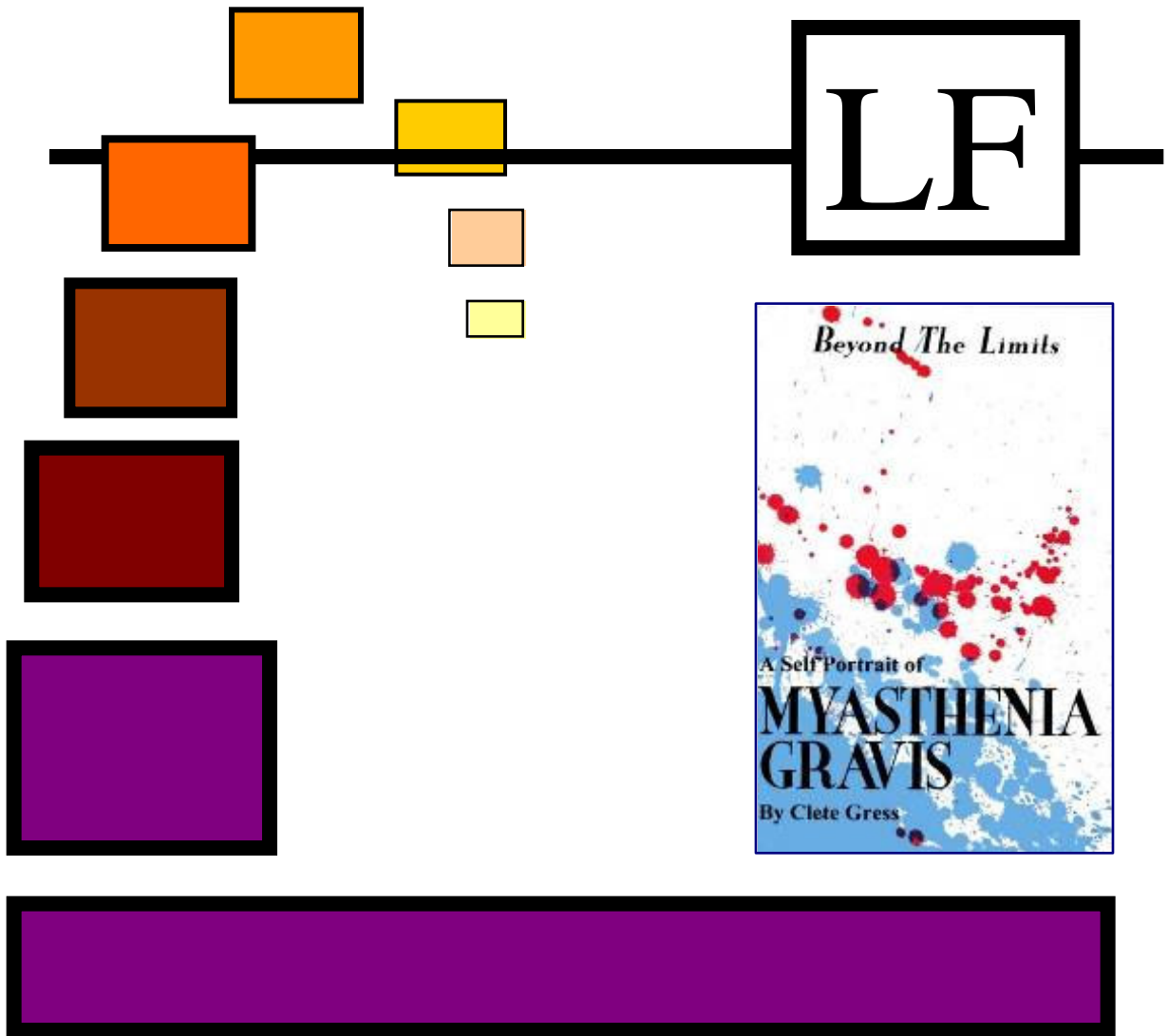


Beyond the Limits

A Self Portrait of Myasthenia Gravis

By
Clete Gress



From: Rev. Carolyn S. Belshe <cbmission@door.net>

To: C Gress <unclete@thegrid.net>

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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The United Methodist Church.

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

PAINT 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.

CHAPTER IV

IN SEARCH OF CONTROL

In the following weeks my thoughts were totally dominated by the events of that night. From the time I awoke until I went to bed, I would lie awake half the night, could think of nothing else.

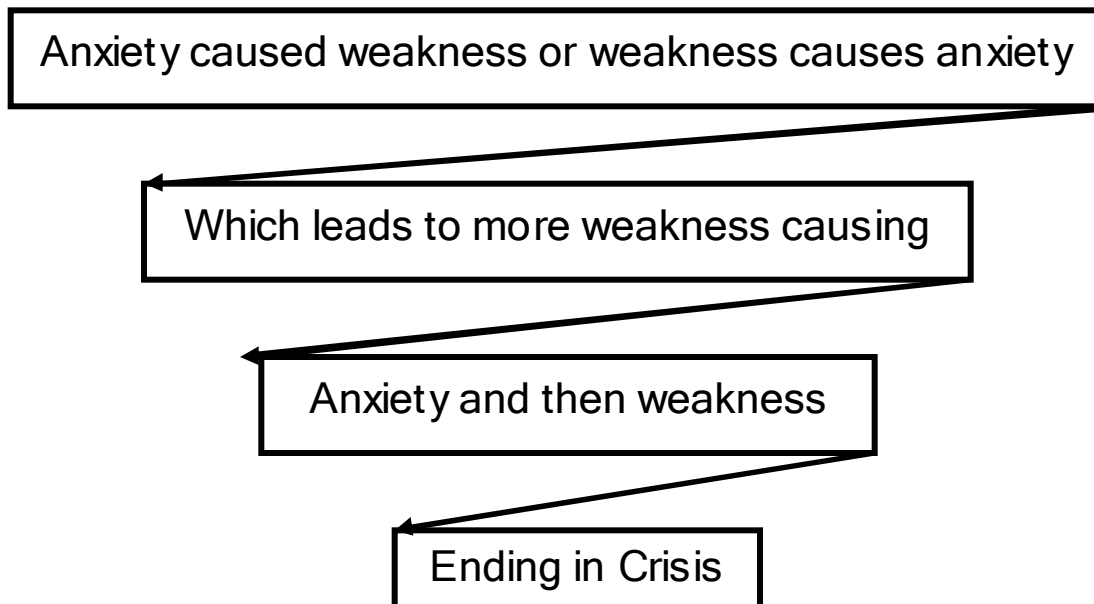
Everything that had happened, I knew, was very important. It raised more questions. How had I worked so long without medicine? Why was this day different than any other? But more exciting was the hint that I could possibly find some answers. Had I been reminded of my pills because I had felt weak? No, I was feeling great until after I realized I had not taken medicine in ten hours. It was fear that had triggered that crisis.

This was no ordinary fear. This fear could kill me!

But how did this day happen anyway? The art class was fun, yes, even exciting. Was that it? Excitement? I had never felt such enthusiasm!

The realization slowly came. The excitement had produced Adrenaline and had raised me up to a level where there was no MG. My enthusiasm had kept me suspended there until fear, anxiety, apprehension slammed me to the ground. Enthusiasm, Excitement, Adrenaline! Fear, Anxiety, Apprehension! They were opposing forces. One was my enemy and the other my friend!

I concentrated on anxiety for awhile. I was fascinated by the power it had exerted over me and wanted to understand. Convinced that the anxiety had come first and had magnified the weakness, I came up with this view of its roll in an MG crisis.



In other words there could be, in the beginning, anxiety that produced weakness or weakness that produced anxiety but once the chain started they fueled one another. Greater anxiety producing greater weakness which in turn produced greater anxiety etc. etc. This view is decidedly different from the view that anxiety is merely a side effect of the disease as all disease will produce more or less anxiety. This anxiety was playing an active roll on the path to CRISIS!

The other view of a crisis was frightening indeed. The immune system, acting entirely on its own, would begin attacking the body, driving it further and further into a state of weakness, until finally the patient would stop breathing and collapse.

That's what would have happened the night of the painting episode had I not been able to take my medicine. But did it have to be that way? If the new view of the role of anxiety was correct I could have simply laid down and relaxed and rid myself of anxiety which would have stopped the downward spiral. I use the word "simply" but I believe it is obvious that controlling anxiety is not simple. Still, this had to be a useful tool.

By understanding this view, and being convinced of its validity, I received an unexpected bonus. In the following months the weakness no longer seemed to generate the fear as it had done before. No longer afraid of crises I began to relax about my condition.

I had effectively neutralized the negative side of MG. Anxiety was still a part of my life but when it did occur, such as in a room full of strangers or people that I wasn't at ease with the resulting MG would be minimal. Further, the MG, having produced no anxiety of its own, would stop there.

A major victory!

I realized I no longer had to fear the disease but this was not enough. Once having tasted victory I wanted more. I wanted to improve my condition, work my way to remission, if possible, and the key had to be on the positive side. The painting episode had strongly suggested that Enthusiasm--Excitement--Adrenaline would do the job.

I had always spent time drinking coffee and thinking in the morning. A very good time to think! These periods, then, were perfect and I don't know if I made a decision or just fell into it but slowly they became periods of meditation with the goal of producing anticipation. Anticipation of the coming days events.

Each job that I wanted or had to do would be put through the wringer until something was found that would excite me, something to look forward to. Something like painting.

Something as mundane as taking out the trash posed a special kind of problem. (It's really, really hard to get excited about taking out the trash.) This type of job I simply side stepped. For instance, I had planted some flowers near the trash can---I wonder if they are doing well, even blooming? The anticipation of finding out would carry me through the job and it was done.

As a child I had been the world's greatest day-dreamer and in my fantasies I always won the battle, always came out on top, always was the hero. I tried using this as a tool with the hope

of producing excitement and discovered something. The fantasy blocked out all anxiety, all worry.

Is this the reason children day-dream? To block out a world that has a lot of bumps or rough spots. Could be. I had been so busy trying to produce the positive experience that I had neglected the negative.

I began thinking of different adventures and placed myself in them as the main character. Soon I had three or four fantasies running at the same time and I would flit in and out as I pleased. When I tired of them I concentrated on the tasks ahead and found it easier and easier to produce the desired anticipation or excitement.

This, then, was my daily routine. Have two or three cups of coffee. Relax. Day-dream a little and meditate on the day ahead until excitement was generated. I did nothing that I wasn't enthused about doing. Jobs that generated no excitement had to be put off until they did. If I was in the middle of something and I lost interest I switched to something else. A lot of things were half done but I usually managed to complete them at another time.

Soon work became easier. More and more my days were free of Myasthenia Gravis. I was pleased with the progress. I was still taking Mestinon every three hours but it was working better.

Months went by.

I began to experience signs of overdose. Mouth watering--stomach--cramps--diarrhea--chest pains. I lowered the dose from six to five every three hours. No more overdose symptoms and I did just as well on the new dosage. This was the first time that I had ever been able to reduce my medicine. Always, in the past, it had to be increased.

A month or two later I lowered it again to four and then to three.

After getting down to three pills every three hours something began to happen. MG weakness was showing up more often and it was getting more severe. I increased the Mestinon back to four and then to five. A cloud of depression set in. What was happening? All of my victories were melting away. Had it all been one big coincidence? What a cruel joke that would be. Maybe all that meditation was so much hooie! The disease had just gotten better on it's own and now it was getting worse on it's own.

God, I couldn't accept that!

Countless hours were spent going over every scrap of information I had, in an effort to find the flaw. Everything has an explanation and I would find this one.

Slowly the realization that, at some point, I had increased my work day to six and seven hours. The last two or three hours of this period would be filled with MG. Apparently working into that area that produced MG wiped out any long term benefit and actually reversed my progress.

I would have to cut back on the hours I was physically active, but how? My enthusiasm was still high after five hours. The solution was not long in coming. I had noticed that if I had a can

of beer or a glass of wine that my enthusiasm diminished. This, then, was the answer I settled on. Meditate and do my work but after four or five hours or at the smallest hint of MG have something to drink and relax. My work day was over. The alcohol effectively mellowed me out, killing my drive and it also helped to block anxiety.

Looking back I'm not sure if this was the best possible solution but for a man who was stumbling and groping for answers it would have to do. It worked and in those days anything that worked, I did!

Since first writing this I have, once again, developed the need to use alcohol in this manner, for this purpose. This time I resisted as I had stopped drinking altogether and didn't really want to start again. Unfortunately I could not find a satisfactory substitute. So far I've succeeded in limiting the drinks to two and this has worked to shut down excessive brain activity in the evening.

At any rate I had to modify my thinking a little. I had thought that all work in the presence of adrenaline was beneficial and would move me toward remission. Now it was: **All work, in the presence of Enthusiasm--Adrenaline is beneficial, provided you stop working short of experiencing physical stress with the resulting MG weakness.**

In the months that followed I once again experienced overdose and reduced my medicine. First to four and then back to three. I had regained a good deal of control and no longer felt helpless.

I approached the VA for schooling and, after testing, was soon in a full time art school. I really had no choice for, by this time, I was as dependent on art as I was on my pills. Art still was the major source of excitement in my life.

CHAPTER V

STEVE

In 1964 our oldest son, Steve, came down with Myasthenia Gravis. Steve was nine years old. Was the condition hereditary? No. I was told, we were the first father-son combination to ever get MG. This honor of being the first father-son to have this disease failed to thrill me.

I first noticed the odd expression on Steve's face and a few days later, when he began walking by dragging his toes, I knew what I would have given my life not to know. Our fears were confirmed at Camp Pendelton with a Tinsalon Test.

Steve went into "Crisis" and as a result spent the next six years on a respirator and gastric tube. Nothing that I had learned, to date, helped us improve his condition.

At one point, using Excitement, we did manage to get him walking. After several weeks of slowly increasing the distance each day, he was taking thirty or forty steps. Then disaster struck in the form of Pneumonia! Steve, once again, was flat on his back and the time spent fighting the Pneumonia left his body even more wasted than when we began.

It is difficult to control one's own emotions and I found it impossible to control or influence Steve's. Emotions were the only tools I had to work with at this time.

I've given Steve a lot of thought over the past twenty five years and I'm left with more questions than answers. To go into detail here would only muddy the waters of my own story.

One point that might be worth mentioning is the idea that there might be more than one TYPE of MG. Both types being Myasthenia Gravis, but arrived at from different directions or by different means.

When Steve died, in 1970, we were all devastated. Losing this battle was, I think, inevitable. Joan and I had taken 12 hour shifts for the past six years and we were both tired beyond description. Steve's younger brothers and sisters also helped when they could have been playing like other kids, and this went a long way in making our job bearable. For the first time in my life I accepted failure. There just was nothing that we could have done. We lacked the knowledge just as the doctors lacked the knowledge. It was not my failure or Joan's failure or the doctors failure. It was a failure of circumstances and a failure of knowledge.

With the burden of Steve's care gone my condition improved. Soon I no longer needed Mestinon on a "every three hour" basis. I still used it on occasion but never more than one or two pills a day. This was a long way from the thirty six plus pills a day I was taking in 1962.

I owed Steve a debt as his care had forced me to work harder than I would have and the end of those six years found me in pretty good shape. Physical conditioning for the MG person is vital and he had given me that gift.

In the dark aftermath of burying our son and brother the family did what it did best. We went camping. I painted a picture, which hangs on our living room wall, and I composed a verse to send to our friends and relatives.

