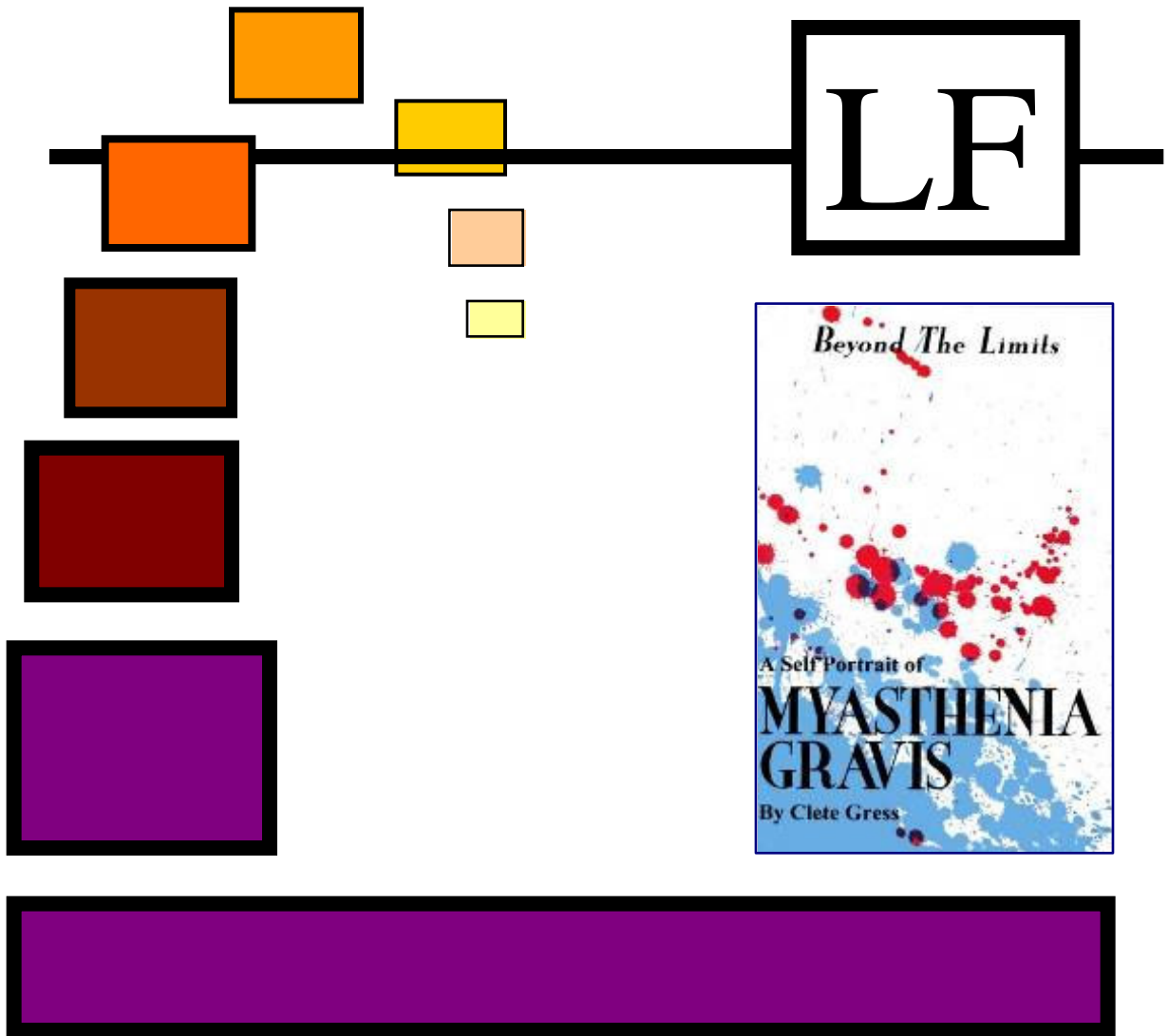


# Beyond the Limits

## A Self Portrait of Myasthenia Gravis

By  
Clete Gress



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Subject: Is this it?

