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Mind Games

by Thomas S. French, M.D.

There is no cure for birth or death save to enjoy the interval.

— George Santayana

WHEN THREATENED, life takes on new meaning and priorities change. Job promotions, bigger paychecks, more luxurious homes and other materialistic things become less important. It's a shame we travel so far before seeing all of life's blossoms and begin to understand the meaningful priorities of life. I wish I could say that I was different. It took 34 years and a catastrophic illness before I began to see the light.

Live as if you were to die tomorrow. Learn as if you were to live forever.

—Gandhi

I don't profess to be an expert in the areas of living or dying. What I do have is nearly four years of experience wearing the label "terminally ill." With that label comes a host of emotions and the need to readjust my priorities and change my perspective of the world around me. In essence, I've been trying to be an optimistic survivor with a catastrophic, "terminal illness."

Were it offered to my choice, I should have no objection to a repetition of the same life from its beginning, only asking the advantages authors have in a second edition to correct some faults in the first.

—Benjamin Franklin

I was 34 years-old when diagnosed with Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's Disease) in January of 1996. Since then, this insidious disease has literally turned my physical body into a human train wreck. I am unable to move my legs, arms, torso and head. I require a ventilator to breathe via a tube that has been surgically placed in my trachea. I am unable to speak and can only make clicking noises. I am unable to swallow and therefore cannot eat or drink. I receive all of my nutrition through a tube that has been placed in my stomach. That's the bad news. The good news, from a physical standpoint is I have normal sensation, complete bowel and bladder control, my "equipment" is working well, I can see and hear normally and my intellect is better than ever. The even better news is I have a gem of a wife, an adorable 1-year-old daughter and loving, supportive parents, siblings and in-laws. The bottom line is despite ALS, I am one lucky guy.

How ridiculous and unrealistic is the man, who is astonished at anything that happens in life.

— Marcus Aurelius
(*Man Plans, God Laughs*)

At the age of 14, I knew I wanted to be a physician, specifically, a plastic surgeon. It seems like yesterday when I was 14; yet, when I think of everything that has happened between then and now, it seems like a lifetime. After high school, I spent four years in college, four years in medical school, five years as an intern, resident and chief resident in General Surgery and

finally, two years as a resident in Plastic Surgery. I then joined a large, hospital-based multispecialty group practice at the hospital where I was born, spent years as a volunteer and countless days and nights on medical school and surgical residency rotations. Were all of those years of training worth only three years of practice? You bet. But, it was a long way from my anticipated path which was to include practicing surgery until the age of 65 or 70, followed by 20+ years of fun. Around the age of ninety, after a day of golf, cocktails and dinner, and several hours of vigorous lovemaking, I would die peacefully in my sleep

During the residency years, I was a witness to many devastating and disabling illnesses as well as deaths of every imaginable cause. No longer was I immortal. The “it can’t happen to me” phase of my life was coming to an end. Despite this realization, it was still difficult to accept that something “bad” could happen to me. This was especially true when I encountered patients with severe burns, quadriplegia, severe head injuries and progressive, disabling neurological diseases such as ALS. Surprise, surprise!

It is not in the stars to hold our destiny but in ourselves.

—William Shakespeare

When I was told I had ALS, it was like a death sentence. I scoured the medical literature looking for a ray of hope. It was not to be found. Every article and text ended with the same conclusion: progressive loss of motor control leading to paralysis and ultimately death within 3 - 5 years. Not exactly the news I was looking for.

Having been trained in traditional science-based medicine didn’t help matters. I saw things as either black or white but no grays. At that point, my options were straight forward:

1. Go with the disease until it kills me.
2. Live with the disease and use any or all life sustaining measures, or
3. Exit this life on my terms — the decision of where, when and how would be mine.

My only symptom early on was slight weakness of my left thumb and it was exceedingly difficult to imagine the devastating toll that this disease would have on my body. Despite such minimal physical loss, I frequently

reviewed my options. I was most comfortable with my third option - suicide. I could never imagine myself living with severe disabilities and eventually ending up on life support. So, I began setting deadlines (no pun intended) as to when I would end my life. My most humorous deadline, in retrospect, was after an incident on the island of Martinique at the end of a month long bare boat sailing trip through the Windward Islands of the Caribbean. At the time, I was still quite functional with only left-hand weakness. One night, a lone mosquito buzzed me throughout the night. I would hear the buzzing near my ear, then silence. I'd jump out of bed, turn the light on, do a little jig then look around for the beast. This routine continued all night. The next morning, I vowed it would be time to move on when I became helpless against a mosquito in the middle of the night. I've seen quite a few self-imposed deadlines come and go. I haven't set any parameters for well over a year and despite my ongoing physical losses, I am very happy to be alive. But, I still leave all my options open.

Be happy while you're living, for you're a long time dead.

— Scottish Proverb

What makes a person with ALS feel the need to hold an option as extreme as suicide? The underlying core, I believe, is FEAR. For me, it was the fear of becoming paralyzed, unable to breathe or eat on my own, being a physical and financial burden on my family, fear of loss of dignity and control over my life and basically fear of the unknown future. Death would seem to be an easy out.