***OUR SON DIED!
We bought a grave.
We went to church.
Then people came that
Steve had touched.
WE CAUGHT A GLIMPSE OF GOD.***

Most of our friends and relatives understood our feelings but, I guess, we left a few people confused and worried about our mental health. They needn't have worried.

Today I don't think of Steve as being dead as he lives in each member of his family. He's in me and Joan and in Dave, Phil, Linda and Brenda.

We gave him our time and we cared for him when he was sick. Silently, secretly, he gave us a finer gift. One that we weren't aware of at the time. Steve's care forced us out of ourselves into a more generous world. A world where we could see beyond our own self interests. A more precious gift has never been given. We could not save Steve's life but he may very well have saved ours.

Thanks Steve.

CHAPTER VI

ACORN MUSH

The benefits of Solitude.

Through the years from about 1964, I have gone camping by myself. I discovered that when Myasthenia Gravis started to become a problem and things became confused in the way I was managing the condition, a four or five day trip would iron out the wrinkles. I think most MG people will agree that social pressures have a direct and usually a negative effect resulting in MG weakness. Camping by myself eliminated these pressures and if I didn't impose pressures of my own, I could have five days of total freedom from MG. The second part, of not creating my own pressures, doesn't just happen and needs some practice but it can be achieved.

I made no plans. No guide lines or timetable that I would have to worry about or try to adhere to. Everything was simplified. The supermarket provided a lot of fresh vegetables, cheese, summer sausage, dried fruit and coffee. A special stop at Mama Lina's for six small loaves of bread with that delicious hard crust and I was on my way. I always forgot something, but veggies packed in clay and thrown into the embers, are every bit as good as veggies baked in foil. Within twenty four hours all confusion, anxiety, cobwebs or whatever, dissolved like the morning mist.

What happens to the mind and body over the next four or five days is so wonderful, so startling, that I would like every human on the face of the earth to experience it. I should emphasize that this is five days of zero contact with other people. If I met someone by accident I simply waved but did not speak. The healing process of mind and emotions under these conditions is swift and sure.

I did many things on these trips. Sometimes I drew or painted. At other times I just hiked and explored my surroundings. I did things that reinforced the fantasies that I used in the mornings.

Once, while hiking, I discovered a small spring in a place where no human had set foot in a jillion years. I named it "Chetusu Springs" and it became mine. (The name "Chetusu" is another story). I could return to Chetusu Springs anytime I wished, in my mind, while having morning coffee.

One time I spent the first day gathering acorns, splitting them and spreading them in the sun. When they were dry I used a native grinding hole in a nearby rock to reduce them to powder. After winnowing the meal, to eliminate any chunks, I made a sand filter in the stream below my camp site. Eight hours of leaching the bitterness from my acorn flour and I hoped I would have my supper.

I had intentionally refrained from eating all day in order to more fully appreciate the experience of surviving on what God had strewn all over the forest floor.

It was eight in the evening when I was ready to cook my days work. I was hungry. I did use one of my metal pans but didn't put the pan in the fire. Just as the natives had done with their clay pots, I heated small stones and dropped them into the flour and water, stirring with a stick.

The mixture thickened into a cream colored mush. I plunged two fingers into the pot and, putting them in my mouth, I ate much the same way that the natives had done.

The mush had little or no flavor and just a hint of bitterness. The leaching had not removed 100% of the tannin but it was enjoyable considering the extent of my hunger after a twenty four hour fast. I resisted the temptation to cap off this feast with a hunk of summer sausage and some bread. I wanted the meal of acorn mush to stand on its own and remain fixed in my memory forever. It has.

How very different this day was from our civilized days in the city with our cars and jobs. I was tired but emotionally refreshed. Everything, at my camp site, had been reduced to a very simple, easily understood, equation. Nothing existed except Me, my camp and God.

As you will see, in this book, I have a visual mind. Everything that I think of or learn I must visualize in some way. That night I saw our lives in mathematical equations. In my minds eye modern man's daily life looked something like this:

$$\left[\cos \frac{a^2}{4b} + \sin \frac{a^2}{4b} \right] \sum_{r=1}^n \gamma \left(2n + \frac{n\pi}{2} \right)$$

On the other hand, at this moment, my life was more like $2+2=4$.

No anxieties, no uncertainties, everything, easily understood. $2+2=4$. It has occurred to me that this experience, unfortunately, might be limited to those few who have the skill to camp and are not afraid to do so by themselves. This obstacle could be overcome in a number of ways.

A husband and wife or a father and daughter, brother and sister etc., could set up camps within easy earshot and agree to not have contact for five days unless absolutely necessary. Agree ahead of time to leave notes when leaving etc. I don't know if this would be the same but certainly it would be better than nothing.

The use of a small hut to reflect, meditate, and restore the spirit has, I understand, been used for centuries. The person lives in the hut with no outside contact. Meals are left on their door step.

I don't believe the means to achieve this goal of solitude is important. Its value is tried and true and, although I did stumble upon the benefit, as it relates to MG, by accident, it has been around for as long as people have become stressed.

Each time I went camping I came back with new ways to enhance my fantasies. Now they were not just daydreams but were solidly anchored in reality and my experiences camping. They now had the same effect, on a smaller scale, as the camping trips themselves. My fantasies were made more effective than they were in 1964.

An unexpected visitor

It was the middle of winter and, as far as I was aware, I was the only one in the campground at Black Canyon in Southern California.

Busy with a painting, I caught a glimpse of movement coming in my direction. I continued with my work. As it grew nearer I recognized the stoop of an old man, flannel shirt, baggy pants, a stocking cap and well worn boots. No pack so he hadn't come far but I wondered where he had been hiding these past three days. He never hesitated, but walked directly into my camp and said "Do you mind if I rest on your bench?" I didn't speak, which was my habit when camping alone, but I smiled and, with my paint brush, pointed to the picnic table. He smiled back and sat down.

In the next twenty minutes not a word was spoken. I painted and he watched and then, rising, he walked to my canvas, bent to get a better look, pointed his walking stick at it and, turning, smiled. He raised his hand slightly, in a gesture of goodbye, walked out of my camp and down the road.

That night, sitting before my campfire, I reflected on the day and my little old man. I wondered who he was. Old men are immediately suspicious. Every night, on TV, some old man has done something. Molested someone. Drunks, bums, homeless people, it seems the list has no end.

As I watched the flames of my campfire a feeling of peace came over me. I was being a fool. Think about this old man. Had he been threatening in any way? Did he do anything to make me think all those thoughts?

He had ask a favor and I had granted it with a smile. He had returned the kindness with a gesture and a smile of his own. I had given him love and he had given me love in return. Can anything in our lives be more simple or more beautiful?

Was I reading more into this happening than it deserved?

That night, for the first time I understood that ones perception of life is, by far, more important than life's realities.

I slept very well that night.



CHAPTER VII

A SEARCH FOR ANSWERS

In 1978 Joan and I, with our son Dave, took a trip to England. Dave had been stationed there, in the Air Force, and had made friends who invited us to stay with them. This was a marvelous opportunity for us. England is where Joan and I had begun our married life and we enjoyed every minute of our revisit.

On our return to our home in southern California, I received a letter from a man in London, I'll call him Dan, who had Myasthenia Gravis. Through a mutual friend he had heard about my use of meditation and ask for details. Now, up until this time I had given little thought to writing anything down much less communicating the things that had been working for me. Dan's letter forced me to try and I soon discovered that my understanding of MG was very incomplete.

My first mistake was not simply writing him what I had done. The things that worked for me. Just give him the facts. Let him figure out why. Unfortunately it's just not in me to be simple. Joan says if you ask me the time I'll build you a clock. True!

I settled in to find the reasons and my thoughts led back to Dr. Brown. From the contacts that I had made, so far, all MG people did seem to have similar personality traits. The one that stuck out the farthest was their drive. They didn't give up. Many had overcome huge obstacles in their lives. Yes, their personalities were very much alike but what exactly was the element that related to MG? The conclusion? Prior to the onset of MG there had always been a strong pressure to perform. This pressure didn't always come from outside i.e. parents, coaches, teachers etc. Many times it was internally brought on by love, loyalty or a strong sense of duty. These are all good things to have but, like all good things, I sensed that they could turn on us with disastrous results.

What would be the circumstances?

Depression and/or Anxiety had to play a role.

I came up with a theory and sent it off to Dan.

Put simply: What would happen if this guy with a "Never say die" personality met a really devastating emotional trauma? The irresistible force meeting the immovable object? Something would have to give.

Dan was not impressed.

Thousands of people every day met this criteria without getting MG. They had nervous break downs or became ill but didn't get MG. In fact, if this was all it took, MG would be very common instead of rare. And why, Dan asked, would he only have MG in his eyes and other people had it in their legs, arms, throat etc.

Dan was in the process of earning his Masters Degree and I wasn't going to slip something over on him.

I knew Dan was right and his rejection only made me try harder.

My theory was incomplete---Something was missing.

Trying to get information from other MG people proved impossible. The time just before they contracted the condition was especially difficult and my mind returned to the idea of a psychiatrist. If their secrets were buried so deep that it required analysis I didn't stand a chance of uncovering something that would be of help.

The answer had to lie within my own life.

Every cell in my body and mind resisted thinking about James Connally Air Force Base, but that's the place where the answers were, and back I knew I must go. Just trying to think of this period in my life was very hard but I knew when I was getting close to something of importance. The tears would come. I had learned that this was a sure fire indicator of something that my mind was trying to protect me from.

It had all started in the summer of 1957. I had just been assigned to James Connally Air Force base. I was a Staff Sergeant and my job was repairing airborne radar sets. My wife, Joan, our two sons and myself had recently returned from a three year tour in England.

No one had prepared us for the differences in pay and living expenses. Bad judgment on my part found us with a new car, new furniture, and more bills than we could handle. The burden of providing for our family was becoming heavier each day.

I had four years in-grade as a Staff Sergeant and was overdue for a promotion so that hope was there. In the meantime I signed up for flying status to add fifty-five dollars to our paycheck.

Soon our third son was born and a year later Joan delivered twin girls and still no promotion.

The Air Force picked this time to have a review board. They ask me questions and at the end, decided that, based on the opinion of their expert, I no longer was qualified to hold a seven level or technicians rating. I needed that seven level rating in order to be eligible for promotion to Tech. Sergeant. A Death sentence would not have been more devastating under the circumstances.

I simply am not good enough with words to communicate the severity of depression that I felt at that time. Add the depression to the anxiety of the test hops, test hops that I was trapped into flying by our financial dilemma, and the outcome spelled disaster.

It was not the depression that did me in, or the anxiety, it was the overblown sense of duty and a personality that refused to accept defeat that finally did the job.

I knew, at this point, in my continuing investigation, that I had two of the things that led to MG but I didn't really know anything more than when I first wrote Dan with the immovable object and the irresistible force idea. All I had really done was nail it down, so to speak. On the sunny side I was now free to go on and look for a third element. An element that I knew had to be there or MG would be very common.

It's amazing how a person believes that everything that they do is normal. Finding a facet of ones life that is not normal, through self examination, proved to be very difficult.

After months of effort I slowly came to the following conclusions: It seems my "Do or Die" personality was formed very early as a result of my small size and birth order. Being the fourth child of five I had to try harder to achieve the same results as my brothers and sisters.

Examples:

Between the age of five and about ten I recall trying to keep up with the neighborhood gang of kids all older and bigger than myself. This is when I remember playing by myself a lot and indulging in frequent daydreaming. I believe, now, that this behavior provided relief from all that "keeping up"

At the age of twelve I joined the boy scouts. They did not believe anyone that small could possibly be twelve until I showed them my birth certificate. I went on many hikes, keeping up with the troop, and always made the top of the mountain. It's true I usually barfed when we arrived but I made it.

When I was twenty I applied for a job in a Lumber mill in Oregon. They needed someone to pull lumber on the "Green Chain". This was one of the harder jobs in the mill and the owner looked me up and down and proclaimed, "Sorry, your just too small to do the job." I had been told that I was too small all of my life so his statement wasn't exactly big news to me. I looked the man in the eye and said, "You let me work for two weeks and if you don't like what you see, then don't pay me." Well, he didn't have a whole lot to loose so, with a big grin, he gave me the job. I know he fully expected me to fall flat on my face within a few days, but I had other plans and collected my pay when the two weeks were through. When I left to join the Air Force this same man told me that I had a job with him anytime I wanted it. Great reinforcement for an attitude that said, "I can do anything anyone else can do and I can do it better."

There didn't seem to be a limit to what I could achieve, if I tried, and I considered this a precious asset.

Further review of my life revealed numerous occasions when I experienced what is usually referred to as "Super Strength".

Was this ability to push myself beyond normal limits a precondition to the onset of Myasthenia Gravis? I thought so, and with excitement, wrote it all to Dan.

Dan rejected the Super Strength idea and I never got the chance to argue the point as he moved, leaving no forwarding address. I would certainly hate to think my theory had anything to do with his sudden disappearance. At any rate I owe him a thanks for getting me started on this book.

It is my belief that Dan's reaction was based on his being a scholar with MG only in his eyelids. He avoided physical work and must have laughed at the idea of himself and super strength.

The idea isn't so ridiculous if you picture this scholar working long hours, past the time when he should sleep and forcing his eyes to stay open when they demanded to close. It is feasible that

he could develop or experience Super Strength in his eyes only. As I said, Dan was gone and I no longer had a sounding board. I would have to go it alone.

I called the trait that showed up in the form of Super Strength and came from a "Never say Die" personality, an Enhanced ability to communicate Mind to muscle.

This, then, was the third element. The one that made MG so rare. Without this ability a person would not get MG. How many people possessed it? Out of this number how many would come up against the other two elements at the right time and with the needed intensity? Not many, I think, so here you had the making of a rare disease!

Pleased with the progress, I felt close to being able to formulate a theory but still needed the answer to the question, How? How did these three things work? I put together a number of possibilities and they all fell apart in short order.

It was time to rest.

CHAPTER VIII

WHY DIDN'T HE FLY?

Without the need to write to Dan the project sort of petered out. Several years went by before my mind came back to review what I had written.

MEDITATION-RELAXATION-ADRENALIN---POSITIVE

ANXIETY-DEPRESSION-STRESS-----NEGATIVE

The enhanced ability to communicate mind to muscle idea was still important.

Meditation and fantasy worked and had put me in pretty good shape. These things worked without fail but I didn't know why. It would be nice to know why.

The key had to be in my ability to send too many signals from my brain. The enhanced ability to communicate. This ability should be a good thing but I was convinced it was working against me. Each time I tried to force an activity I became weak and failed. The most progress was made by relaxing. That's backwards. Something is definitely backwards.

Where could I go from here? Could I, indeed, go anywhere? What was my next move? I was doing well but the holes in my understanding were, or seemed to be huge. How could I get off this plateau and on to the next one. There had to be a higher one. It didn't take Sherlock Holmes to arrive at that conclusion but how could I get there? The thought that medical researchers, all over the world, were probably working on these questions with their millions of dollars in research grants and dozens of straight "A" technicians, was a depressing thought. Who the hell was I, anyway, to think that I could have a chance to unravel this enough to really understand. I wanted to give up but my "never say die" was working overtime. Part of the problem was Steve. He had died and I was still alive and, try as I might to not think in these terms, the thought left me feeling guilty. I could get rid of this feeling if I could gain enough understanding to help other "Steves".

I had nothing to grab hold of. Not a clue that would start my mind going in the right direction. "It's fine to have an analytical mind," I thought, " but, with nothing to analyze I was nowhere."

This whole project was an ego trip! Vanity! Stupidity! Stop it, Clete, and get on with your painting! A painter should paint and researchers should research and brain surgeons should surge and barbers should barb. I was finally back to reality.