Date: Tuesday, December 28, 1999 10:46 PM

## FORWARD

Getting the glorious news that I had been selected to manage a hospital in Southeast Africa meant that I would pass a rigid physical examination with lots of laboratory testing and to begin a series of inoculations to enter foreign countries. The excitement of foreign missionary work had been with me since age seven. Nearing the ripe age of fifty meant leaving behind two adult sons, two grandchildren, a host of friends and a successful career in long-term care administration. Protection consisted of shots and pills and such for protection against everything from Yellow Fever to Rabies. I was to start taking chlorquin tablets to build up immunity against Malaria.

I had always been on the management end of health care and left all those medical debates and decisions to those so trained. My nurse colleague made arrangements for our pill taking amounts and times and faithfulness to the task. I took my turn at other duties more related to training schedule departure dates and the like. We arrived in upstate New York to experience a month of intense foreign service orientation. I thought my recent mid-life weight gain was slowing me down. My colleague was comprehending things in training that seemed to just float over my head. Never daring to question what was happening, I continued to blame the weight gain and all those shots that could possibly make us feel badly a few days.

Arriving in Portugal a few weeks later, I collapsed upon entering our apartment and slept for eight hours without moving, while she got acquainted with the beautiful living arrangement, scouted the neighborhood for grocery stores and bus stops. Two days later it was time for us to enter language training. Oh sure, the reason she was learning Portuguese so much easier was her background in Latin in nursing school. Oh well, there will be equalization along the way, I thought.

We continued our daily routine of pills, then more shots, then time for that long anticipated flight to Africa. Our work began. Several weeks passed into months and the civil war was carrying on and our hospital was serving the injured of both sides along with Malnourished being the primary diagnosis on all admissions and Malaria being the second on all admissions. Then came the third and main cause for their arrival in the emergency room (usually) - that being war-related atrocities of which most Americans can not fathom.

One, then the other of us, began having episodes of Malaria. She would be down a day or two at the most and spring back. For me, no way. Fear for my life would fly through the mission station, making news in the Church office 500 miles away where that news would be transmitted 10,000 miles back around the world to the New York office. Reserves of four different treatments would be administered with the local folks praying that their missionary friend would not die on their hands. Plans would be made and I would be shipped stateside for medical leave, recovery and return to the most interesting and fulfilling job of my life.

Five years and eight documented bouts like I have just described and I was brought to Atlanta, GA for further testing and several months medical leave. Upon completing that course of action

I was sent to New York to work in the finance office of our mission agency. I contacted a private physician there who had 35 years experience in Malaria work, hoping that he would have a formula for freeing me of what seemed to be post-malaria complications. He tested and observed me for several months with a final dismissal of not providing clearance to even leave the States. Supposedly there was a heart murmur or some similar minor reason he provided.

In order to return to frontline missions work, I took an assignment in New Mexico with a K-12 school. That position provided schooling benefits for my adopted children who were still in Africa. I had managed to accumulate enough vacation and sick time to stop over in West Texas for Ordination and gall bladder surgery. Both programs were successfully accomplished. I returned for the post-op check up to report the instantaneous relief from the gall stone surgery but I continued with this dreadful sensation of fatigue, particularly in my back muscles. I then asked, "would there be any chance of this problem being linked to Myasthenia Gravis since I had had a thymectomy in 1978 --- as a result of chest pain? An appointment was set with the neurologist and eight days into my new assignment (and new insurance plan) I was given the diagnosis of MG.

Starting a new medication called Mestinon, I continued to work long hours, thinking the medication would make the difference. As with many new assignments in the world of finances I had come upon an interesting challenge of budget problems that no one wanted to claim --- meaning longer hours and more stress. It took eight months of stress over the scale before my body said enough and shut down right into a MG crisis.

Most folks would have been willing to stop back up the road several years but I was one of those die-hards that kept going. I had cut my teeth on Management by Objective, setting all sorts of records for resolving management problems and made lots of money for ownership as results. Why was I so driven? Why did I have to prove to family, co-workers, and to me that my strength was equal to my size - extra large?