Historically, I started circling the drain in August 1998. I had been having trouble breathing and had been choking on food for quite some time, although I had been eating a regular, unrestricted diet. My first ALS related trip to the emergency room was at 3:00 A.M. after choking for 12 hours on a burger and fries. It didn't take long for them to confirm my greatest fears. My ability to breathe and swallow were both severely compromised by failing muscles. This was no big surprise to me. I just didn't want to face it. My original plan was to let nature take its course. I wanted it to be known that I was not to be resuscitated if I crashed (do not resuscitate or DNR). My condition worsened later that day. I thought long and hard about my situation. Jacque, my wife, remained optimistic about our future, despite the gruesome

prognosis. She always had little rays of hope which would conquer any pessimistic thinking. I thought about my daughter, Lauren, who was born ten days earlier with me attempting to coach in an almost unintelligible voice from another hospital bed adjacent to Jacquie's. For the first time, I was thinking about the good things in my life, and less about the negatives. It was a real turning point. I changed my mind about the DNR status, not because of a fear of death but because I wanted more out of life. Death is permanent — bottom line. The doctors tuned me up & I went home. Four days later I was back in the intensive care unit (ICU). My decision was a no none-sense one. I didn't want to linger. I wanted to get the necessary procedures done and get on with my life. I had a tracheotomy and feeding tube placed and six days later I was off to a rehabilitation hospital for a month and then home. Dorothy had it right. There's no place like home.

But, home was different. It was now necessary to have nurses and nursing aides with me around the clock. Jacquie's life changed as much if not more than mine. In addition to having the responsibilities of a new baby and running a household, she continued to play the major role in my care. It was chaotic to the point that I openly questioned whether I had made the right decision. I put my trust in Jacquie, myself and God, and stopped trying to second guess our mutual decision. It was a new situation, a new life. It would get better

No matter where you go or what you do, you live your entire life within the confines of your head.

—Terry Josephson

Another major turning point in my struggle with ALS was when I finally stopped looking solely at the physical destruction that was taking place and shifted my thoughts to the psychological impact of the disease. ALS is a mind game — the ultimate mind game. This revelation allowed me to try new strategies. First, I became pro active. I told the “beast” that although it had wreaked havoc on me physically, in no uncertain terms would it ever conquer my mind. I became more optimistic, not necessarily about being cured, but with accepting my co-host/parasite and setting limits. It was psychological warfare and I intended to win.

The secret of health for both body & mind is not to mourn for the past, not to worry about the future, or not to anticipate troubles, but to live in the present moment wisely and earnestly.

—Buddha

Since traditional medicine didn't have anything to offer, I turned to alternative or complementary medicine, which was completely new to me. The topic of the mind-body connection is complex and there tends to be a significant overlap among its different modalities. There is no definitive nomenclature that I am aware of, which tends to add confusion to the subject. Despite my traditional science background, I have always believed in, but have had limited knowledge about the mind-body connection. I have tried various relaxation techniques and meditations in the past. I bought the books, listened to the tapes, etc. I was always expecting to reach some definable state that would be awesomely overwhelming. I tried and tried but nothing ever happened. Why? I was trying too hard and expecting too much.

Shortly after I was diagnosed, I started having weekly sessions of Reiki, a natural healing method that uses the hands of a healer to channel energy to another person through chakras or energy centers. It has been practiced for thousands of years and was reintroduced in the 1800's by Mikado Usui in Japan. Three Reiki masters worked on me for two to three hours a week. I learned to reach a meditative state during these sessions. It was a feeling that was as close to nirvana as I could imagine. I was aware of my surroundings but had no reaction to them. Jumbled thoughts, which consciously may have ranged from elation to deep depression or fear, would calmly percolate in and out of my unconscious mind and somehow become processed into a rational form. It is in this state of mindfulness that the unconscious mind becomes unlocked and accessible for either "work," i.e. solving complex issues or as just a calm place to hang out. Our conscious mind is too irrational and too emotional to really do anything with complex issues other than to temporarily patch them. The unconscious mind is the real work horse.

I have realized that the past and future are real illusions, that they exist in the present, which is what there is and all there is.

—Alan Watts

During the past four years, I have processed a great deal of information. It was necessary to accept the fact that I could no longer do the things that I used to take for granted such as walking, eating, talking, skiing, sailing, playing the piano etc. In a sense, my conscious physical world has become smaller. I can remember a lot of “last times” such as my last time on skis, which by the way, was not a pretty sight. Two years ago, I would have mourned the loss of many of these activities. Today, I actually enjoy closing my eyes and reliving some of the hobbies that I used to love so much. There are times when I can actually put myself on skis or on a sailboat and write the script from there. These are incredible experiences. While most people have to pay for similar experiences, I can enjoy them anytime, with my eyes closed, free of charge.