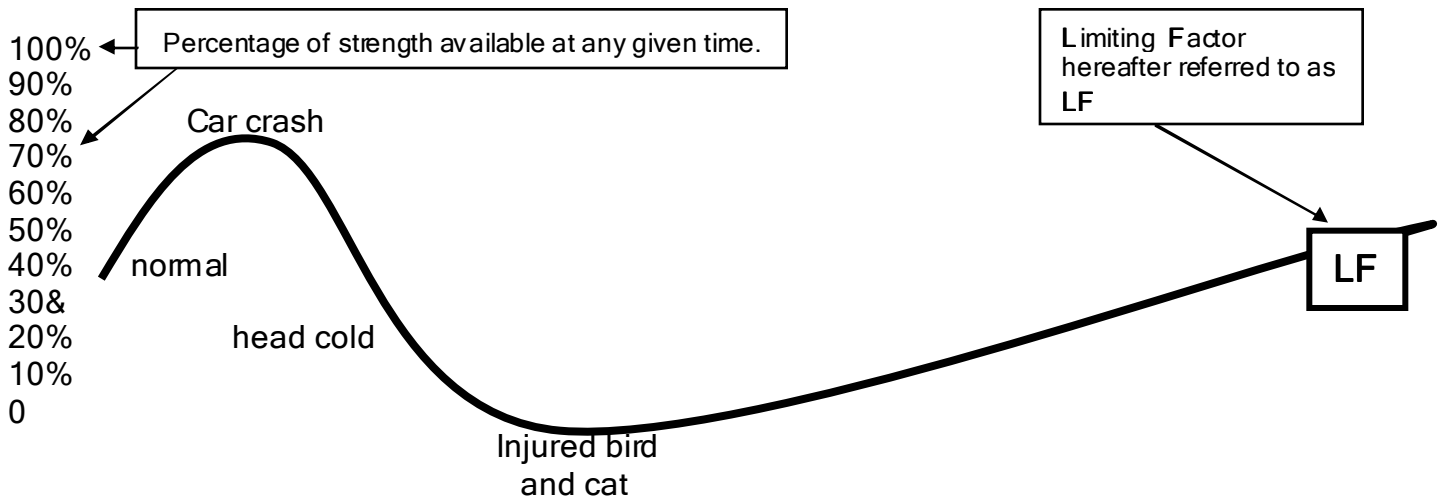
A small bird flew into our window and lay motionless on the grass. Its eyes were open and it blinked but it didn't move a muscle. I picked it up and placed it on its feet. It just stood there and blinked, never moving for at least two hours. Why? Didn't it know it was in danger? A cat could have walked up and eaten it and I don't think it would have tried to fly. Why?

A cat was hit by a car and dragged itself under the neighbor's house. It didn't move for four days. It was alive as I could see its eyes, but it didn't move. Finally it came out and looked for food. Its injuries were healed. What did this mean?

Were the bird and cats total immobilization the opposite of Super Strength? If this were true it opened a whole new avenue to explore. The bird and cat were both injured and apparently their bodies shut down completely to give them a chance to heal. A question of survival. In the car crash the man was allowed to lift two thousand pounds to save his wife. Also a question of survival. In both cases the limits were different. Limits. Yes. A limiting factor. It had to be. I reasoned that Adrenaline would raise it but it surely didn't lower it. If it was connected to healing it must be connected to the Immune System. Possibly the Immune System played a roll in both raising and lowering it.

Finally I had something to visualize. A line. A limit that could be moved up with Enthusiasm--Excitement--Adrenaline and a limit that could be lowered with Anxiety--Depression--Stress. A limit that had been lowered to almost the bottom when both the bird and cat were injured. Survival! Survival at the expense of safety!

I drew graphs.



The Limiting factor went up and down and limited our activity and it was all regulated by our immune system. It kept us safe and helped us survive.

If it kept us safe then why did I have MG? Why was it not working right? Why did I have to spend two hours each morning meditating so that I could do even simple jobs?

Maybe-----and my thoughts went back to the Enhanced Ability to Communicate, maybe now I could figure out what happened when the "irresistible force" came face to face with the "immovable object".

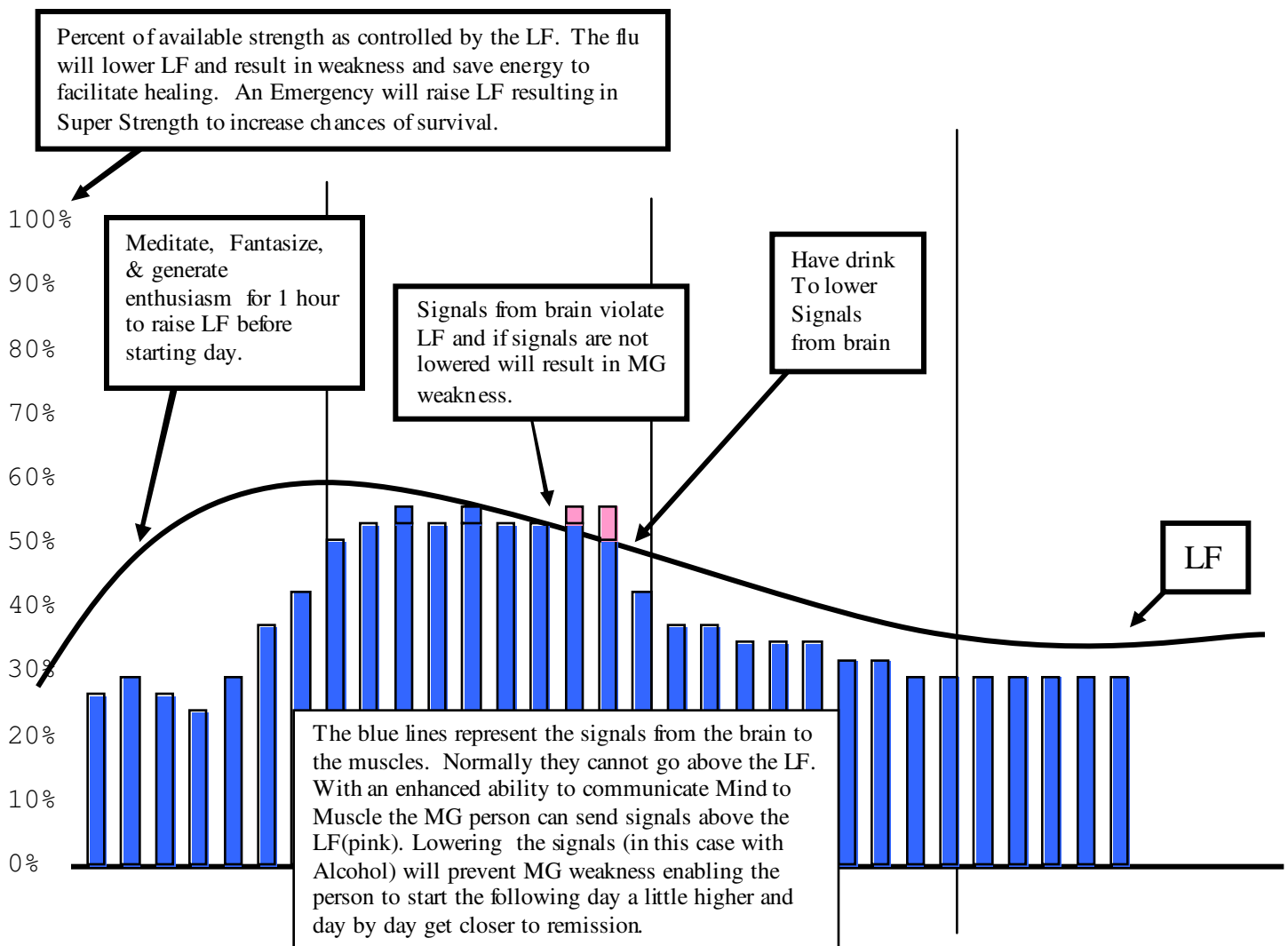
What if I were hurt and my Immune System lowered the Limiting Factor in an attempt to protect me and what if I then applied signals from the brain in a quantity and amplitude that my system was never designed for. What would happen? Could the signals break through the Limiting Factor (LF)? If they did what would happen? Would the Immune System perceive the violation of the LF as another threat and lower the LF further?

If all this happened wouldn't it be call Myasthenia Gravis?

At James Connally AFB my injury was emotional. I was already stressed out when the Review Board failed me. Add the depression with the stress and then the anxiety from the test hops. Good old "Never say die" did a good job hiding all this from the world, even from myself, but I couldn't hide it from my Immune System. It knew that all this was a threat to my survival and it did what it was designed to do. It lowered my LF. When things got worse it lowered it again and this should have slowed me down to a level that would protect me. It would have, I believe, if I had had a normal ability to send signals from my brain to my muscles. My enhanced ability overwhelmed the safety system and threatened my very existence.

All this seemed to fit and, as I had always done, when something fit I would assume its validity until experience proved otherwise.

My daily routine looked like this on a graph:



In the morning, when the LF is at 20%, starting work immediately would result in MG. The LF must be raised while the amplitude of signal are still low. One thing still bothered me. Why was the LF so low when I got up? What was suppressing the LF?

I believe the answer lies in the hurt that I felt from my Air Force experience. The things that I wanted to talk about and couldn't. The pain was all still there even if I had built a wall to keep it out of my life. My Immune System knew it still hurt even if my mind had forgotten. My Immune System was still trying to protect me.

In the past thirty years, as I've written this book, there have been periods of uncontrolled tears. Each time I approached the hidden hurt, water would fill my eyes and flood down my cheeks. The feeling of calm and peace that followed told me that this was a good thing. Slowly, over the years, my LF has been higher when I get up in the morning making fantasy and meditation less essential. I believe, very strongly, that writing of my experiences has served as excellent therapy. I would strongly recommend it.

CHAPTER IX

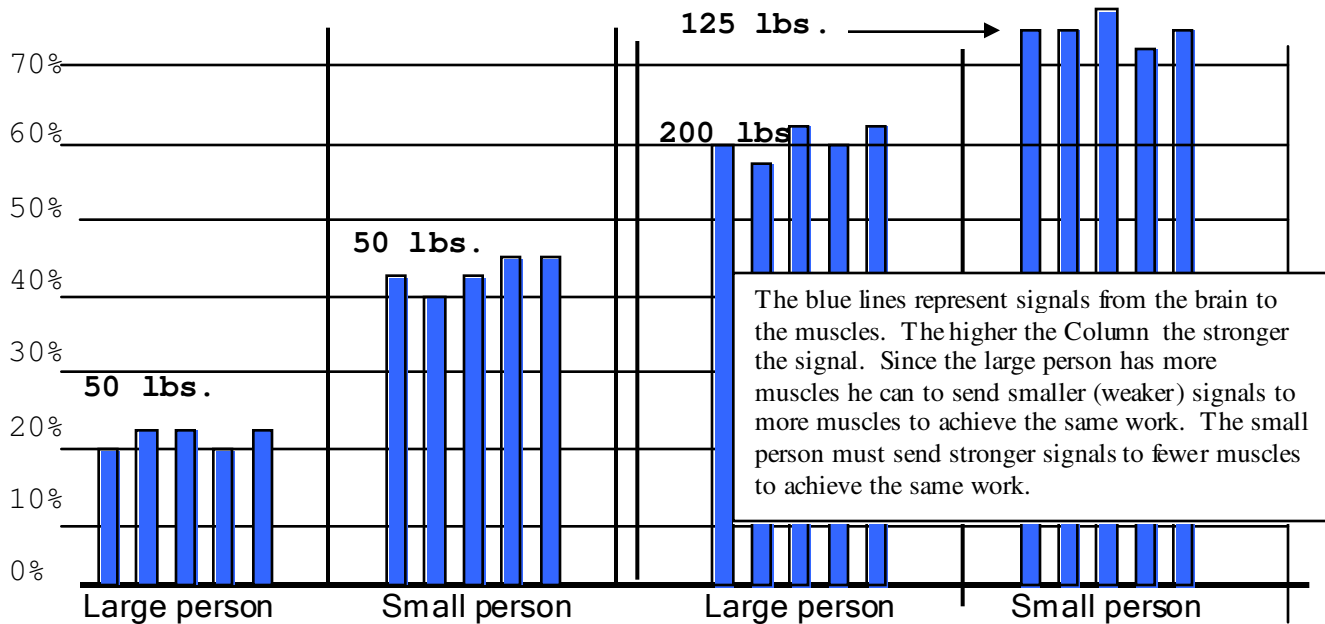
THE ROAD TO MG

A theory of Mind-Muscle Communication as it relates to Myasthenia Gravis

Our muscles work by contraction due to electrical stimulation. The brain controls this system and it is very selective. When electric signals are generated they don't go to the whole body but are sent to one or more selected sites by the brains control. In addition to where the electric impulses go, the brain controls the amount and amplitude of the impulses. By this complex system we can move the tip of our little finger and leave the hand, the arm, and the rest of the body very still. This is the selective part.

The amount that we move our musde is controlled by the amplitude of the signals sent to it. We can hold a baby bird gently in one hand and pick up a fifty pound weight with the other, and we can do this at the same time. The other factor to be considered is the size of our musdes. We all know that a small person cannot lift as much as a large person. If a 200 lb. person picks up a 50 lb. weight and a 100lb. person picks up the same weight--what has happened? They both pick up the weight but the large person didn't have to exert himself to the same degree as the small person. In other words, in order to do the same amount of work the small person had to send more and greater signals to his muscles.

If viewed on an oscilloscope the signals would look like this:



It appears that the small person can compensate for his size by generating more and higher signals but what happens when they both try to lift 200 lbs.? The large person generates greater impulses and succeeds while the small person does not. He has reached his LIMIT. He cannot lift more than, say, 125 lbs.. This then is the LIMIT of his Strength.

It is obvious that we are limited by the size of our muscles and our ability to generate electrical impulses. The small person would conclude, at this point that, "It is too heavy, I cannot lift it."