I did not know. I just knew it must be done.

After the MG crisis I began recuperation slowly. Some days I seemed to go backwards then to regain a little only to loose ground again. I had decided that maybe buried in all this was a point or two of anger that had not been processed. I sought out our pastoral counselor for our church. When we inventoried after not three or four sessions that I thought would be sufficient, but 18 months' worth, we were able to identify thirteen points of grieving. Still, a lot of questions remained in my mind about the personality and the disease and how could they work together to benefit someone - how could I use those two factors to re-enter mission work.

One of the great blessings of illness is that you can be recipient to many cards, letters, phone calls, visits and e-mails. Somewhere along that part of my journey I came in contact with a childhood friend. She brought her husband along and they came to visit me after forty-two years of not seeing one another. What a wonderful visit! We have continued to stay in close contact through the wonderful advances of technology called e-mail. They sent a magnet belt to try on the muscle fatigue. Then she found a book about Myasthenia Gravis and asked if I had read it.

That little book has been a missing link in understanding Myasthenia Gravis and the personality involvement. When I began reading Clete Gress', "Beyond the Limits", I began

writing notes in the margins, underlining, making references, remembering dates and incidents. Ultimately I began getting acquainted with the man who has written words in algebraic equations, personality traits, and sequential steps of behavior. He has done this in a simplistic way that makes this little book my best advisor to living with Myasthenia Gravis.

Clete Gress is a man who has lived forty years with the disease because he has figured out long ago that personality is a major part of the governing of entering the world of MG and living there after one has entered. I can only say "Thanks Friend." As he brings to the internet the edition, I look forward to the freshness of breath of the Holy Spirit to bless him for the strength needed to accomplish this task so that many others may have the opportunity to find some Peace in mountain streams and contentment in the forests of one's Soul.

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## CHAPTER I

### *I think you might have* **MYASTHENIA GRAVIS**

The shower was warm and good, a sharp contrast to the rest of this day's events. As the warm water soothed my body, my mind replayed scenes from today's Test Hop of a T29.

About fifteen minutes into the flight, still climbing from take off at about five thousand feet, our left engine caught fire. Smoke rolled off the wing and when it thinned I could clearly see flames. This was serious trouble but no reason to panic as I had faith in the engineer on today's flight.

I had always been able to function during emergencies, but today, looking out at our engine burning, on a wing full of explosive fuel, I began to feel a strong and terrible anxiety.

The fate of our plane rested squarely on the judgment of the flight engineer. He would decide at precisely which moment to trigger the fire extinguishers that were built into the engine pods. You had only one shot and timing was everything. When they were used up it would be time for plan "B". Jump!

The Flight Engineer's hand was raised high, as he stared at the burning engine. From my seat, behind his position, I could see the copilot looking around the bulkhead, waiting for the signal to activate the extinguishers. I looked out the window at the flaming engine, then to the engineer's hand poised in the air, then to the copilot with his hand on the switch. Ten lifetimes passed before the engineer's hand finally sliced downward. A huge puff of smoke billowed from the engine and then---nothing!

The next thirty seconds were excruciating as we waited to see if the fire was completely extinguished. If it rekindled we would have no choice but to abandon the plane.

I looked behind me to the escape door in the tail. A number of times I had stood at that door, ready to go, but had never had to jump. My body tensed as I considered my chances of exiting the hatch safely if the fire reignited.

As the tension thickened, all of us watched for new signs of smoke or flame. Realizing that the fire was truly out the pilot turned the plane and we headed for the base.

Later I figured out that I had earned an extra dollar fifty for that ten minutes of hell.

The shower washed over me and I hoped it would, somehow, heal the shattered emotions of today's trauma.

Were the emergencies becoming more severe or was I losing my nerve? The very thought of flying another test hop filled me with dread. Flying had been fun, I recalled, until when? Shortly after failing a review board and losing my Technicians rating. The depression that

followed seemed to change everything. I should have quit flying at that time but we simply needed the money too much.