There remain some issues which I have not fully processed or come to terms with. On a conscious level, thoughts of these incompletely processed issues are unsettling and anxiety producing. I deal with this type of situation by automatically telling myself, “WE DON’T GO THERE.” What I’m actually telling myself is “you’re not ready to confront this issue on a conscious level.” It’s not conflict avoidance but what I consider to be a “transition in progress.” The biggest issue involves eating. This is a difficult obstacle for me to hurdle with any grace, perhaps because Jacquie has such a talent for cooking and with or without guests, mealtime was always an event for the two of us. I can still enjoy a morning coffee and a happy hour cocktail. The only difference is the entry point of the beverage. After that, it’s all the same.

Some days you’re the dog, some days you’re the hydrant.

— Anonymous

Technological advances have made it possible for me to fully access my computer with my eyes. At one point about six months ago, I was working on the computer when I suddenly stopped. Tears started rolling down my cheeks. I had been writing away on the computer using only my eyes and it felt completely normal, as if I had been doing it all my life. My feelings were totally mixed. Was I giving in to the “beast” or was I unconsciously coming to terms with and acceptance of the technology that would ultimately improve my daily life? I slept on it and it resolved itself. Change, even for the better, could still be difficult. But, I realize that now. It is just another small

step toward accepting not only my physical limitations but also toward accepting those advances that will ultimately allow me more independence and a better quality of life.

The best thing about the future is that it comes one day at a time

— Abraham Lincoln

“One day at a time.” This is everyday advice handed out freely for everything from a minor headache to the loss of a loved one. How many people have thought about the true the meaning of this phrase? How many actually live life one day at a time? My guess would be, not many. I know I was great at giving out this advice but had never sat down and pondered the true meaning of it, let alone lived it. I’ve thought about it a lot in recent years and it makes a lot of sense. Living in the present eliminates negative comparisons between the past and present as well as anxieties about the future. So, I join the ranks of people everywhere who have made this a motto to overcome addictions or to simply get more out of life.

In theory one is aware that the earth revolves but in practice one does not perceive it, the ground on which one treads seems not to move, and one can live undisturbed.

So it is with Time in one’s life.

— Marcel Proust, *In Search of Lost Time: Within a Budding Grove*

The concept of time has taken on new meaning to me. In the past, it meant you had to be in Surgery or the office in 10 minutes. It meant that fractures take six weeks to heal, if all goes well, then things go back to normal. It meant that most things could be measured or interpreted as a function of time. Now, time has a new meaning. In some ways, it doesn’t seem to exist. I don’t have a broken leg or appendicitis, things that get better, usually, in a defined amount of time. I have a condition with no time parameters but with complex needs. Living with ALS under my previous time parameters would be impossible. There were so many changes including structural changes to our home to make it more accessible, the need for complex med-

ical equipment and a well-trained staff that it was unrealistic of me to expect to have everything in place, & all the loopholes worked out in a short period of time. Put a health insurance company in the middle of everything, and you might as well go hibernate for six months or so. Slowing down and having no control over it was one of the most frustrating parts of my journey, thus far. On the upside, it sure went a long way toward developing patience and resetting my levels of tolerance. Patience and tolerance go a long way when you are dependent on others for all of your needs. Unfortunately, in the working world, time is usually money, and therefore, patience is not necessarily a virtue. But, in my situation, patience or the lack thereof, can make or break you. I am at the point where virtually no amount of time alone with absolutely nothing to do, is too much. These are the times that I do “mind work,” or simply watch the happenings around me. I no longer expect things to happen overnight, but I do expect them to happen in a reasonable amount of time. I have been known to write and send some unforgiving e-mails which leave little doubt about my interpretation of the given situation. I no longer say “when will such and such improve etc.” I now tell myself that “it” will happen with time.

For a long time it had seemed to me that life was about to begin — real life. But there was always some obstacle in the way. Something to be got through first, some unfinished business, time still to be served, a debt to be paid. Then life would begin. At last it dawned on me that these obstacles were my life.

—Fr. Alfred D’Souza

At some point, we all think that things can’t get any worse in our lives and tomorrow, the next month or even next year will be better. Unfortunately, the problems that generate these thoughts and comments are all part of life’s obstacles. We cannot make them disappear but we have options in how we face and overcome them. These obstacles, which seem so unfair, are simply bumps on our chosen paths in life. They are there for a purpose, for us to learn, to develop skills to allow us to cope with future problems down the road. If I think that I am immune from future problems because I have the physical and psychological burdens of ALS, then I’m in for a big surprise. These “bumps” are not bargaining chips for the future. They

are simply today's lessons to help us in an unknowing way, prepare for future "bumps." This is life folks. We have to take the good with the bad. But, again, we do have options — options involving our attitude and reactions to a given situation.