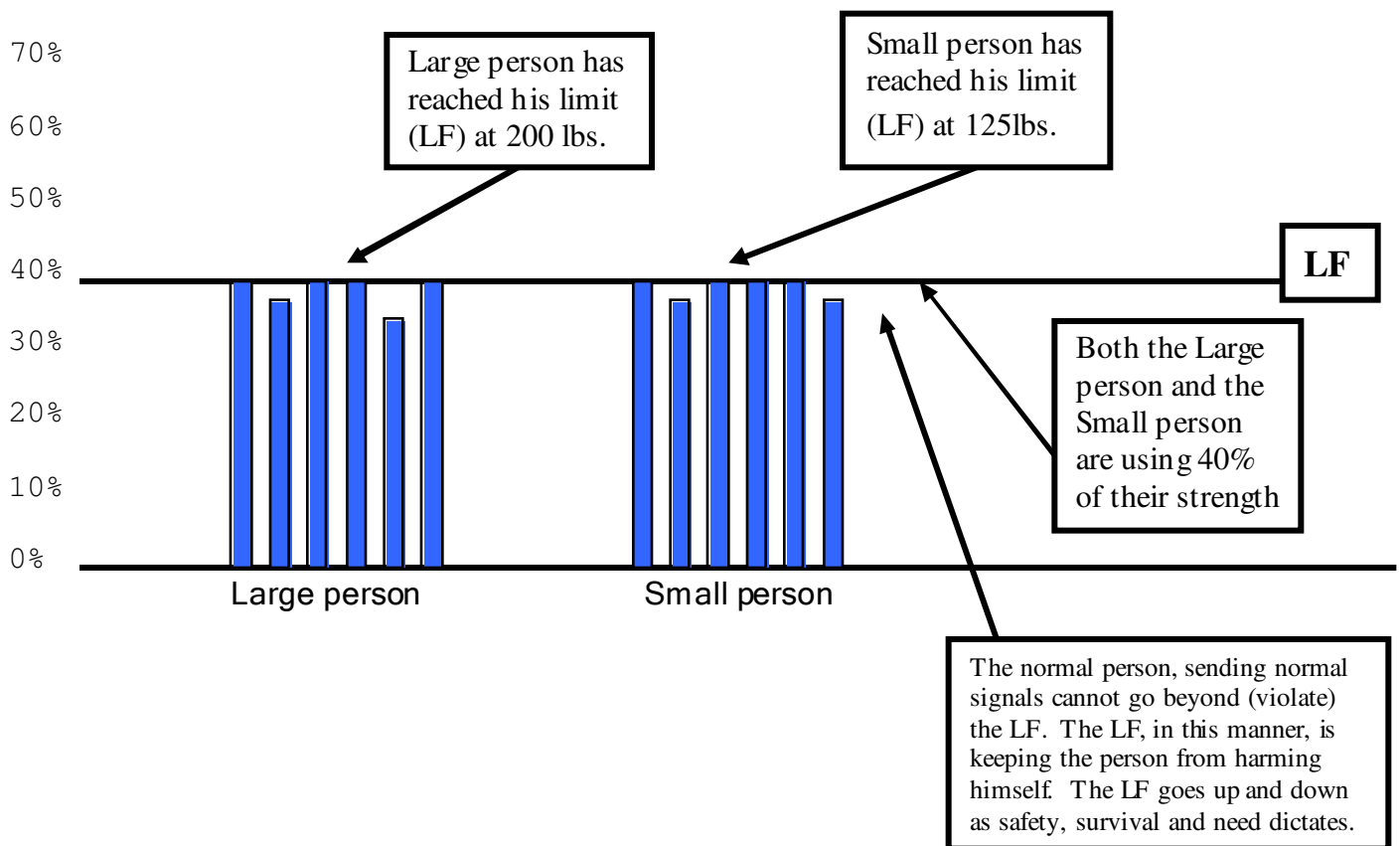
There is another factor to be considered. There is evidence that we are capable of using only a fraction of our potential strength. This conclusion was reached, in part, by the phenomena known as Super Strength. Under certain conditions, such as a car crash, people like you and me, have been known to lift a car off a loved one. Several thousand pounds when normally they would be limited to several hundred.

This shows that under normal day to day activity there must be a LIMITING FACTOR, AN LF that sets the maximum that we can stimulate our muscles to work.

Why, if we can lift 2000 lbs. under extreme conditions, should we be limited to only 200?

I believe our Limiting Factor is the body's way of protecting us. With no limits we would literally tear ourselves apart. We would stimulate the muscles until they would rip. The damage would threaten our lives. This Limiting Factor (LF) is a matter of safety.

For the purpose of visualizing the system the LF can be represented on the graph as an imaginary line.



RAISING THE LF

It has already been discussed how the LF can be raised in the event of an accident. The question then arises--can we move our LF in circumstances other than an emergency? Can it be lowered? Does it in fact go up and down during the course of our everyday lives? Does this function regulate our activities in such a way as to provide a continuing level of safety? Does it work closely with our immune system?

I believe the answer to all of the above is YES!

In the case of the auto accident a large amount of adrenaline was produced, raising the LF and stimulating electrical impulses at a rate and amplitude many times greater than normal.

I would conclude from this that in the natural order of things survival is more important than safety. If a matter of safety and a matter of survival occur at the same time the matter of survival will dominate.

In our lives, ordinary activity is accompanied by more or less excitement. Excitement would produce adrenaline and raise the LF. Not to the degree present at the auto accident but by varying amounts relative to the degree of excitement.

I submit to you that imagination plays an important role here. I can, by simply imagining the possibilities of a coming adventure or event, produce the excitement that results in the production of adrenaline. This ability to easily raise the LF may be common to all potential MG's. It may also be a key ingredient to the MG persons ability to find a road to remission.

The potential MG person, through exercising his ability to raise the Limiting Factor (LF), develops an Enhanced ability to communicate mind to muscle. He may, in fact, be capable of generating two or even three times the amount of electrical impulses that the Non MG prone person can. (He does this on an everyday basis but without a way to compare with others, is not aware that he has the ability.)

LOWERING THE LF

In looking for elements that lower the LF we must only think of things that make us feel weak or listless. Anything that drags us down and robs us of energy.

1. A common cold. The flu or any viral or bacterial infection
2. A day of extreme physical activity will result in a day or two of recuperation when the body needs to rebuild.
3. Depression leaves us listless and physically droopy.
4. Emotional and physical Stress.

At the same time these things occur we find it very difficult to feel excited about any activity. Under these conditions it would be difficult to produce adrenaline.

In addition to this general lowering of the LF there is a local lowering of the LF. In the case of infection or trauma in the right arm the LF is lowered at that point with a corresponding but lesser lowering in the entire body.

The element that lowers the LF I call:

ANXIETY-DEPRESSION-STRESS

We have now established a LIMITING FACTOR (LF) and the ability to raise the LF by **Excitement-Anticipation-Adrenaline** and the ability to lower the LF by **Anxiety-Depression-Stress**.

The last culprit in the cast of characters leading to MG I call **Pressure to perform**. This is necessarily a very general term because it depends on each person's life. In one person it could be the pressure to support one's family. In a young person it could be the desire to please parents or teacher. Put simply it is the element in a person's life that puts pressure on that person to perform no matter what obstacle is put in his way. While there are pressures in everyone's life to perform I refer, here, to an over developed sense of duty. The kind that simply will not allow failure.

With this last piece in place I can now make the following statement.

A strong Pressure to perform, in the presence of Severe Anxiety-Depression-Stress will lead to MYASTHENIA GRAVIS, provided the person is predisposed by the development of an Enhanced ability to communicate mind to muscle.

CHAPTER X

SALLY

Sally, a young girl of sixteen, who is a high achiever in school, has the leading role in the school play.

There is the normal amount of anxiety and stress but she handles that perfectly.

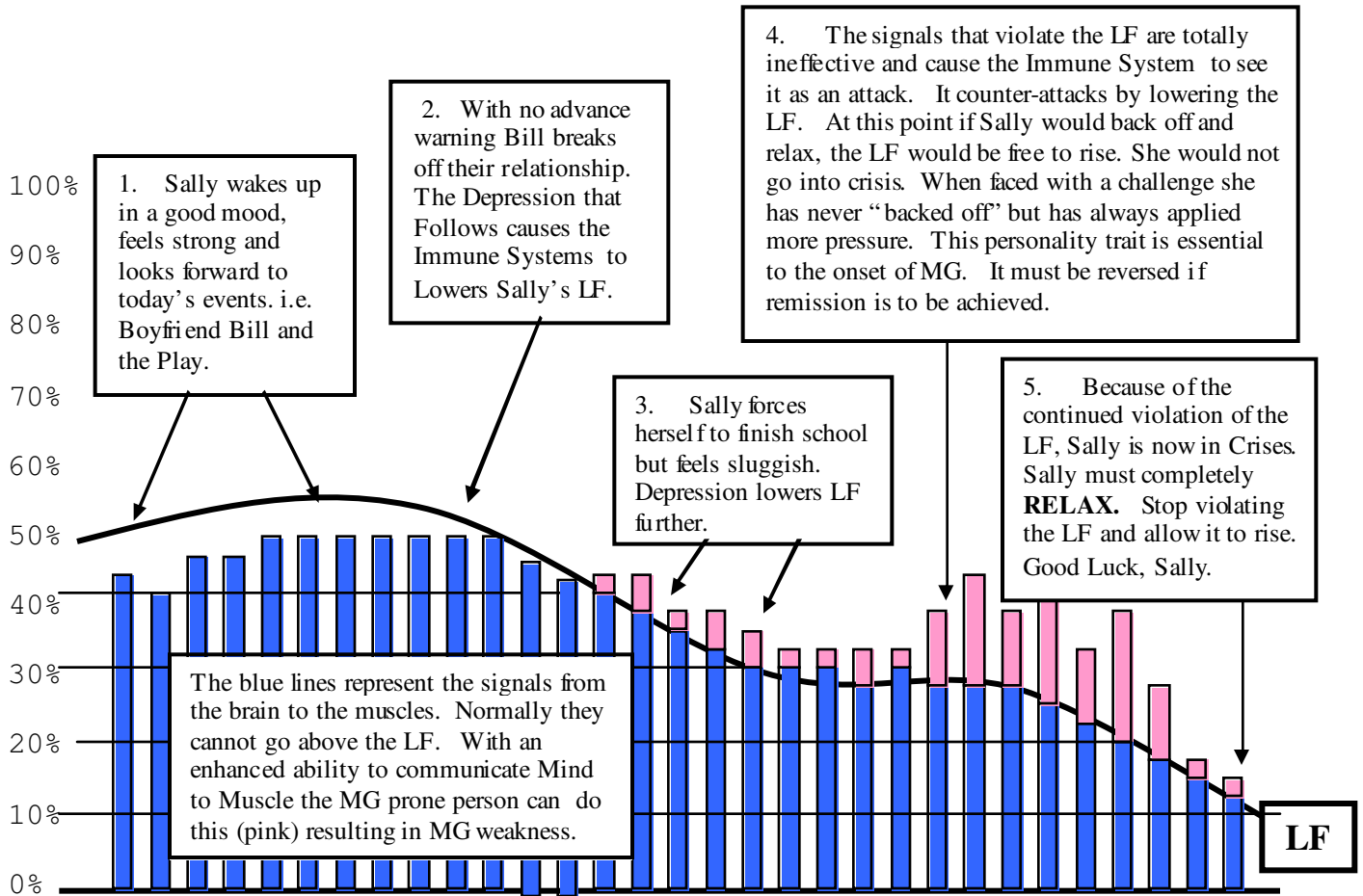
Around noon on the day of the performance her boy friend breaks up with her. The resulting DEPRESSION and EMOTIONAL STRESS is devastating and Sally finds it hard to think much less function. She has always been dependable and she knows the play depends heavily on her performance. She **would** not let them down. She **COULD** not let them down. She would go on and succeed as she had always done. She was a girl with resolve. She was a girl with guts. She could do whatever she put her mind to.

Sally trips on the stairs leading to the stage. Her toes are dragging and she has a strange expression on her face. She has trouble fixing her eyes on one spot and is vaguely aware that something is not right but this simply strengthens her resolve to push-on. There is the ever present pressure to succeed. As her path becomes more difficult this pressure grows in a way that is not anchored in reality. She is losing her ability to judge and right now this play has become far more important than it deserves.

Five minutes into the first act Sally's legs will no longer support her and she falls to the stage. She can barely talk and reality has slipped away. She is rushed to the hospital and tested for drug overdose.

What happens next is mostly up to luck. Very few doctors will be able to diagnose MG from the confused and fragmented account that Sally can give. She is frightened and has never experienced anything like this. She has failed for the first time in her life. She still has the determination, however, and it is her determination to overcome that will LOCK her into MYASTHENIA GRAVIS.

On the following page is a graph showing how Sally got into this mess. It all happened to Sally in a single day but the events leading to MG could just as easily take place over the course of a week or a month or a year.



I believe if it were possible to diagnose Sally immediately after her first MG experience and if the correct course were followed, based on an understanding of the LF and her enhanced ability to communicate mind to muscle, it would be possible to stabilize or reverse her condition. It seems logical but I can not prove, that the longer a person functions under the condition called MG, the longer it may take to achieve remission or control.

If the original cause of this attack, i.e. the boy friend, would walk into the hospital and give Sally a kiss and tell her he loves her, it would remove the depression that is pulling Sally's LF down. Then if the hospital with its equipment and Doctors and Nurses would inspire enough confidence to negate the anxiety that is generated by the disease, Sally could probably walk out of the hospital with no one even knowing she had Myasthenia Gravis. It would be written off as a case of nerves and stress.

What are the chances of this happening? Zero to none for the boy friend but there's a little better chance that the hospital will relieve the anxiety that's caused by the MG.

How did Sally get into this mess anyway? Earlier I said that it takes three things, coming together at the right time, to produce the condition called Myasthenia Gravis. Severe Anxiety-Depression-Stress, a strong Pressure to Perform together with an Enhanced Ability to Communicate Mind to Muscle. Sally's enhanced Ability was developed at age nine when she was hit by a car. The months of recuperating, hours and hours of superhuman effort in therapy, always determined to do what they said probably couldn't be done led to this ability. It

also produced a mind-set that said, "I can do anything I put my mind to." The word "FAILURE" was eliminated from her thinking.

Her intense "Pressure to Perform" was mostly self generated and it also came from the support she had received during her recuperation. Her ties to her family had been greatly strengthened and she would not think of disappointing them.

On the surface the "Severe Anxiety-Depression-Stress" doesn't seem to hold up but Sally's left arm had never fully recovered and was a little misshapen. To Sally this had meant that she was not as attractive as the other girls and when Bill had come along she was on cloud Nine! The intensity of joy at having attracted a boy friend was matched only by her depression when she was dumped. The depression was more than intense enough to lower her LF.

At this moment Sally is laying in a hospital bed, her insides eaten up by the loss of Bill.

It doesn't matter how great or serious the causes of the hurt. It's how serious it is perceived and to Sally this hurt is so monstrous, so big, that she can not talk to anyone about it.

"They wouldn't understand. They would say stupid things like He's just a boy. There is more than one fish in the ocean etc. etc. I would just end up agreeing to get them to shut up so why try." She thought. "They wouldn't understand! I just don't want to have to explain."

In fact, Sally wasn't capable of explaining since she didn't understand any of this. It just was, that's all!

The depression and real hurt is holding her LF down and when she tries to function and fails, the anxiety that's generated, further suppresses the LF. When she gives it her all, really tries, as she has always done, she violates the LF and the immune system lowers the LF further, trying to protect her.

The immune-LF system is really a very good system that was designed to keep Sally safe but has been turned back on itself.

Sally must RELAX. She must do many things that are contrary to her nature. She must not try anything beyond the point where MG weakness is experienced. Above all, and this is the hard part, Sally must rid herself of anxiety and that monster that is destroying her from within.

The chances are good that she won't get rid of the hurt that being dumped by Bill caused. The chances are real good that Sally will do just as I did! Block it out!-----Build a wall-chink the cracks-get on with your life!

If only Sally had not developed her Enhanced ability to Communicate Mind to Muscle. When Bill dumped her, she would have been depressed, but, without the ability to violate the LF, she would not have developed MG. She would not have collapsed on stage. She would simply have turned in a very poor performance. Of course, if Sally had not developed her Enhanced Ability she would probably be in a wheel chair today. She would not have been able to overcome the very serious damages to her body from the Auto Accident. It was a trade off. Once again survival had won out over safety. You might say that Sally was paying the Piper.

In case you're wondering if Sally is a real girl, she's not. She's a composite of myself, a girl in Illinois, another in England and a half a dozen men and women.

I found it much easier to discuss Sally than to constantly talk about myself.

The question has come to my mind many times why is MG so selective? Why in one person does it affect the legs and not the arms and in another the arms more than the legs? Why do some have trouble opening their eye lids and others don't?

There is evidence, from my own experience and from talking to others, that leads me to conclude that these areas are preconditioned to the disorder by subsequent occurrences of overriding the LF in that area.