The shower mixed with the tears that streamed down my face.

What was happening to me? Lately The tears would flow for no apparent reason. Not a single tear but a flood of tears. Always when I was alone. Thank God for that but, Why? I had never been much of a crier and now I felt uneasy and a little ashamed. In addition to everything else I didn't need this!

I moved the soapy washcloth to my chest. Nothing! I couldn't apply pressure! I could raise it up but could not apply the slightest bit of pressure to my chest. What was happening to me?

The next day I went on sick call. The Flight Surgeon gave me some tranquilizers and told me not to fly for a couple of weeks but he didn't take me off flight status, so I continued to get my precious fifty-five dollars.

The tranquilizers proved worthless and in the next few weeks I experienced double vision, weak legs, weak arms, droopy eyelids, difficulty in breathing, trouble chewing, trouble brushing my teeth, and difficulty combing my hair but the doctor didn't know what was wrong.

The dread of flying was gone now, but it had been replaced by new and more terrifying fears. I could not command my body to do as I wished. It just would not work as I asked it to!

Finally, out of pure desperation and frustration at the inability of the doctors to diagnose the problem, I pushed myself as hard as I could to intensify the symptoms, and when they were all at their peak I struggled into the Flight Surgeons office, past the other men waiting, and said, "Here! Look at me!" My speech was slurred and I could barely keep my eyes open. My breathing was shallow and my legs were rubber.

A look of recognition came over the doctor's face and he disappeared for a few minutes, returning with a medical book.

"Here it is," He said. "I believe you might have Myasthenia Gravis."

## CHAPTER II

### YOU'RE ON YOUR OWN

My relief at having a name for what was happening to me was indescribable. There was a reason for my weakness and my recent failures and it had a name.

Myasthenia Gravis? How did I catch this disease? What exactly is it? Nobody seemed to know much about it.

My doctor told me they had a medication that would control MG and that I would be able to lead a perfectly normal life. This good news held up for about two days of taking the medication, but the side effects were so severe that I wondered which was more disabling, the disease or the cure.

The following months were filled with doctors, hospitals, tests, medicine that didn't work, more tests, more doctors, medicine that worked and then didn't and then, finally the verdict that I was "stabilized." At least I could function a little better.

Words like "Incurable," "Rare" and "Crisis" became very important and personal to me, and it was soon clear that the amount of real knowledge about this disease was minuscule. So that was something new to worry about.

The relief of having identified it slowly eroded as I came to realize, more and more, that I was on my own. There would be no magic cure. No doctor was going to solve my problem. This feeling resulted in a sense of isolation that was with me for years. I tried but couldn't shake it. I felt very much alone. True, I was alone with a loving and supportive wife and five great kids, but in this one area I felt a need to communicate, but couldn't. I tried from time to time but was always misunderstood until I felt it best to keep it to myself. The fault was not theirs, I knew. It was mine.

What exactly was I trying to say? Why did I hurt so much inside? Why wouldn't the events at James Connally Air Force Base near Waco Texas, leave me alone, get out of my mind? The Tears! Always the tears and why was it impossible to express any of this?

There was no shortage of questions but very few answers.

Medically retired from the Air Force, we returned to our home town, San Diego. The VA awarded me a 100% disability rating and assigned me to a Dr. Brown who was in charge of the psychiatric dept. Normally MG would fall under neurology but San Diego's VA didn't have a neurologist. Since I still needed someone to write my prescriptions, Dr. Brown was my man.

Compared to the Air Force Hospital where I had been poked in every place that it's feasible to poke a person and stuck in every other place the VA was a very friendly place. No one wanted tests because they admitted that they knew very little about MG and apparently weren't the least bit interested. That was fine with me.

Dr. Brown looked up the medication and wrote my prescriptions. He would ask if I wanted to try something and would get it for me if I did. He knew enough about the medicine to keep me out of trouble and, at the same time, gave me the feeling that I had some control. This seemed very important. We always talked when we met and, although I wanted to, I never managed to talk about James Connally or the pain and tears.