*The game of life is not so much in holding a good hand as playing
a poor hand well.*

—H.T. Leslie

With a disease such as ALS, it is very easy to compare oneself to others and drown in self pity. My mother has said on multiple occasions over the years that "ALS is the worst disease there is." I have felt the same way at times. Many people believe and live as if "the grass is greener on the other side," I believe that the grass only APPEARS greener on the other side. We all carry our burdens, some of which are more visible and heavier than others. When I would hear people complaining about this or that, I would think, "you think you have problems." It didn't take me long to lose that attitude. Someone's problem(s) may seem minor to me but to the other person, they may be overwhelming. When I watched Dr. Kevorkian euthanize the gentleman with ALS on national television, I remember thinking, why? Here was a man who was in physically better shape than I, determined to die. For a fleeting moment I thought the man was a wimp. But then I felt sorry for him, for the conflict and fear he must have had inside to make him not only want to be "put to sleep," but to have it done on camera by Dr. Death himself. God forbid I ever feel the necessity to consider taking such drastic measures.

To put my life with ALS into positive perspective, all I have to do is read the paper, watch the news and go back through history. There have been countless atrocities during the last century alone, causing human suffering at levels that are unfathomable to me. I'm not a cold, scared teenager on a battle field in a foreign land or a prisoner of the Holocaust. I am not living a tormented life surrounded by adversity and I do not carry the burden of deeply buried emotional scars. I am simply a man with a malfunctioning neuromuscular system. I do not lack shelter or food and I am surrounded by love. This is an opportunity. Although some days it's hard to see it as such, it is an opportunity to learn valuable lessons about life that very few people ever have the opportunity to learn.

Suicide (the real unassisted kind that is most familiar) is LEGAL in most states. Perhaps it's legal because the responsible party is dead and therefore cannot be held accountable. Whatever the reason, it's very clear that when you start involving other people, the terminology and the laws change. There is physician-assisted suicide, active euthanasia, passive euthanasia and involuntary euthanasia, all variations of a central theme. There are many arguments, pro and con, in the debate on physician assisted suicide. It's a no win situation, no matter which side of the fence you are on. I am pro-choice and am of the opinion that the potential for abuse with strict regulation is extremely low. My dependence on artificial life support puts me in a unique position. Without the ventilator, I would be unable to survive. Therefore, if with my consent, a physician took me off the ventilator and allowed nature to take its course, it would not be considered physician-assisted suicide. It would be an example of passive euthanasia. On the other hand, if I were able to breathe on my own, I would not be a candidate for passive euthanasia. In order to end my life, I would have to go the route of physician-assisted suicide which is only legal in Oregon. It is an option that I would want available to me if I were in a situation where physician-assisted suicide was my only choice. Whether or not I would use it doesn't matter. I like options.

In 1998, Oregon became the first, & remains the only state to legalize physician assisted suicide. Contrary to what was expected, only 23 individuals took advantage of the new law. Fifteen of these individuals committed suicide, usually within a day of receiving their prescription, 6 died of their illness without using the medication, and 2 were still alive at the end of 1998. These numbers don't suggest people lining up and knocking down their doctor's door to get a prescription for a lethal dose of drugs. They suggest to me, that people don't necessarily want to die. Rather, they want options, a way out if their worst nightmares come true.

Realists know that adequate pain relief sometimes requires dosages of narcotics in the lethal range. If you have a cancer-ridden patient in severe pain, uncontrolled by high doses of morphine, are the doctors thinking "you'll just have to suffer until your time has come?". I very much doubt it. There are groups who feel suffering is a necessary part of the dying process — "through suffering comes insight." There is truth to that statement, but not as a generalization. If the suffering comes in the form of uncontrollable pain, I'm not sure how much insight I would gain.

Can a physician morally, ethically and legally administer or prescribe such dosages? Or is this perceived as an intent to kill or assist suicide rather than an attempt to minimize human suffering? I don't know a single physician who gets any satisfaction from seeing a patient suffer. I do know doctors who will not give "off the chart doses" of narcotics in order to control pain for fear of prosecution. I have never heard a patient say "The pain is unbearable but don't give me any more pain medication." If you could really know what those patients with unrelenting pain and anti-physician assisted suicide beliefs are thinking, my guess is they would want the extra pain medication and the hastening of death, as long as it was termed "pain control" and not assisted suicide or euthanasia. For those healthy individuals who deny this is all semantics, I recommend they spend some time in a hypothetical "dying simulator." Like a flight simulator this device would simulate real-life dying with the ability to control different parameters such as the underlying disease symptoms including pain, and the ability to monitor the "patient's" responses and decisions. I'll bet the results would show that, at a certain point, the vast majority of "patients" would welcome pain relief and death, no matter what it's called.

Various studies have found undiagnosed and untreated depression as a leading cause of suicidal ideation in the terminally ill. I don't think that adding Prozac to terminal patients' coffee every morning, will necessarily eradicate the problem. But, treating the depression may lift a significant number of individuals up to a more functional level where they can think more rationally and hopefully discover ways to enjoy life, despite their illness.

Sometimes even to live is an act of courage.