An example would be a runner in the last five seconds of a race. The extreme pressure to perform would stimulate the production of excessive mind to muscle signals that could override the LF. The resulting weakness, after the race is over, due to any suppression of the LF by the Immune System, would be accepted as a normal reaction to a great effort. Since Severe Anxiety-Depression-Stress is not present it would not result in MG. The moment the race was over the person would stop overriding the LF and, with nothing else to keep it down, it would return to normal.

I BELIEVE WHEN THE LF IS OVERRIDDEN, EVEN FOR A SHORT TIME, IT IS WEAKENED AND BECOMES INCREASINGLY SUSCEPTIBLE TO FUTURE VIOLATIONS. The runner is preconditioned to MG in his legs.

Keep in mind the simple fact that he violates his LF from time to time does not in itself put him in danger. The other elements that make up the MG person must also be present.

In my own case I recall many times doing things with my hands and arms that others had tried and failed. I did seem to be able to continue to apply pressure until the job was accomplished. Simple jobs like removing a lid from a jar. Two or three people would try, some bigger and stronger, and would give up. On removing the lid they would usually say, "I loosened it for you." Maybe they did, once or twice, but I find it hard to accept every time. This type of occurrence has happened all of my life.

When I first encountered MG my arms were the first to be affected. Next double vision and then, to a lesser degree, my legs. At this time I thought that I could continue to insist that they work and they had to obey. I had a lot to learn. I was my own worst enemy. The determination that had served me so well now insured that I would lock myself into MG.

In the absence of MG, determination led to better performance. Once the LF is suppressed by severe Anxiety-Depression-Stress and this is met with a determined effort it leads to less or zero performance. The MG person must understand this and reverse his approach. The continuation of the old pattern of behavior leads to MG crises. Determination is still useful as, I would hate to see anyone give up, but the approach must change. Instead of the direct "apply more impulses full steam ahead" approach, the MG person must learn to go backwards in order to go forward. In many cases relaxing and applying fewer impulses will achieve a greater result. This seeming contradiction may explain why so few MG people find their own way out of this condition.

Automatic Transmission or Four on the floor?

Most of us don't have to think about shifting gears when it comes to our bodies. As healthy people we were born with automatic transmissions that do all the thinking for us. It's built into our design and it's a very good design. I doubt if anyone in Detroit could improve on it.

Sally, however, has just been betrayed by her automatic transmission. She wanted to go full speed ahead during the play but, instead, found herself at a dead standstill on the stage. Until Sally improves a great deal she can look forward to the same results every time she relies on her automatic transmission. (Without help it took me, at least, twenty years.)

Sally's best bet is to start thinking in terms of a Stick Shift. When she gets up, in the morning, She must not put her body into gear until her LF has a chance to rise above the level that she will be applying signals. She can, from my experience, help this process a great deal by the use of meditation and fantasy. I think of this as opening the garage door. Obviously if we put it into gear before we open the door the result will be less than we desire.

Sally now has the door open. What next? She puts it into Low and then into Second and now she's in High Gear. Can she go the rest of the day, just driving around like a person with an automatic transmission? As "Al" on "Home Improvement" would say "I don't think so, Tim."

How far Sally can go is determined by the amount of fuel in her tank. After thirty-six years I have almost a full tank and can get through a pretty full day but Sally, at this point, has only a couple of gallons.

All this must be calculated by Sally. How far can she go before she has gone too far and can't get back again. If her gas will run out (MG Weakness) at, say, 60 mile, then it would be foolish to go past the 30 mile mark before turning around and coming home.

Keep in mind, again from my own experience, that if she goes beyond the 60 mile limit at this point in her recovery, she will damage her condition further and tomorrow will only be able to go 30 miles. Her goal should be to stay within her limits. Be active, yes, but stop short of MG weakness.

Sally is a minor so I can't suggest that she take up drinking. Alcohol is the way I found to limit my day but there must be other solutions to this problem and I'm confident that as soon as the medical profession is aware of the need, a dozen solutions will be found.

From the above it is apparent that Sally faces a difficult future. The good news is that, while difficult, Sally can master the skills needed to gain control of her body and her life. It is, after all, not impossible to learn to drive with a Stick Shift!

CHAPTER XI

WOOD CUTTING

THE MG EXPERIENCE AS TRIGGERED BY A PURELY PHYSICAL ACTIVITY

It was the last week in October in a drought year. The forest had been closed because of the low humidity. The fire danger was high and, until now, Joan and I hadn't been able to get out and bring in our winters supply of wood.

The first snow, that usually came in September, could come at any time, making it impossible to drive on the dirt roads. The situation was looking urgent and I was anxious to get out and cut.

The fact that I hadn't used a chain saw in over a year didn't seem all that important. I hardly gave it a thought as I had been very active, of late, and was feeling good.

This late in the year there would be no time for the wood to dry before we used it so we must bring in dry wood. This meant mostly limb wood. The limbs that were left behind by the loggers when they harvested the big pines. This could be a problem. When cutting wood 12 inches in diameter or greater the weight of the saw is on the log most of the time. The operators job is to guide it but not bear its weight. Limb wood is different in that you must bear the weight of the saw all the time.

Apparently the muscles needed for this activity hadn't been used in a while and were not up to the task, for, after two hours of cutting, they were left in a very damaged condition. Proof of this came the next morning in the form of numerous aches and pains. I was not, at this point, experiencing any MG.

I would normally have waited a day or two, until the aches disappeared, before going out again but the pressure to get in the wood was great.

Now I've preached (I've tried hard not to but I know I've preached) all through this book about the MG persons need for patience etc. How he must ignore outside pressures and back off in order to make real progress. How he must listen to his body and pay attention to the signs. My body was saying "Rest" and the signs of sore muscles were crystal clear and what was I going to do? Would I practice what I preached?

Into the woods we went and after several hours we had another truck load of wood. My arm muscles complained and gave out but, clever me, I had shifted most of the lifting to my shoulders and back. My grip on the saw was still very good as my hands are strong and in good shape.

When doing any activity that leads to MG, the muscles with the poorest conditioning will show MG first. The better the conditioning of the MG prone person the farther he is away from the MG symptom.

On the third day I told Joan that we must go for bigger wood so I could rest the saw on the logs most of the time. This worked, to a degree, but I was still using damaged muscles when I should have been resting them and allowing them to rebuild. This demonstrates how easy it is to fall into a trap. Circumstances can, and do, push us into situations that are destructive and dangerous.

At the end of the third day my arms were hurting bad and I was experiencing definite signs of MG. Going against my own rules of good sense and everything that I had learned over the past twenty-five years had produced very predictable results. I felt stupid. Was it worth it?

Then I had a thought. I had already done the deed and maybe I could learn something. Turn a negative into a positive. Could I find out if MG that was brought on by physical trauma stay local or would it spill into other areas. One more day would intensify the MG to the point that, if it were going to do any traveling, it would.

I would not have tried this if I weren't absolutely sure that I could control my emotions in the presents of MG. I knew that I would not become apprehensive because I couldn't use my arms.

It was the evening of the third day and I was having difficulty feeding myself. I could not get the food to my mouth. It seemed that when I stimulated the muscles that held my fork I then could not move my arm. The two actions seemed related. If I relaxed my hand and arm I could then raise my arm but as soon as I held the fork with food, my arm would not work. I finished eating by lowering my head to my plate. Not a pretty sight but we do what we must do.

Dressing was very difficult on the fourth morning and I had trouble brushing my teeth and combing my hair. The symptoms were clear cut MG. I found that by letting my arms hang limp for 15 seconds I could, in one motion, get them over my head and comb my hair. They quickly became heavy and I had to repeat the process four or five time before the job was complete. The Left Arm, the weaker one normally as I am Right handed, was now showing more MG weakness. I washed fairly well with my right arm but when I tried to wash my right arm with my left it became impossible. With the wash cloth in my left hand I couldn't raise my arm above my waist. On impulse I turned my hand over and placed the cloth on the back of my hand. Now I could raise my arm. By turning my hand over the job of raising it up was shifted to a different set of muscles. The MG was not in my whole arm but only in those specific muscles that were stressed by the wood cutting.

From this I concluded that MG that is the result of physical stress or trauma will not spill over into other areas. If it had not affected neighboring muscles it is very unlikely that it would affect other, more distant parts of the body without the help of emotional stress or anxiety.

I did go and cut wood on the fourth day which was rather stupid. My muscles screamed for relief and the MG got worse. I had already determined the answer to my question and this added nothing to my knowledge except, possibly, that I was more than a little crazy. There must be a guardian angel of stupidity or half the human race would not survive. I had the feeling my angel was earning his pay.

The one question remaining was: Will the MG disappear at the same rate as the muscles recover or will there be a residual effect? Will I experience MG in my arms for a period after the muscles are mended? Probably not too important but I was curious.

After twenty four hours of little or mild activity the MG was greatly diminished. This was much faster than I had anticipated. The MG was going away at the same rate as the sore muscles were healing. Without fear or anxiety to prolong the MG experience there would be no residual effect. **Cool!**

After four days of rest we, once again, went into the woods to finish our job. The soreness was gone and, with a new smaller chain saw, I managed to do the job. There was some MG noticeable in the evenings but it was mild and not too inconvenient.

The day after we completed our wood pile I experienced a real let down. I had no energy and little strength. This weakness was more like the weakness experienced with the flu than MG weakness.

I believe this let down is to be expected after any prolonged period of raising the LF by meditation and excitement. It can be compared to the let down after an emergency has been handled.

The LF had been propped up for ten or twelve days and when the reason and motivation was removed it came down to a level below its original level. My body was saying, "Its time to rest. You can't abuse me forever." Interestingly, while I experienced this weakening over my entire body, I only had MG in my arms. I believe this supports an earlier conclusion that once the LF is violated it is damaged and can be violated easier the second time. The more the muscles are pushed, in the presence of MG, the farther they are driven from a state of remission.

My job, then, was to return them to a state of remission by avoiding MG as much as possible, allowing the LF to rebuild. I believe that I can do this by combing my hair and resting--- brushing my teeth and resting---washing my face and resting etc. If I do experience MG I will immediately rest my arms until I can continue. By proceeding in this manner my arms should return to normal. Past experience says that it will take two or three times longer to return my arm to remission than it took to get to MG. That means about a month. Patience.

"Ah! the best laid plans etc."

Two days after I wrote the above I went to my studio and began sifting through old drawings and papers. I ran across a short story that I had started writing twelve years earlier. It had a good beginning and a good ending but it seems my creative juices had dried up when it came to the middle.

I sat before the fireplace and read it. "It wasn't bad", I told myself and then some thoughts came to mind that might, just possibly, fit the middle. Before I realized it I was making notes and the aforementioned dried up juices once more began to flow. I could feel the adrenaline and in the three weeks that followed I was totally free of any MG weakness. The healing powers of this type of experience should not be underestimated. No matter how many times I have lived this phenomena, relative to MG, it has always left me amazed.

CHAPTER XII

MOUNT ST. HELEN

Our son, Dave, had finished college and had taken a job with the Forestry in Missouri. His heart was still on the West Coast so when a summer opening at Mount St. Helen presented itself he jumped at the chance.

Dave invited us up, while he would be there. A state campground was across the road from where he would be working and we could all explore the park in his off hours.

Joan and I still like to tent camp. We're good at it and I imagine that's why we enjoy it. Actually, if the truth were known, Joan would probably prefer a good motel but she has always been willing to bend a little and I love her for it.

Mount St. Helen had erupted on May, 18 1980, changing the land around it forever. The first reaction is to mourn the loss of life and the destruction of so much forest. Summer cabins and campgrounds, all gone. Fifty seven people and millions of trees and animals ceased to exist in a matter of seconds because of this monumental act of nature.

People who had lived in the area or camped and hiked and enjoyed the lakes and streams could be forgiven for asking why? Why had such beauty been destroyed? Why did God allow such a waste? I imagine their wish would be to put it all back, but this could never be.

When we arrived in the summer of 1988 our first impression was one of total destruction. As we studied the area, read the reports from the many scientists on the mountain, and looked at the beautiful displays at the visitor center our eyes were opened to the life around us. This was not just life but a new vigorous life that, with a small stretch of the imagination, could be seen surpassing all that had been destroyed.

I took it all in and understood that life is change. The closer we get to a static condition, the closer we are to death. All of nature must be the same. All of the Universe. All of the extinct species are now gone because they failed to change. Failed to adapt. To be really alive we must stay flexible and yielding, stay open to change.

It was too big to comprehend during our short stay but I would think and meditate on this experience for months and years to come.

All of my senses were sharpened and they fueled a desire to get closer, look into the volcano, be a part of this marvel.

Joan and Dave discovered a helicopter service that, for a fee, would fly them up-in-and around the Lava Dome that had formed in the crater. This dome was busy smoking and rumbling and doing what lava domes are meant to do and I'm sure flying around it in a helicopter would be a thrill. Joan and Dave saw it that way. Test Hop Clete, on the other hand, was having trouble seeing it as anything but a death wish and chose to stay on the ground.

I would like to make it clear that I don't have a real phobia about flying but, after my Air Force experiences, it just triggers the wrong set of juices. I have flown since leaving the service but never do so if I have an option and, I soon discovered an option at Mount St. Helen.

A hiking trail had been cut into one side of the mountain and, after registering at a local restaurant, a limited number of hearty souls were allowed to make the ascent each day. I have always wanted to be a "Hearty Soul" and if you put that desire with the excitement and eagerness to see more---well---I just couldn't help myself. Dave agreed to go with me and Joan would remain at the base camp and read a book.

Dave took care of getting us on the right list and we arrived at the restaurant early on the day of the hike. After a good breakfast we signed in and headed for the base camp where we would leave our car, and Joan, and begin our adventure.

On our return we would stop again at the restaurant and sign out. This proved that we were no longer on the mountain and the rescue crews could go home and have a beer. If we failed to sign out I guessed they would have to go up and check all the cracks to see which one we had fallen into. I suppose they would mark it and then go home and have a beer. I really didn't want to give this any serious thought as you can see.

The idea of someone with a serious disability climbing a mountain might, on the surface, seem a little overly ambitious.

In 1984 my other son, Phil, his cousin Jack Crocker and myself had attempted to climb Mt. Lassen in northern California. Joan had chosen to stay in the parking lot just as she was going to do this morning.

Joan had promised us each a pin that stated "I climbed Mt. Lassen" if we succeeded. This time Joan had no intention of reading a book and, unknown to the three of us, had positioned herself, with a pair of binoculars, to verify our progress.

We hadn't gone half the distance when Jack suggested that we hide in a grove of trees for a couple hours and then triumphantly return and claim our prize. Luckily two Gresses can out vote one Crocker and he was overruled.

(Joan would have nailed us! How did she know?)

We continued the climb with a great many moans and groans and each of us took turns in wanting to surrender. Each time the other two would overrule the pleads. Finally, still short of the top, we were all stretched across the trail, bleary eyed with sweat dripping and tongues dragging. Three more pitiful examples of humanity have never occupied this planet.

Suddenly, from somewhere below our position, women's voices clearly reached our pathetic ears. We sat up, not wanting to believe. As we watched, two women walked briskly around the bend, talking and laughing, past our graves and disappeared up the mountain, their lunch packs bobbing on their seventy year old little fannies.

Oh, Lord, how could you be so cruel?

Thus fortified by this massive infusion of ego we continued until the top was reached. I was fifty one years old at the time and probably would have survived being bested by two seventy year old women. I could have blamed it on Myasthenia Gravis. (Convenient?) Phil and Jack were both healthy and still in their twenties and, I know, would have died before giving up after the women's blatant exhibition. All in all I felt a real sense of accomplishment.