Build a wall--Chink the cracks--and get on with your life!

During one of our talks, Dr. Brown mentioned that he had read about a psychiatrist who had achieved some success with nine or ten MG patients. Unfortunately the doctor had died without writing about his treatment. A Good News-Bad News joke! An interesting piece of information but it just raised more questions. How could a Psychiatrist help someone with MG? Wasn't this a physical disability? The nerve can't transmit the signal to the muscle. That's physical. Well then back to the first question. How could a psychiatrist help someone with MG?

During another of our talks Dr. Brown mentioned an article that said that all MG patients seemed to have very similar personalities. If this were true it would seem feasible that a psychiatrist could play a role in this puzzle. Did ones personality have something to do with why they got MG? Interesting.

I filed all this away along with the new questions. At this time I had no hope of ever making progress toward real understanding.



## CHAPTER III

### *PAIN A PICTURE & DIE*

The year was 1961 and I had been out of the Air Force for two years. My disability, Myasthenia Gravis, now affected my legs, arms, eyes, breathing, swallowing, speech and facial expression. When I say affected I mean these areas had varying degrees of weakness at different times up to and including total shut down.

Without the medicine, Mestinon, all of the above muscles would cease to function and I would end up in the hospital. This is called "going in to crisis" and is something that occupied my mind quite a bit lately. Crisis is something that I, very much, wanted to avoid.

The Mestinon dose that had started with one 60mg pill every three hours had slowly, through necessity, been raised to six 60mg pills every three hours. In addition, two 180mg Time Span capsules had been added to get me through the night. A Time Span is a slow release capsule that lasts twelve hours. Without this Time Span I had, on a number of occasions, stopped breathing in my sleep. This had always resulted in my waking with a giant gasp. The confidence of that always happening was wearing thin.

Continuing to raise the level of Medication, as it became less effective, was fine but I knew the time would soon come where I could not tolerate the increased dose. This worried me a lot. I would end up in the hospital on "God knows what" kind of machine until the mestinon became effective again.

My life was in a very precarious state. I believe Howard Cossell once said "Perched on the precipice of peril." That certainly described Clete Gress in 1961.

Joan and I had managed to buy a small house in the town of Escondido, California. I was unable to work but, still needing something to do, I signed up for an Art Class in oil painting. On the first day, after getting our materials and tools together, a potted plant was positioned in the center of the room and we were told to paint it.

Having never painted before I was surprised at the challenge. I liked the atmosphere and the people and felt good about this new direction. At the end of class the teacher told us to take our work home and finish it before our next class.

Fine! I could do that. Good Plan.

That evening Joan went to bed shortly after getting the kids down and I found myself with peace and quiet and the kitchen table to continue my painting. It was 9 o'clock and, I was still pumped up from the afternoons class. Totally immersed in my work, I painted on without regard to time or the whole universe. This feeling of excitement and enthusiasm had been absent from my life for several years and it felt real good to have it back.

There-----it's finished, I thought, as I looked at the clock for the first time. 6 AM--LORD! I should get some sleep but couldn't resist sitting and admiring what I had done. Marvelous, Grand-----It is wonderful and I am wonderful and All is right with the world!!!!

And then a thought---MEDICINE!

I hadn't taken any since-----when? 8 o'clock yesterday evening. Oh God ten hours!

Within seconds Myasthenia Gravis rushed at me from every direction. Weak LEGS, ARMS, DOUBLE VISION!

"I have to get my pills," I thought.

Panic swept over me like a blanket of ink!

Swallow, I commanded, Oh God swallow! But my throat would not obey.

Under your tongue--fool--put it under your tongue--Geez it tastes bad.

Slowly I felt I could swallow and I put five pills in my mouth, some water, and with a silent "God don't let me aspirate," felt them slide down my throat.

I lay on the couch, breathing with my stomach muscles until the Mestinon took hold.

Scared? You bet. Probably more scared than ever in my life!

Exhausted, I went to bed.

I had not Died.

Not this time.

I had won.

Barely.

I went to sleep.

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