—Lucius Annaeus Seneca

I am sure, depression plays a major role in individuals with ALS as well as their families and close friends. Is fear the result of depression or is depression the result of fear? I'm not sure but my gut tells me they feed each other. If we look at the major physical and psychological issues confronting individuals with ALS, it is overwhelming, depressing and frightening. By breaking "fear" down into individual components, although still depressing and scary, they are more manageable. Earlier, I mentioned the things I feared most about ALS including paralysis, the inability to breathe and eat; the fear

of becoming a physical and financial burden; the fear of losing dignity and independence; and the overall fear of what the future held. To address these fears, I've found some successful strategies.

Recognizing my fears and how they affected me was step one. An important realization for me was to trust myself and listen to my "gut." Then I had to reexamine my concept of time and to realize that living with ALS is an evolving process. It cannot be rushed. Sometimes I fared better if I allowed my mind to go on cruise control and let the schizophrenic parts hash things out.

Conquering these fears requires taking control of your mind and learning to stay centered in the present. If you let your mind run free and under the control of ALS, you will only remain in a state of raw panic. It does not have to be that way. Do whatever it takes "mind work," counseling, alternative therapies etc. — anything to allow yourself to develop a new way of thinking, a new perception of life. One-day-at-a-time.

Being quadriplegic and on a ventilator requires around the clock nurses and/or aides. In addition, our families, especially our spouse or significant other, will have to take on a good deal of both physical and emotional responsibility. This leads to a very heavy load of guilt or at least it did for me. Am I being selfish and destroying their lives so I can continue my life and all the needs that go with it? These are real concerns that have to be brought into the open and discussed. Fortunately, Jacquie stood by my side, frightened and knowing what the future could bring, but not immobilized. We have similar beliefs and philosophies which have helped immensely. Yet, I still can't help but feel guilty when I see her physically and emotionally exhausted.

A good friend of ours who has many virtuous qualities, not the least of which is wisdom, once explained the situation simply: Jacquie owes me big time from a past life. I wonder what that means for me in our next life. The best I can do right now is to show her love, patience and a strong will. I can listen to her needs and allow her to vent, even if it is something to do with me. I can help her with her struggles just as she helps me. Despite my limitations, to Jacquie and Lauren, I am a husband and father first, and a person with ALS last. It is equally important that I keep in mind the fact that even though she plays a significant role in my care, first and foremost, she is my wife.

ALS is a very expensive disease, especially if you receive your care at home as I do. I estimate around the clock nurse or aide and durable medical equipment and supplies, including the ventilator, to average about \$180,000 per year. Where is all that money going to come from when my Cobra period ends? I don't know and unfortunately, it remains one of the few problems I have to solve. It is a very real concern. Do I want to financially ruin my family, in order to be medicaid eligible? Absolutely not. Do I want to physically burn out my family by shifting my care to them? Absolutely not. I'm letting this problem percolate. I suspect part of the solution will involve my returning to work. Unfortunately, a hands-on medical career is not possible, right now. Another solution would be to have a philanthropist set up a trust fund and allow me to pay my home care expenses from the interest generated by the fund. I am not above soliciting funds and let there be no doubt — that was definitely a solicitation! Actually, the best way to solve all of these problems would be to find a cure and a reversal process. Hopefully, sooner than later.

While I am on the financial end of things, I would like to sidetrack and make a few personal remarks about how our government reacts to these types of medical and financial issues. It seems that every four years, the politicians have a new plan for solving all the woes of our health care system. Then, nothing happens until another four years go by, and then the cycle repeats itself. Eventually, something will have to break this bureaucratic cycle. Medicare and Social Security funding also get tossed into the campaign melting pot. Home health care was supposed to have a significant effect in reducing the total health care budget. What happened to the advocated practice of keeping patients at home rather than in institutions? I thought this was a time of greatly expanding home health care. From where I sit, it ain't happening. Is it possible that our government has its priorities screwed up?

None but a mule denies his own family

—Anonymous

Let's take a hypothetical situation. I have a child who needs a kidney transplant and a child in the next town needs a kidney transplant. I just happen to be a compatible donor for both. Who should receive my kidney? Would it be selfish if I decided to donate my kidney to my child? I wouldn't

think so. I would certainly empathize with the other family and hope and pray the other child would soon get a kidney. This sounds somewhat harsh, but realistically and instinctively, we take care of our own first and help others whenever we can.

Every year, our government sends billions of dollars in aid to countries all over the world. I can certainly understand the need for outside help after a massive natural disaster, but I don't see how or why we have to get politically, financially or militarily involved in solving the rest of the planet's problems. I am a U.S. citizen sitting on American soil hoping that someday, the U.S. government will think enough of us to increase research funding and provide more help for those of us with this debilitating disease. The problem is there are ONLY 30,000 of us in this country. Thirty thousand individual catastrophes. Thirty thousand people may not seem like many, but to those of us and our families who are living with the disease, it is an astronomical figure. If you put 30,000 of us under one roof and added a major catastrophic event, then we would possibly see some government action. There are many, many people who have generously given of their time and money in an effort to help those with ALS. But, the private sector can't do it alone. To our government, all that I can say is please, help us put ALS in the category of "diseases of the past."