The thought of the Mt. Lassen climb gave me encouragement and I sensed another victory on today's hike.

On the way to the base camp we stopped and picked up some good walking sticks. We both had day packs with a little food and of course water. I carried a pack stove with a coffee pot and coffee.

The morning was perfect. Cool, crisp air that felt chilly if one stood still but was a perfect walking temperature. Broken clouds over head moved fast enough to give long periods of sunshine. The first two or three miles were almost flat, through trees that had, somehow, survived the blast of the volcano.

Excitement propped up my LF and I felt strong.

The trail became steeper as we neared the mountain. Strange rock formations were everywhere. Fallen trees and ash, everywhere there was ash. We walked on. Ahead we could see what appeared to be a glacier and the trail seemed to be heading straight for the foot.

It was about here that I felt the first, very small, sensation of MG weakness. We had gone, maybe three miles, and it was too soon. The real challenge of the mountain still lay ahead. It was just too damned soon and, in spite of myself, I began to feel disappointment replace the excitement that held up my LF. My first impulse was to ignore it, as I looked around finding new wonders to marvel at. I walked on.

I wanted to climb this mountain. I really did. Others climbed it. Why not me? Why couldn't I be like others with strong legs and healthy bodies? Why did I have to always give in, to quit before I reached the top? Of course I knew the answer to "Why not me?" The answer was Myasthenia Gravis! All the self pity in the world would not change that.

The trail did, indeed, end at the foot of the glacier where steps, cut into the face, showed us our new challenge. At first, climbing the steps, using different muscles than those used walking the trail made the going easier. After a half mile the initial hope of going all the way turned to frustration. No amount of mind control was going to overcome the weakness. Oh, I could still climb by using my arms and shoulders with the walking stick. Dozens of hikes, however, had impressed one thing on my mind. Going up the hill was twice as easy as going down.

Most of the muscles used to go up hill are also used walking on the level. They get more exercise and are in better shape. The muscles used to hold us back as we descend a mountain are used less and are, therefore, weaker. This makes them more likely to experience MG weakness.

I could probably make the top of the mountain but would be very weak, making the return trip impossible. It would be more humiliating to be rescued from the top than it would be to not make it so I motioned Dave to head for a lava outcropping to the left of the trail. We sat on the rock overlooking the valley and we were the only two people on the planet.

I had to give up. I had to quit. As many times as I've had to do this over thirty-five years you would think that it would get easier. It hasn't.

While I brewed a pot of coffee I explained to Dave my situation and he said that he understood. He could see that I was down and he sensed the magnitude of my disappointment. Dave changed the subject and we discussed how really excellent the coffee tasted and maybe this would be a good place to open a coffee shop. Half way up Mount St. Helen on the side of a glacier. We laughed, relaxed, and talked of everything and nothing. Finally we agreed that this outcropping was really the top of the mountain and, having achieved our goal, we could go home.

The trip back was uneventful if you ignore the five of six times that my legs gave out and I nearly fell on my face. My staff saved me.

I still had a lot to learn. Someday I would come back. The next time I would win. The mountain would not get away with such an easy victory.

As I later reflected on this day I realized that the mountain hadn't defeated me. I had defeated myself. All my experience with MG and I had fallen into the trap of giving in to negative emotions.

"The mountain was not my foe but was my instructor." And in this way I turned the negative into a positive.

The lesson was simple enough. I had thrown myself at the mountain relying solely on my enthusiasm to get me to the top. I had ignored every lesson learned in the past thirty years.

The mountain was saying, "Go back and do your homework, Clete. You aren't the average Joe with enough reserve energy to just "Will" yourself to do something and it will happen. To succeed you will need to plan carefully using every ounce of your knowledge. You will have to shift your gears at just the right moment and you will have to always choose the correct gear. Your automatic transmission hasn't worked in years, Stupid. Why did you forget."

Self pity is an interesting thing. Like hatred it can be very enjoyable and very addictive. It seems to be a part of all human nature. In the past I would have believed that I should suppress it. Demand that it get out of my life. Deny that it even existed. Anything to prevent the idea that I was capable of self pity or hatred. Today I accept these things as part of who I am. I am not perfect. Imagine. What a revelation. They exist and I can do nothing about that but I can look for ways to turn their negative energy into a positive force.

This idea of positive thinking has been written about in very good books on the market today. I can add very little to what has already been said. The one point I would like to make is that while hearing the truth and reading the truth and even agreeing that it is the truth is rather easy, making it a part of our life is another and more difficult thing. I think the current saying is "You

talk the talk but can you walk the walk." Not an easy thing and worth a great deal of meditation. More fuel for the thought machine.

CHAPTER XIII

REBOUND

After the lessons of Mount St. Helen, I now had to give physical conditioning some serious thought. I knew that it was important, but had taken it for granted.

The principle of exercise was simple. The development of muscle tissue is based on a demand system. We are as strong as we need to be. To increase our strength the need must be increased.

If the need stays the same the muscles do the job. If the need is increased, beyond normal, the muscles are damaged and this triggers the system to rebuild them, but with added muscle, to meet the increased demand. The weight lifters say "No pain-No gain."

The important point, here, is that the muscles need time to rebuild. If we tear them down and don't give them this time they will not only not get stronger but will continue to be damaged as in the chapter on woodcutting.

I decided on walking on Monday--Recover on Tuesday--Walk on Wednesday--Recover on Thursday--Walk on Friday and take the week-end off.

The first week I would walk two miles on each of the three days. Fast and hard enough to stress my legs but still stay below MG.

The second week I increased the miles to three and tried to improve my time.

In the third week I was doing four miles. On Monday this took me one hour and fifteen minutes. By Friday I had cut it to one hour and eight minutes. I felt I was making good progress.

Fourth week and I was doing five miles and maintaining my time.

In the fifth week I did six miles and was feeling good. Total time was one hour and thirty eight minutes. I wondered if I'd ever go four miles an hour but it didn't matter. This wasn't a race. I was trying for endurance and I was succeeding.

At the beginning of this training I had been very careful to mentally prepare myself for the walks. Fantasy-meditation and coffee with one mestinon. (I still use one or two mestinon tablet's each day.) I can't recall, exactly, what happened in the sixth week to distract me but I am sure my preparations were disturbed or forgotten on that Monday morning.

Two hundred yards into the walk MG appeared in my legs. Just a little, but enough to make me stop and consider my situation. I didn't want to continue if it meant not being able to make the return trip. I was resting on my staff with my legs locked and the muscles relaxed. My mood was good. My frame of mind was good and after about sixty seconds I decided to try again. "If MG showed up again I would return home.", I thought.

I walked another two hundred yards and was doing fine. The MG had not returned so I shrugged my shoulders and continued. I had just convinced myself that it had been a fluke when it occurred again. This time I had gone almost four hundred yards. I stopped again, relaxing my legs. This time I had walked at least twice as far as I did the first time that I had to stop and rest. Two hundred yards, stop, four hundred yards, stop. This didn't make sense. I had fully expected to go a shorter distance, have it set in again and then return home after a short rest. I made the decision to go one more time, so, after sixty seconds of leaning on my staff, I began to walk. I passed the two hundred yards that had seen the first appearance of MG, past the four hundred yards that had forced the second stop and I continued to walk down the road, apparently free.

The necessity to make a third stop did not occur until I was at least a mile from home. I used the sixty second rest to consider what had happened so far. The one thing that stood out was that each segment of my walk was longer than the one before it. This did not make sense and went against all past knowledge. The reverse should have been true because, once I had experienced MG, if I pushed myself to continue in the same direction I should have intensified the MG. I decided to keep walking.

Six miles later I was back at my home with no further evidence of MG weakness.

I knew what had happened and now I had to know the "why" and the "how."

While everything was clear in my mind I went straight to my studio to draw a graph. Maybe I could get a clue. I wanted to understand this. Maybe it would cancel out earlier theories. I didn't know.

I reasoned that if I had goofed on my preparations for today's walk then my LF must have been low. Using fifty percent as normal I put my LF at forty percent on the graph.

If my walking resulted in MG then I must have violated the LF from the beginning and it took the Immune System 200yds to lower the LF to produce the MG weakness. I then stopped, relaxed my muscles, allowing the Immune System to release its hold on the LF, letting it rise again.

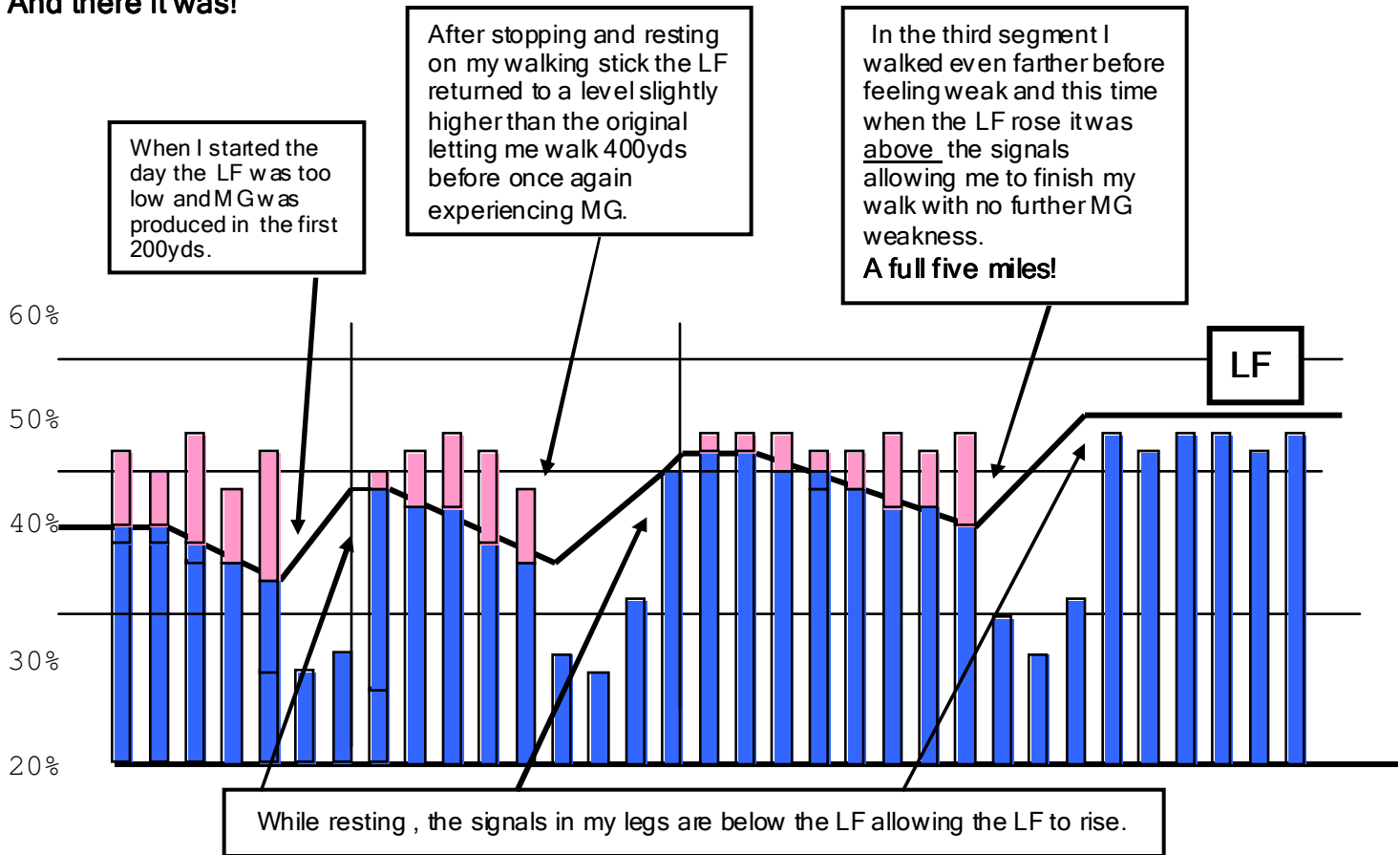
I reasoned that if the MG did not return the second time for 400yds then I either had produced lower impulses on this segment or the LF had been higher resulting in a smaller violation.

My effort had been as near the same the second time as the first so it must be that I started the second segment with a higher LF.

I put this information on the graph.

The third segment was a repeat of the second. The fourth, since I experienced no MG, had to have been walked entirely below the LF. The LF must have been up to normal for the last five miles.

And there it was!



When I stopped to rest the LF didn't just return to where it had been. It went higher. It rebounded! A rebound effect that I had accidentally controlled with a result that I would not have imagined.

It is my belief that all Truth, Knowledge, and Wisdom is from God. It exists like the air we breath. We merely borrow it, use it for our purposes. Man has never had a single thought that God did not have before him. If we are in need of knowledge we should ask God, the source, and He will give it to us. First, though, and this is important, we must stop our shouting so that we can hear God's whisper.

"Wow!"

When Joan's sister-in-law, and my friend, Sue Mountain, read about the rebound effect she said "Wow!" Wow is the perfect word. Sue could appreciate the importance of the discovery of the rebound as it would apply to a person with MG. She sensed how valuable this little tool might be in the management of the condition. We sat and discussed the possibilities and my thoughts returned to Steve. Joan and I could have made great progress. How would we have applied it to Steve? My mind grappled with the problem. Let's see.

Having thirty years practice in relaxing my muscles I've become some what of an expert. So much so that I take it for granted, but, working with a child, it is not something that one can assume they will be able to do. When I say relaxing, I'm not speaking of just sitting still but, more importantly, lowering the amplitude and quantity of signals to the muscles.

Bio-feed-back, as I understand it, would have been an excellent tool and I think I would have used it as a first approach. Steve was very smart (Proud Father) and would have caught on fast. Train him to remove the signals from his muscles while he was standing with his legs locked. Once he had mastered this the road to rebuilding his very tiny muscles would be open.

Remember? I said, from my experience, the farther the MG person is away from good strong muscles the closer he is to MG. The smaller his muscles are, relative to his size, the closer he is also. Muscles that have been bedridden for a year or so, are both small and weak.

Before sufficient effort can be made to actually "STRESS" the muscle, Myasthenia Gravis is experienced. On the surface it seems hopeless. Without the ability to stress the muscle, new muscle cannot be developed. It is a demand system and MG blocks the possibility of making that demand.

Lets assume that several months have passed and Steve has mastered the lowering of signals to his muscles by applying the techniques of Bio-feed-back. The next step would have been to explain our goals. Show Steve, on the graphs, what we would be trying to achieve and explain the importance of his role. Prepare him, in advance, for the possibility of small failures along the way and then build his excitement by showing the goal that we could achieve.

Using a "walker" we get him to take enough steps to begin to experience MG. It is very important that he recognize the very early signs and not wait until he is in full MG weakness. In the past, we had always tried to avoid the onset of MG weakness but now it would be our first goal. In this way it should generate excitement instead of disappointment. The excitement would help to raise Steve's LF. Steve is now given the walker to rest on, while he locks his legs and removes the signals from his muscles. (60 seconds was the perfect time for me and we probably would have to experiment to find Steve's "Perfect time.")

The second segment would be like the first and, if we had done everything perfectly, would be longer because of the rebound effect. The third, then, would be longer still and before Steve returned to his bed he would have stressed his muscles enough to stimulate the building of new muscle tissue. At first this might consist of only a few dozen cells but, when you are at the bottom, any progress is fantastic.