Being the world's major super power cannot be easy. We live in a great nation but with all of its responsibilities, many "smaller" issues get swept under the rug. Politicians are looking for issues that attract the numbers and will not only receive a big round of applause, but a standing ovation. They give the public what they want to hear, especially during election years.

The incestuous relationship between government and big business thrives in the dark."

— Jack Anderson

One example is the pharmaceutical industry. Why do our own senior citizens have to cross the border into Canada to buy their prescription drugs? These are drugs that are identical to those sold in the U.S. but for half the cost. This is only my opinion, but I believe that the answer very simple. If you lower the price, you lower the profits. If you lower the profits, you lower the top dogs exuberant salaries and bonuses down to a still exuberant level.

At some point, the lower profits would trickle down to the politicians as a decrease in political contributions. The pharmaceutical industry tries to have us believe that research and development would suffer. If that is where they choose to make their budgetary cuts, then R and D will suffer. If they trim fat in other areas, then there would be plenty of money to go around. It's just another example of money, power and selfishness at the expense of the American public.

Tobacco. This one takes the cake. We now have billions of dollars going to individuals, their families and state governments from the tobacco industry, as compensation for smoking related illnesses. Are we to believe that smokers did not know smoking was bad for them? I knew it was bad when I first lit a cigarette at age 13 or so. To a teenager, the taboo and mystery of smoking, and the fact that adults are smoking everywhere, makes smoking even more intriguing. Nobody held a gun to my head when I lit up, and I would assume the same is true for the other millions of smokers worldwide. I really don't understand it.

I am glad I do not have to explain to a man from Mars why each day I set fire to dozens of little pieces of paper, and then put them in my mouth

— Michael McLaughlin

It is common knowledge today that smoking causes a multitude of serious health problems and in many cases, kills. The tobacco industry has blatantly lied in court regarding the addictive potential of cigarettes and their ability to cause serious health problems and death. They also tried to cover up the fact that they even put additives in the tobacco to increase their addictiveness. These are criminal acts. In addition, the tobacco industry is guilty of assisted suicide on a grand scale.

So, how does our government, judicial system and tobacco industry resolve this problem? Money, of course. The tobacco industry is now shelling out billions of dollars to state governments as compensation for smoking-related illnesses. They have lost lawsuits brought by smokers and their families for smoking-related illnesses and wrongful death with juries awarding multimillion dollar settlements. People who chose to smoke and then lost the coin toss are now getting millions because they were stupid enough to smoke in the first place. I'm sure a sizeable number of these people had their

smoking related illnesses covered by medicare. Tobacco companies are spending millions on advertising campaigns that target teenagers and children, promoting their efforts to keep kids from starting smoking. Unless they have a more subtle, self-serving agenda, I would consider this corporate castration. This industry's ability to remain solvent despite the money they are spending on anti-smoking campaigns etc., can only mean one thing: they are still making a shitload of money.

Why is a product that has proven to be responsible for a great number of serious illnesses and deaths, still legal? Again, money. These giant billion dollar industries have tremendous power on Capital Hill. I don't see how there could be any other reason. Since we have potential problems with medicare funding in the not-too-distant future why not pump all of this "tobacco" money right back into health care? Better yet, have the tobacco industry self-insure health benefits for all smokers. That would solve a lot of problems. As for the consumer, you have options. Either quit or take full responsibility for your actions when you face a smoking related illness.

Although I've gone astray, there is still some relevancy to these issues. The cure for ALS is out there, probably right under our noses. To get it uncovered and to the point where it can help those of us with ALS, takes time and money. To see money squandered for political gain is a darn shame. It's high time our country reexamines its priorities and acts on campaign promises instead of trying to pacify us with lip service.

*Lord, grant me the serenity to accept the things I cannot change,
the courage to change the things I can, and the wisdom to know
the difference.*

—St. Francis of Assisi

Loss of dignity and independence play heavily on those of us with ALS. No doubt, ALS robs us of varying degrees of dignity, depending on our individual perceptions and interpretations of what constitutes dignity. We have some control over how much or how little dignity we maintain but we have to let others know what is important to us. A few of my quirks include having a shave and getting fully dressed everyday. I don't like hanging out in sweats or pajamas. I like doors closed when using the bathroom, or getting dressed or undressed. For some reason, people act as if I don't need privacy

and even a closed door is an invitation to walk right into my space. Knock. I am no different from anyone else. I like my privacy too. Some people also feel that they can look over my shoulder and read whatever I'm doing on the computer. To those who feel like my work on the computer is open to the public, think again. Take control and speak up about those things which would make you more comfortable and those that make you uncomfortable. As for those indignities that we can't seem to get over, accept them with dignity.

While physical independence is not easy to maintain or regain, intellectual independence remains, with few exceptions, fully intact. We can take advantage of that and continue to be involved in family and household decisions. The computer has been a life saver for me. Using Eye Gaze technology on my desktop computer and GUS software with switch scanning on my laptop, I handle a chunk of the household paperwork and correspondence via e-mail, fax and the Internet. It gives me independence and allows me to contribute to the household.