The next day would be a rest day and, if MG was still present on the third day, then another rest day should follow. Getting him back walking as soon as possible, to use the new muscle tissue would be essential so that the old and new could be stressed, building still more cells.

I think the rebound effect could have been the tool to get Steve out of bed!

Wow!
DEFINITLY WOW!

After the discovery of the rebound effect my thoughts, once again, returned to the problem of climbing Mt. St. Helen. I now had a new tool in my tool pouch. In addition to good conditioning I had the rebound to fall back on. The next several months found me testing the validity of the rebound theory. It never failed in working from the tests I applied, and soon I had built a good bit of confidence in it.

In the evenings, after putting in a good day of work, I usually had double vision as I would sit and watch the TV news. This is very annoying and I have wrestled with the problem for as long as I can remember. I usually fought the onset of double vision until I couldn't stand it and then would close one eye so that I could escape it. Maybe, now, I could solve this problem.

I tried relaxing the muscles as soon as the double vision started and discovered that it is very hard to relax or remove the signals from my eyes. I did achieve a partial success and knew that the rebound would work with this problem but new ways would have to be found to relax the eye muscles.

On review of my daily activity I wondered why I didn't have double vision more, as I used my eyes a great deal in my work. Why did it only occur when I sat and watched TV? What was different? I had thought that it was simply because I was tired. Was it truly that simple or was there more to it? I reasoned that it couldn't be fatigue alone because, many times, when I'm tired, I drive the car without experiencing double vision. What was the difference?

The problem lingered in my mind for several months. Each time I watched TV or drove the car it came to the surface. In this way the answer became apparent and it proved to be rather simple.

When I drove the car or did anything else during the day my eyes were constantly moving. When I watched TV they were fixed to one spot. Simple.

I found that the best way to remove the signal from the muscles that move my eyes to the left was to move them to the right. I could also remove the signals from the eye muscles that I used to watch TV by keeping my head stationary and looking at the ceiling. At the first signs of double vision I would look at the ceiling for 15-20 second. Then back to the TV. After repeating three or four times the problem was solved.

By applying this new technique I have since watched TV free of double vision on many occasions. There are limits, of course, and if I'm very, very tired I might as well go to bed. With my new tool I felt good about the chances for success in climbing Mt. St. Helen and was ready to put together a plan. A good part of the trouble the last time, I felt, happened because I failed to properly prepare. We had camped ten or twelve miles from the base camp and in my rush to get started I had driven off without opening the garage door, without meditating and fantasizing. The next time I would:

1. Train for a month walking before leaving home.
2. Camp at the base of the mountain to minimize effort before starting the climb.
3. Have someone else sign me in while I concentrated on coffee, Mestinon, meditation and fantasy.
4. Use rebound if all else failed.

Mt. St. Helen was in for the fight of her life!

REBOUND

The chapter on "Rebound" was almost left out of this book as it had occurred so close to the publication date. I really had very little time to play with the concept and prove it to my own mind. I'm glad I took the chance as I have used the technique many times since then with excellent success. Double vision while driving, when it does occur, is a problem and I pull off the road immediately, relax the muscles and within minutes can be on my way. A small inconvenience instead of a major catastrophe. I still walk a half mile or more each day and I stop often. The "rebound" seems to work even when my legs are just sluggish with no true MG weakness. I believe I have become sensitive to signs that occur BEFORE MG signs occur. The ability to relax muscles completely is something that requires practice and does not come easy. All the signals to the muscles must be removed. Just holding a muscle still, without movement, does not mean that it is in a relaxed state.

I want very much to emphasize the value of this tool that I call "rebound" in the management of MG. If it fails to work for the reader on the first attempt, don't discard the idea too quickly. Play with it, practice relaxing and I believe it will become a good friend.

CHAPTER XIV

DUMBER THAN DIRT

As I sat and thought of my trip to Mount St. Helen I brought her back to the eyes of my mind and the eyes of my spirit. It was five o'clock on a cold winter morning and I had just finished my first cup of coffee.

I was in my fantasy mode and as the mountain became clearer and more solid in my senses she began to speak: *I'm really disappointed.* (the mountain said.) *All that "why me?" Crap I heard when you were here. That's really "light weight" stuff.* (She added.) *I thought you had grown bigger than that.*

You sayin' that I'm too small? (My defenses were up and I was ready for a fight!) Nobody tells Clete Gress that he's too small and gets away with it.

No! No! Calm down, I didn't mean that. Boy you're touchy about that "too small" thing, aren't you? Maybe it's time you got rid of it! Get rid of it! Get rid of it! That's damned easy for a mountain to say. You've been big all your life. Walk a mile in my shoes Volcano Breath!

Oh Shut up Clete, you're sounding stupid!

Wow, being called stupid by a mountain. That's a laugh. She acts like she's smarter than me. That's like saying that I'm dumber than DIRT! Hey Helen, if your going to be abusive I'll just put you back where I found you. *Sorry, I didn't mean to offend. By the way there are worse things than being dumber than dirt!*

Okay, okay lets get back to our conversation. Whoops, just a minute Helen, I've got another call. *What? You've got "call waiting" on your fantasies?* Yeah! Its the latest thing. Neat Huh?

And a very small voice said: *Cletus, you're talking to a mountain.* Yeah, I know, but at five thirty in the morning there wasn't anybody else. *You ever think of giving me a call. I'm still at the same address you know. Its not like I moved and failed to give a new address or something.*

Who is this? Is this my Mother in law?

This is God. Oh, how come you're talking like that? *It's the way I talk, you've got a problem with that?* No, but how come? *This way the only people who can hear me are the ones who don't talk over me. If they would stop all the racket I could be heard real easy. It makes me really unhappy when people talk over me. Do I do that?* Sometimes. Oh. *It's alright.*

Why? You try. Oh. *I could talk real loud if you want me to.* Sure and blow out my eardrums and turn my brain to oatmeal. *Don't tempt me.* Okay but if you're really God, how come there wasn't a "ding" before you started to talk? Answer that one!

Yes Cletus, I'm really God and William Cosby just made the "ding" thing up. I've been stuck with it ever since. Which reminds me I've been meaning to have a little talk with William about that.

God? Yes. I'm still confused. Why whisper when you could talk real loud and everyone could hear you? You haven't figured that out? No, it doesn't make sense. You keep trying. How? Go camping. Why? I'll send someone. Why? (This one just might be dumber than dirt.) What, God? I said I like your shirt. Oh, thanks, it was a Christmas present. (Great, My Son has a birthday and he gets a shirt.) By the way which mountain are you talking to? Mount St. Helen. Aw! Helen, she's one of the good ones. A nasty temper but she's got a lot of fire. She'll set you straight so listen to her, Okay? Sure, but now that You're here maybe? Forget it Cletus, I've got bigger fish to fry. I wonder if I can find William without going through his agent. Agents really give me a pain, oh yes, Cletus,----- I love you. I love you too God.

And the room fell silent and the air was filled with an odorless fragrance, the very essence of peace.

"If I could just bottle that", I thought, as I reached for the other line. I hope I didn't get the "Cos" in trouble!

Hey, Mountain, are you still on hold? What do you think? And without music, yet! Take it easy--calm down--remember 1980! That call had better have been important, leaving me here cooling my vents! It was God. Oh! Okay, that's cool, He really lights my fire! (Hee hee, just a little volcano humor.)

Very little, I'd say. If you're ready to get serious I think you made some nasty insinuations before we were beatifically interrupted. You think I insinuated? I laid it out plain as day. You were on the "pity pot" on a rock half way up me. You think I didn't hear the sounds of "Woe is me."? Enough to make a mountain barf!

Hey! Take it easy, huh? It's not easy being disabled! To be kept from doing things, from realizing your full potential. Ha! That is to laugh! Your full potential indeed. You're mostly water, man, you have the potential of being a mud puddle!

Hey! I don't have to take this from a pile of rocks. Just because God piled you high doesn't mean you're better than me. What would you know about disability anyway? I blew my stack in "80", right? Lost thirteen hundred, that's one thousand and three hundred feet! The whole top of my peak. That was no walk in the park! You might say I'm an amputee!

Yeah, well God said to listen to you so go ahead. He did? Really? Listen to Helen? Wow! Are you finished? Yes. Then please try to contain yourself and get to the point!

Okay, this book you're writing, what are you going to do with it? Have it published, I hope. And---- And what? Is that the goal? I guess. Listen to me Clete, you've been writing it for sixteen years, right? Yeah. Plus spending the past thirty-five years gathering all the information. That's a lot of time and work. Yeah. Okay, so lets just say that that's the journey, the path, the trail and the publishing is the Top of the Mountain. Sounds good so far. You learn anything on the trail? What do you mean? Learn anything----did you learn anything over the last thirty-five years? When you painted your first picture and nearly bought the farm did it teach you anything or did you stay just as dumb as you were before? Well, I learned that anxiety, depression and stress were my enemy and they made me weak. Go on. And Enthusiasm and Excitement were my friends and they made me strong. You're on a roll, then what? I learned how to meditate and fantasizes in the mornings and

this made my days better. I learned how to relax and enjoy life. Well what do you know. The man's maybe just a tad smarter than dirt. What did you do in these fantasies? What do you mean? Did you talk to anyone special? I guess you want me to say that I learned to talk to mountains. Right? Praise the Lord, it's like pullin' teeth! Talking to mountains is most important! Most important indeed! Ego What? I didn't say anything. Talking to mountains is probably the most supersplendatious thing you've ever done. Oh, brother. I'm getting a buzzing here. Do we have a good connection? Lets get back to what you've learned. You've got the idea so list them all. Go ahead.

From the little old man I learned that a positive perspective is more important than reality itself. That it's better to always see the good in others and to risked being wrong, sometimes, and being disappointed, than it is to always see the bad and be disappointed all the time. Fine. And of coarse I learned the benefits of solitude. The Acorn Mush taught me that we complicate our lives too much and that 2+2 can equal 4 if we really try. What else? Did you forget someone? You mean Steve? No, I didn't forget but it's still a little painful. Learn anything? Sure. I learned that the most selfish thing we can do is give others our unconditional love. How's that selfish? When we put others before ourselves we gain the best prizes. Get the biggest rewards. Wow! If this ever gets around we'll be overwhelmed with love. Don't hold your breath. I guess that does it.

Hey wait! I haven't mentioned the stick shift and rebound yet. Well now you have. Anything else? If I think of something I'll let you know. Do that.

Clete? You know what? I think you've leamed more than the average human bean-- being whatever----learns in a lifetime! Would you say all the things you've learned are important? They saved my life. They're as precious as life itself then? Yes. How many jewels do you think are at the top? What do you mean? When you publish what will be the rewards? The feeling of success, the knowledge that I finished it, that I really accomplished something! Ego! Costume Jewelry, Worthless, what else? People will read it and know that I wrote it? Vanity, also worthless! Try again. There'll be royalties, I'll get paid. Greed! Disgusting and worse than worthless, its self destructive. You know, Clete, the laborer is worthy of his hire but it isn't exactly a jewel to get paid. You haven't shown me a single Gem. The book might help someone else. That one's not bad. Is it? A semi-precious stone. Somewhere between Ego and Love. It'll make you feel good. So now we've gone over the whole trip, what have you learned? That all the rewards are on the path and not at the top of the mountain. Good. And-----that-----uh-----the only failure is the failure to walk the path. Now you're getting creative. I don't think I can stand it! I think I've got all that but what does writing a book have to do with the real thing. Climbing up you is different than writing and there aren't any diamonds on your trails. Must I lead you by the hand? You said, when you were half way up me, sitting on my outcropping, no, I'll quote you word for word: "He could see that I was down, and he sensed the magnitude of my disappointment. Dave changed the subject and we discussed how really excellent the coffee tasted and maybe this would be a good place to open a coffee shop. Half way up Mount St. Helen on the side of a glacier. We laughed, relaxed, and talked of everything and nothing. Finally we agreed that this outcropping was really the top of the mountain, and, having achieved our goal, we could go home." Is that what you said? Yes.

He worried about you, he changed the subject, you joked and finally felt better? Yes. That's Love, Man! The most precious stone of all! Right on the side of me. On my trail! Ninety

percent of the people that made it to the top, that day, would have given their strong legs to be in your boots. And you know what else? There's nothing at the top except the same things when you publish. There's Ego and Vanity and, if you could talk someone into buying your story, there would be Greed and you know what I think of that Garbage! You don't even have the semi-precious stone!

By the way, speaking of money, have you ever tried calling God from a pay Phone?

Clete? Yes? I was pretty rough on you back there, wasn't I? You came down pretty hard with the pity pot stuff. Sorry. I think it was the mud puddle thing that hurt the most. Real sorry. It's alright. Hope I didn't damage your self esteem? It hurt but my self esteem is intact. Actually it's never been higher. In fact its so high I don't deserve it. Huh? You never know when to quit, do you? What does that mean?

The coffee's almost gone. I noticed.

It's almost time for you to go. Uhuh.

That's the routine. I know, I sure wouldn't want to mess with your routine. I have to leave, I'm tired. You could wear out a whole range of mountains.

Anyway, you're a fun date Clete.

Thanks. You too, Helen.

Well I guess its time.

Helen? Yes.

I love you. I love you too, Clete. Bye.

Bye

Would I go back to Mount St. Helen? Yes, I know I will, someday, and whatever progress I make up the trail, I will enjoy every step. If I don't make the top it will be OK. If I do it will be a bonus. I won't go back to conquer her. Just to thank her.

This painting is finished.

ADD-ONS AND SECOND THOUGHTS

MEDITATION

We have all had the experience where we were having an average day, a ho hum day, when someone that we're close to, a boy friend, girl friend, husband, wife, or just a friend comes in with a really good idea. "Let's go to the lake or have a picnic, maybe the park or zoo or somewhere. Let's do something!" We immediately have a surge of energy, born of excitement and anticipation.

I will venture a guess that, if you have Myasthenia Gravis, you have had days that were filled with excitement. These same days are notable because of the lack of MG weakness. A really good day. I refer to these days as a Positive MG day.

I'm sure you have also had days where you were down, gloomy, not really depressed but there was no excitement either. You take your medicine and drag around. MG Weakness seems to haunt you, no matter what you attempt. This is definitely a Negative MG day.

It is easy to assume that we had a good day, filled with excitement, because of the absence of MG and that we had a bad day because of the presence of MG but I believe that the absence of MG is the direct result of the good day that was filled with excitement. That the absence of MG was the direct result of a good mental state on that day and that a lousy state of mind/emotions caused the MG on the bad day. This is an important point. The distinction can be the first subject that you meditate on. Go over your good and bad days and ask yourself "which came first?" The day or the MG! Once you accept the position that your MG follows your mind and emotions the door is open to using meditation as a mean to reduce the MG by improving your mental and emotional state. The mind stimulates ones emotions, makes us excited, gets the juices flowing and provides us with a positive experience, free of MG. The mind also, can work against us and give us a negative day.

All this is a result of my own use and success with an hour of meditation each morning. My primary goal in writing this essay is to convince the reader that meditation is a valuable tool and to encourage them to explore the possibility of using this discipline to improve their lives.

This picture of Good days and Bad days is an important clue to improving the lot of the MG person but up until now he/she is merely "Going with the flow." Whether or not they have a Good, Bad, or in the middle day depends entirely on the faulty thinking that assumes outside forces and influences are to blame.

When dealing with the benefits of Meditation the person with the disease or condition known as Myasthenia Gravis has a distinct advantage over someone who simply wishes to improve their life by using this discipline. The weakness that occurs with this disease becomes a valuable way to gage progress. Success to the MG person results in less and less days filled with weakness. This knowledge, however, should be viewed by the non-MG person as a plus. Here is physical evidence of the value of Meditation! When dealing with the mind and spirit and emotions, physical evidence of any kind is really hard to come by.