*When you come to the end of everything you know
And are faced with
the darkness of the unknown, **Faith** is knowing one of two things will
happen. Either there will be something solid for you to stand on,
Or you will be taught how to fly."*

—Barbara J. Winter

During the past four years, I have reinvented the wheel more times than I like to think; I have learned a great deal from these experiences.. I have developed a much greater understanding of who I am and what makes me who I am. I have answers which are satisfactory to me as why I have ALS and why am I still alive. It all hinges on a strong faith in God, Jacquie and myself. When I first was diagnosed with ALS, I prayed it wasn't true or would disappear. Nothing happened. Next, I prayed it would at least progress slowly. Nothing happened. Finally, I prayed for the strength to keep myself, Jacquie and others going and for the ability to continue on with a happy, fulfilling life. I believe that my prayers have been answered... not exactly the way I had hoped, but answered, nonetheless. The reason I am still here is two-fold. First, I'm tough and am not about to let this beast break my spirit, take away my hope and faith, or that of those around me. Secondly, God has other plans

for me, of which I am not yet privy. There are other lessons for me to learn, lessons that can only be learned through my experiences with ALS. Faith in God and myself allows me to take the next step without knowing where it goes. Faith allows me to live in the “now,” one day at a time, without worrying about tomorrow.

Hope is the last thing that dies in a man, and although it be exceedingly deceitful, yet it is of good use to us, that while we are traveling through life it conducts us in an easier and more pleasant way to our journey's end.

—**Francois de La Rochefoucaul**

“No hope is better than false hope.” I’ve heard this line used with relative frequency and I couldn’t disagree more. Hope, amongst other things, has helped me bridge the times when I have been in a ditch. It is a distant gleam when everything else seems to be in complete darkness. In addition to Jacquie and Lauren, who are hope in and of themselves, I sought hope in everything and everyone. I tried Reiki with the hope that the ALS would disappear. Is that false hope? No. At the time, that was truly hope. Although it didn’t eradicate the disease, it brought me many tools and taught me many skills, which I’ve put to good use since then. My hope swelled when I was chosen by lottery to be on the experimental drug, Myotrophin. Despite the drug, my symptoms continued to progress, but it was another bridge of hope. I tried Acupuncture and Chinese herbs with the hope they would slow down the disease. They didn’t, but they helped my shoulder pain and again, bridged a gap. I’ve tried reflexology, craniosacral therapy, therapeutic massage, Trager, and combinations of the different alternative therapies. I didn’t have to spend a fortune and although they didn’t seem to have much of an effect on the ALS, they did more than conventional medicine. They all gave me hope when I needed a charge and taught me little lessons to get me to where I am today — alive and thriving.

I like living. I have sometimes been wildly, despairingly, acutely miserable, racked with sorrow, but through it all I still know quite certainly that just to be alive is a grand thing.

— Agatha Christie

One of the problems with ALS is that from day one, there are no written or spoken words that convey any hope. The only thing you read or hear about ALS is that Lou Gehrig had it and that it is “uniformly fatal within 3 to 5 years,” along with all the nasty things that happen to your body before you die. Finally, there was good news. The FDA had approved the first drug ever to treat ALS-Rilutek. When I finally read about it, I had to laugh. This new landmark drug which was being sold for \$600 +a month, was shown to prolong tracheotomy free survival for 90 days. In other words, it bought you 3 more months of life before you needed a trach. My 90 days are long gone, but I wonder if I would have had my trach done in May 1998 instead of August 1998, if I hadn’t taken Rilutek. Despite my bit of sarcasm, I am still taking the drug. Why? I suppose it offers a glimmer of hope and a first step towards treating and curing a disease which everyone associates with disability and death.

Q: Do you know what the death rate around here is?

A: One per person.

—Anonymous

According to most information written about ALS, I’m smack in the middle of the death zone — three to five years. What most literature doesn’t mention anything about are the numerous people who have survived beyond 5 years. That’s the category I’m shooting for and hope to stay there for years to come.

I wonder if we would see any changes in the progression of ALS if patients were told they have an 80% chance of living more than 5 years with minimal to moderate disability — a kind of psychological placebo. I’m not suggesting lying to patients, but to me, it’s an interesting question in stark contrast to “bang, bang, in 3-5 years your dead.” I don’t put a lot of weight or faith in statistics. Let’s face it, a 80% survival rate for disease X is great if

you are one of the 80 out of 100 who survive. But it really stinks for the 20 out of 100 that die. It's aggravating data with little relevance to the individual.

I wonder where the number crunchers would put me in their ALS statistics. Am I considered dead because I require an electrical outlet or battery to stay alive? Do I really care? No! It took me awhile to reach this point where I can calmly say, I die when I die. Numbers are only numbers and in no way do they seal our fate. There is hope everywhere. Grab it and run with it.

Omnia vincit Amor. Love conquers all.