Here I have two good questions for anyone who's interested. How much do we control our own minds? How much are our minds controlled by our environment?

Answered honestly I believe one will find that our minds are pretty much controlled by the forces around us. If we are happy and someone gives us bad news, what are the odds that we can maintain a degree of happiness? Doesn't look good, does it? We accept this state as permanent because we have lived with it all of our life, but is it permanent or can we change it? Can we gain some control over our minds and thereby control our emotions?

If we can control our minds/emotions then we don't have to sit and wait for things to happen. We can control our days, and determine if today will be good or bad. I don't think that I need to tell someone who is in the grip of a disease like MG that the worst part is that very lack of control. Wouldn't it be wonderful to achieve that control? Isn't such a thing worth devoting a great deal of effort and time? Of course you only have my word that this whole thing is valid and I do believe that poses a real problem. No matter your age, you have spent your entire life with your mind being programmed, by your environment, to function in a certain way. That's a lot of programming and now the goal is to change the program. Can't be done in a day-week-month but will require at least a year or two. I find it frustrating trying to convince people, who don't even know me, that they should, on a stranger's word alone, hang in there, don't give up, tough it out when the rewards, at first are so small and so few.

Meditation is a form of exercise. Exercise for the mind and not the body but there are many similarities. A person would never start to lift weights and expect to be Mr. America in a week. Improvement is slow and a long range goal. Usually years. The same is true of Meditation. The human animal does, however, need rewards in order to keep going. In the gym one is measured in all directions so that, after a month, some progress can be realized (the reward) and with this progress a desire to continue is produced. We must do the same with Meditation or the effort is doomed from the start.

Pay close attention to the type and degree of weakness in your average day. Also; what is your mood? At work? At home? Are you Draggly, Droopy, Listless? When? How much? For the MG and non-MG person alike this process can be the same. Write it down so that, after a period of time, you can refer back and measure your progress. Play games with your mind so that you create your own reward system. This will become less important as progress is made but the concern here is to get through those first days and weeks when progress is so small and so hard to find.

To remind you, through Meditation and the gaining of a degree of control of the mind we can generate excitement and make the juices flow. This will result in a positive MG day, and put more life in our lives.

What I didn't realize in the beginning, had no way of knowing, was that each one of these positive MG days that is produced in this fashion and put together in a chain of Pos. MG days results in our beginning at a little higher level. When I say little I really mean little. So small that it can't be measured on a daily basis but it will become evident over a longer period of time.

Don't be threatened by the word "Meditation." The dictionary defines it this way:-----a thinking over -- to think over -- to think or reflect upon -- revolve in one's mind -- to ponder, ruminate, reflect.

There are more but those should give you the idea. Nothing very threatening and, in fact, nothing that any of us hasn't done many times without thinking that we might be meditating. The difference here is that, this time, we have a specific goal in mind and it is a very important goal. It will determine how we spend the rest of our lives. Important enough, I think, to devote all the time necessary to achieving it.

Oh yes, another definition of meditation is: solemn reflection on sacred matters as a devotional act." This statement may give some a problem if they think that meditation will, somehow, conflict or compete with their religious beliefs. My answer to that is simple. Meditate on your religious beliefs and thereby strengthen the things that you worry will be weakened or that you feel are threatened.

Religious beliefs are one facet of our lives. It would be foolish to buy a diamond with a single facet. If we consider our life a diamond (It is certainly more precious than a diamond) then we should not be timid when it comes to adding to the beauty of our particular diamond. While religion is one facet, our mind and emotions are another. The practice of meditation simply polishes this facet and makes the whole diamond more beautiful.

Nature has always fascinated me and I sometimes go as far as referring to it as Nature/God. On the one hand that's an attempt to make it more palatable to those who have a problem with the concept of God. Then again, I really have trouble separating the two in my mind. My uncle, Father Al, who was a Catholic priest, had trouble with this and I think a little threatened by it. He saw the possibility that I might give up my religion and go worship a redwood grove. In Father Al's mind a person worshipped God in Church. Worshiping God in nature seemed wrong. The possibility of two separate and distinct facets existing without either threatening the other never came up in our discussions and he is now dead so the opportunity to test the debate is lost. Incidentally the concept of multiple facets existing side by side was discovered during meditation.

I believe, more and more, that all of us should be more proactive when it comes to our health and well being. Leaving everything to the doctors is a lazy and sometimes dangerous thing to do. Dangerous because with this approach we drift with the current thinking that, if we get into trouble the doctor will always be there to help. If we do get sick and find the doctors have little to offer it is then too late. Instead of sitting by and letting the winds of time and chance create who we are we should be busy polishing the facets of our lives. Elbow grease! It is amazing how little physical exercise is required to feel good and yet many people never even go for a walk. The same is true of meditation. Think of it as going for a mental/emotion walk. The rewards far outweigh the effort.

Once one has decided to Meditate, the trick is in finding the reward system that works best for the individual.

When I sit, with coffee, in the mornings I first empty my mind. (Not too difficult before coffee at 6 AM.) The first thoughts after this are usually negative or neutral and I flow with this. As my mind drifts I work toward a fantasy. In the fantasy the negatives are replaced with pure

positives. I am the hero and I always win, always succeed. After all, it is my fantasy and I am in complete control. Twenty minutes to a half hour the fantasy starts to fade and is replaced with the project that I happen to be working on at the time. A painting or story or a subject such as this one that occupies my mind. This is relaxed thought with very little structure. It seems, for me, the less structure the better the chance that I find a new thought or a new avenue to go down and develop. Here's the kicker for me. With new thoughts or ideas comes excitement and I have achieved my goal. I can now start my day "up". The negatives of life are still there but are overshadowed by the positives.

To reiterate: A good day should be the result of our mental/emotion state. A good day should reinforce the mental/emotional state that we began the day with. We should never merely hope that our day will be good so that we will be happy. Happiness is too important to leave to chance. Meditation is a means of taking control. Our mental/emotional state is not a result of how good our day was.

Does this always work? No, not always. Sometimes life has lumps and we find ourselves in a real funk. Lower than low and when this happens I have learned to simply flow with it. Oh I keep trying each morning but have found that if I let the fact that I'm in a slump put me in a slump, well, you see where that's going. Make small changes, get a new project, think of a new subject and "Bingo" one morning you find a new positive level again. It has always worked for me.

What I have described is my approach, the thing that works for me. You, the reader, will have to find the approach that will work for you. If it sounds like what I do will work, try it. If it fails then please don't give up. There are real experts in this field and it is up to you to find them. Elbow grease, remember?

DECK

What follows is an example of fantasy. After printing "Beyond the Limits" and attempting to get someone interested, I returned from San Diego with a good case of depression. Below was the type of thinking that occupied me for several weeks. The upswing in my mood evolved slowly, as you will see. Remember there is always a way out of the dumper and meditation is the key. It's written just as I thought it. No paragraphs, just one big run-on sentence.

You know----- a deck is a marvelous thing--it's flat and it lets us be outside and it keeps us from getting our feet dirty and we enjoy nature with no rocks to walk around or stumble over. Sometimes I think that God really missed the boat---He should have made the earth flat and--- you know--put down some linoleum or something and then we could have just walked around and well----just skated wherever we wanted to go. Wouldn't be any bumps. That's a thought--- a world without bumps! Right now I could use a world without bumps. I look out over the back lawn. It's as bleak and dead and burned as my spirits right now. There's my old 58 Ford pick-up. In the past it's been a symbol of hope and good times. Spent a lot of hours in the back country and camping with my family. It's a good truck. It's a symbol. I guess as an artist I look for symbols. Live by them. Hang on to them when I should let go. Good old truck. No windows now, and no windshield wipers and I guess I should fix it up some day. Aw well, maybe----someday. To the left is the woodshed, mostly empty. Doesn't seem to be much fullness in my life. Not even in the woodshed. In the back part is my wanna-be sail boat. Never really made it to a sail boat. A boat that I started to build twenty two years ago and all I

have is the hull. Just a shell. It was a dream. I don't know what other people see when they see old things, old broken down weathered things. I wonder some times. All cracked and rotting like an old farm house. Others call these old wrecks "Picturesque" and no one, I mean no one can pass without taking a picture-----but why? I mean I know why I might but why do others feel things that make them take a picture? What do they see---I wonder. I always see dreams. I can go back, back in my mind and see the people before the house was even built and feel the dreams. It's a good warm feeling. It's always Fall and there's a chill breeze and an urgency and they're hauling in lumber. They spent last winter in the cellar covered with raw beams and sod and the dirt sifted down and mixed with their food and every thing was dirty. Not like on my deck right here. Now they're building the house to put all of that in the past. Dreams. There's happiness here because they know this winter will be different--better--above ground. Next year they'll till the land and have chickens and a couple pigs and a cow. Milk, cheese, eggs, pork and once in awhile fried chicken on Sunday. Always on Sunday. Fresh bread and butter from a Mason jar and they were happy. They worked and struggled and were happy because of their struggle and not in spite of it. In the evening they sat by the fire--real close--cause they didn't have R-30 insulation and by the fire were 3 rocks, not touching but near the flames and when they went to bed each kid got a warm rock wrapped in paper and rags placed down by his feet. All night he was warm and breathed cool fresh air and it was better than central heating. They were poor and had little education but they understood much and I look at their houses all broken and rotting with paint gone some twenty years and I think--that was a dream. This is the raw bones of that dream that's gone. Dissolved like the morning mist in the early sun. Why? Well, it was good---a happy time---they had their time. Everyone has their time only some people know how to grab it and others just let it go by. I wonder what people will say I did when I'm no longer around. I hope they say I grabbed on with what strength I had. Didn't just sit and let it go by. I'll think more on that tomorrow.

RELAXATION

ITS USE WITH THE "STICK SHIFT" AGAINST THE THREAT OF CHOKING AND THE DIFFICULTY IN SWALLOWING.

I was thinking, last night, that there is no better example of the "Stick Shift" than when dealing with the difficulty MG people have with swallowing and coughing. When I refer to the "stick shift" I'm talking about changing our instincts as opposed to relying on what comes automatically; the program that we are all born with.

Here are two things that seem to be automatic, both being tied to the most powerful instinct that we possess. The instinct to survive. Without this very strong force man would have disappeared from this earth thousands of years ago. Nature, in every form, relies on it to keep going. I emphasize this, not only to show its purpose, but to show how very difficult it is to go against something that exists in a way that is, normally, basic to our very existence. As in many things with MG, what nature had meant as an aid to our survival----- something good to help us----hurts us.

From my own experience, while eating vegetables such as peas or corn I have from time to time aspirated. Sucked one of the little devils down my wind pipe. This is very easy to do if

one has MG because the control over the muscles in the throat becomes less effective as one eats and swallows. The repetition that is necessary to consume an average meal is more than enough to bring on an episode of MG weakness and, if a person is not careful, toward the end of said meal he or she will let some little piece of food slide down the wind pipe. I think every Myasthenic has had this experience.

At first, when I was new to the MG club, I would do what nature told me to do. What my survival instinct dictated. I would **aspirate and then:**

cough

cough

cough

cough

cough

cough

By this time my cough was so small and worthless that, if I had not dislodged the offending vegie, I would be forced to rest and slowly build up a stronger cough and eventually, after scaring myself, my wife, and anyone else that happened to be present, half to death, I would succeed in clearing my air passage.

The futility of continuing to cough after the first few strong coughs became apparent and it required a different approach. After many episodes I settled on the following:

COUGH COUGH COUGH

RELAX RELAX

RELAX RELAX

RELAX RELAX

COUGH COUGH COUGH

It required a lot of will power to relax when my survival instinct was saying "Keep coughing-- keep coughing-- keep coughing." Slowly I re-educated this and all my reflex actions to operate in a way that did not end in disaster. The result was a renewed confidence in my ability to handle situations relative to MG. This requires a strong effort against our basic instincts.

By using relaxation, for this purpose, I believe that one is taking advantage of the "rebound effect" that I speak of in the book, Beyond the Limits. I wasn't aware of "rebound" at the time that I started using relaxation in this manner. This also points up the benefit of relaxing before getting very far into MG. This principle is valid in all aspects of MG such as combing ones hair or brushing ones teeth. Don't wait for a full blown episode to relax. Anticipate and beat it to the punch. If experience shows you that after twelve or fourteen strokes with the brush your arm will be very weak, rest your arm after six strokes and then continue with six strokes and rest

etc. While this may seem awkward at first it becomes second nature after a few years of thinking in terms of a stick shift.

The same technique is useful when having trouble swallowing.
Instead of

SWALLOW

SWALLOW

SWALLOW

SWALLOW

swallow

swallow..

Try **SWALLOW SWALLOW**

RELAX RELAX

RELAX RELAX

RELAX RELAX

SWALLOW SWALLOW

It seems that the protective impulse to continue swallowing or coughing is a force that actually threatens a person with Myasthenia Gravis.

PREDNISONE

In the early years of my experience with MG the use of the drug Prednisone was unknown. Later, with the success that I was having in managing my own condition, I grew further and further from the advice of doctors and was unaware that they were using Prednisone on a more or less routine basis. This is a very strong drug and my understanding is that it replaces certain natural functions of the body. This is the part that concerns me.

Everything in this book involves the stimulation of these same natural body functions and I have the fear that, with the use of Prednisone, this stimulation becomes more and more difficult, if not outright impossible. As I said, I have no experience with Prednisone, and I pray I never will, but reason suggests that the approach of this book and the lessons that I've learned are at odds with the use of this drug.

Meditation may not work to heighten the level of excitement if the drug is being used to do the same thing. If the drug raises the LF then the "Rebound" won't work. Of course, if the drug works it could be said that the MG person doesn't need the "Rebound" effect and the hour of

meditation can be done away with completely. It would seem that Prednisone is a short cut to all the things that I have worked so hard to accomplish.

My question is: Considering the side effects for the patient, is it worth it except in the case of actually saving the patients life?

As I see it the Meditation and Rebound are an attempt to return oneself, in a natural way, to the state that was enjoyed before the onset of MG. I haven't achieved 100% but I do enjoy five or six very good hours each day. Most important I have achieved these hours without the fear of side effects.

At this point I will leave it to those of you who are on Prednisone to judge if the short cut and its side effects are preferable to the hard work and self discipline required to achieve the things that I have achieved. If your doctor feels that you truly need this drug and cannot do without it then, maybe, you will have to wait until sometime in the future when you are in at least a partial remission, and with the help of your doctor, can discontinue the use of this drug. Good Luck and please write if you have first hand knowledge of prednisone that you think might interest me.

ALCOHOL

I did not become aware of the real dangers of alcohol until after I had completed this book. It seems that I was lucky in the choices of how much and when I drank. As the saying goes "You win some and you loose some." This time I won one. Doctors advise people with MG to abstain from all alcohol but obviously I was successful in the use of a small amount and even used it in a way that had positive benefits. I have since discovered that if I have a drink while working, no matter how hard or easy the work, the results can be devastating. If, however, I wait until my work day is done and there are no pressures, social or otherwise, I can sit quietly and enjoy a glass of scotch with no ill effects. The key is the phrase "no pressures." For me the optimum amount is three or four scotches and no more than one in any hour. What would work for others I haven't a clue and I include this information mainly to show that, with MG, there are no absolute rules. Well, maybe one-----

IF SOMETHING WORKS--USE IT!_____

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