— Virgil

Jacque and I met in high school but didn't start dating until several years later. We actually double-dated in high school but with our own separate dates. On July 3rd 1983, during the summer between college graduation and medical school matriculation, Jacque and I were married. Between my schooling and her working, life was chaotic at times. After about five years of marriage, we tried to start a family. No luck. Over a period of about 4 years, Jacque underwent a myriad of tests, multiple laparoscopic surgeries and series of treatments with fertility drugs. Still no luck. More frustrating were the positive pregnancy tests followed in several weeks by miscarriages on two occasions and a tubal pregnancy. It was a tough time for both of us.

During this time, I was in the hospital more than at home — a 100+ hours a week. Many nights off were spent moonlighting to supplement our incomes. These jobs included being the physician on the medical center's helicopter, covering the emergency room at a small local hospital and a walk-in clinic on weekends and finally, covering the open heart surgery unit at a local teaching hospital. My life and our marriage belonged to the hospital.

In 1992, several months after moving to Virginia to start my Plastic Surgery residency, the marriage came to a screeching halt. I was the initiator. We separated and eventually divorced, but remained friends throughout. In many ways, it was an amusing relationship. We lived separate lives but were best friends. We shared our ups and downs and confided in each other about such unlikely subjects as our relationships. There was never any love lost.

“Falling in love with someone isn’t always going to be easy... Anger... tears... laughter.. It’s when you want to be together despite it all. That’s when you truly love another. I’m sure of it.”

—Keiichi Morisata

Jacque was the first person I called after learning the possible diagnosis. She reacted by showing up at my door within the hour and told me she would be by my side through thick and thin. Those words were music to my ears, spoken by the only voice that could give them any meaning..

Nearly nine months later, I was putting away my shingle as a plastic surgeon. I was thirty-five. It was a difficult decision but I knew it was coming. On a whim, we decided that the city no longer needed us and we no longer needed it. We wanted someplace rural but not so far off the beaten path that we would be isolated from family and friends. Within 24 hours we were headed for New Hampshire and Vermont searching for the perfect spot to call home. We landed in central Vermont where my sister and her family live. The next day we went for a drive. It was a perfect, cool, crisp fall day. We fell in love with one particular road. It had several farms, unbelievable views and a quaint little town center located on a small lake called Silver Lake. We both agreed that we would somehow make our home on this road, the North Road in Barnard, Vermont. There were several properties for sale including one with overgrown fields, and a long driveway leading to a rustic looking cottage-like house. My sister checked it out and we returned the following weekend. The size of the house was deceiving from the front. It was rustic inside but had beautiful wide oak floors throughout and two huge stone fireplaces, a beautiful large spring fed pond behind the house and spectacular views to the west. The whole package included the house, and 89 acres of land of which about 5 acres was fields and the remainder was woods with hiking trail. We both saw potential in it but it would need a lot of work. We bought it and the demolition began. Tearing down the attached two car garage, a deck and the ensuing bonfire was a family affair. We gutted the entire house, added a sizeable living room, dining room, master bedroom/bathroom suite/loft. We replaced bathrooms, stairways, kitchen, decks, garage, all wiring and plumbing, siding, roofing and a whole lot more. It was our over-budget, behind schedule dream house.

The following spring, Jacquie and I were remarried in our living room and in late November of 1997, we held our breath as we watched a home pregnancy test turn positive. It was unbelievable, no fertility drugs, no medical intervention of any kind. On August 3rd 1998, after nearly a decade of trying to conceive, our 7 lb.7oz. miracle baby girl was born. We named her Lauren — “crown of laurel.” The timing of our having a child seemed to be more than just a random event. Lauren was born about 10 days before I had to make the decision of life or death. I’m still alive. Coincidence? I doubt it. A perfectly timed gift from God? Undoubtedly!

*I don't need to be king of the world, as long as I'm the hero of
this little girl.*

—Jani Lane

Where do I go from here? I’m really not sure. New doors are continually opening as I try to meet the challenges of ALS. I see the world in a completely different light. No longer am I a member of the overachiever’s club. The only areas that I have any ambition in being the best, are as a father, as a husband and as a person. My niche in the world has yet to be carved out and as far as I’m concerned, it can wait. For the time being, I’m enjoying the ride — despite ALS.

Still round the corner there may wait, A new road or a secret gate

— J. R. R. Tolkien

It is impossible for me to close this chapter without a few words of gratitude to the many individuals that have helped me during these challenging years.

To Jacquie, Lauren and both of our families:

“If I could reach up and hold a star for every time you’ve made me smile, the entire evening sky would be in th palm of my hand.”

—Unknown

To the congregation of the First Congregational Church of Woodstock,

To Con and Terri

To Dan, Gene, Beth, Sarah and Annette,

To Scott and Karen

To Lynn and Bud

To Terri, Lisa and the rest of the gang

To Austin and Trudi

To the physicians, nurses and Priscilla at
Dartmouth-Hitchcock Medical Center

To Mala

To my patients

*Thanks to all of you and the many more whose simple words and acts of
kindness have kept my spirit alive.*

La Vita e Belle — Life is Beautiful