ALS and PLS Fundamentals – Death or Life?

By Elwin C. Penski, June 2012, updated July 2012

I have no formal training in medicine and do not want to pass myself off as any kind of expert. I am just a victim of PLS who believes his research, experience and thoughts are worth sharing with other sufferers and the medical profession.

At the beginning of 2004, I was playing competitive tennis. In the spring, I started to have a little difficulty with my balance. I thought the problem was solely arthritis and had to quit playing tennis due the pain. After knee replacement, I had problems with bladder retention due to damage from the catheter, painful bladder stones, temporary loss of bladder control, greater loss of balance and more loss of leg strength, and much pain. The doctors started suggesting I had Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's disease) one of the most terrible incurable diseases known. I had the main initial symptoms – muscle weakness in my legs, speech problems, and minor difficulties swallowing.

When I read about ALS online at the U.S. National Library of Medicine, communicated with doctors and to people with ALS; I quickly learned that no significant progress had been made in the last century for curing ALS although I recall that in about 1943 the movie industry collecting money for ALS research.

Primary Lateral Sclerosis (PLS)

The book titled "Amyotrophic Lateral Sclerosis"[1] has only a few sentences on PLS and the encyclopedia like book titled "Fundamental Neuroscience"[2] has nothing on PLS and only a few sentences on ALS. Primary Lateral Sclerosis is a group of rare, degenerative, and supposedly neurological disorders. Many neurologists admitted that they knew little about ALS or PLS and can treat only the symptoms.

PLS is a disease causing rigidity and weakness of muscles, often referred to as a benign or initial variation of ALS because life expectancy is normal for PLS or may deteriorate into ALS. The primary difference between the two is that in PLS, there is no muscle wasting which is the symptom that eventually causes fatal problems in ALS. ALS typically begins in the legs, but can begin with the speech and swallowing muscles. The age of commencement is normally between 35 and 66 years of age, with an average age of 50. I was 68.

Some people and I find the tightness in our muscles worsens occasionally when we are exhausted, irritated or stressed making it more difficult to walk and speak.[3] The most commonly used drugs to help ease stiffness include oral Baclofen and the injection of Baclofen into the sheath surrounding the spinal cord. Also Tizanidine, Diazepam, Clonazepam, and Dantrolene are used for stiffness; as well as many other drugs for treating all kinds of symptoms…

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[1] *Miller, R.G., Gelinas, D., et al, Amyotrophic Lateral Sclerosis, American Academy of Neurology, Demos Medical Publishing, New York, 2005.*
[2] *Squire, L. R., Berg, D., et al, Fundamental Neuroscience, Third Edition, Academic Press, Burlington, MA, 2008.*
[3] *About PLS (Primary Lateral Sclerosis), The Spastic Paraplegia Foundation, http://www.sp-foundation.org/pls.html, Accessed June 14, 2012.*

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My Strategy

The following is a quote from a school teacher that was inflicted with ALS and was referred to write to me. She corresponded with me frequently from April 2010 until September of 2010.

"Hi El, How are you? I'm the same. Very bored and worried all the time what is going to happen to me and my husband. I've been looking at the stages of ALS and I think I'm at the beginning of the final stage. I pray all the time that I pass away. I hope every night that I go. It would be the perfect solution for me and my husband. I can't dress myself, wash myself, have in-grown toenails now again, go to the bathroom by myself, it's horrible. My husband ordered a new frig yesterday. It will come tomorrow. I have irritable bowel syndrome. We've had a lot of company, they breeze in and out, but we need family and friends to help us. I've been giving a lot of my things away. I have a feeling sometimes that I'm not going to last too much longer. I want to walk again and do things for others and the only way I can do that is by death and being a guardian angel. I go from my dining room hospital bed to the living room all day. I haven't been out since June 17. My friend from Binghamton New York came down last week. Please write soon, Love, D____"

She did what her neurologist told her: wheelchair, feeding tube surgery, breathing apparatus, preparing for death, and taking ineffective drugs. She passed away in April 2011.

Once I was well informed about many cases like this, I realized that I had to do my own research, make my own decisions, and construct my own theories. I realized that first I had to follow the fundamental principles for a healthy life that apply to everybody even if it was an extraordinary, seemly impossible, frustrating struggle in 2004. My initial principles were:

1. Get sufficient sleep
2. Do as much exercise as possible with my condition without injury and reject wheel chairs if possible
3. Evade excessive stress and avoid overworked, hostile, depressed, negative, panicky, and untrained people like found in medical facilities
4. Maintain good nutrition without eating unnecessary empty carbohydrates
5. No smoking, no alcohol, and no prescribed drugs unless clearly proved essential. No drugs for ALS have been scientifically proven effective although many are prescribed.
6. Side-step disabling surgery
7. Avoid dependence on electricity, at least, plan for a week breakdown of electricity
8. Avoid disrupting anyone else's life
9. When I catch myself being angry, take a fun break or a short nap
10. Continue with a productive, purposeful, charitable and satisfying life

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Logic Behind My Principles

I have studied the literature on ALS. First I read the book titled "Amyotrophic Lateral Sclerosis[4]" published by the American Academy of Neurology and authored by nine doctors and ALS experts. The book highlights a number of conclusions. A few of the most important are listed below:

"ALS is a treatable disease even though **it is not curable**." The U.S. National Library of Medicine agrees.

"**At the present time, there is no effective medicine available to stop the progression of ALS**." Why take the several drugs which warn of many terrible side effects including "weakness" when "weakness" is probably the main problem with ALS?

"**No one knows why people get this disease.**"

"**ALS is a progressive disease, but its rate of progression is different for every individual**." I have noticed a progression in myself when I was taking doctors' advice on drugs, but since I stopped all drugs for ALS; progression of the disease has at least stopped and reversed a little.

I have often wondered if neurologists are merely observing the self-fulfillment of their own prophesy. My observation is that very weak and frightened people are extremely susceptible to foolish recommendations. Outcomes are often the result of expectations.

The quote as follows was taken from a blog called **"ALS** Chronicle:"[5] The blogger is talking about his very young wife.

"H____ didn't do anything wrong. One day she woke up and couldn't clip her ski boots. That's how it started. 95 out of 100 people that get this disease will never know why they got it. YOU COULD WAKE UP TOMORROW AND NOT BE ABLE TO CLIP YOUR SKI BOOTS, or zip your kids jacket, or turn the keys in your car's ignition on a cold day, or fumble on the last button of your shirt.

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[4] *Miller, R.G., Gelinas, D., et al, Amyotrophic Lateral Sclerosis, American Academy of Neurology, Demos Medical Publishing, New York, 2005.*

[5] *ALS Chronicle, February 25, 2009, http://alschronicle.blogspot.com/2009/02/readers-comment-and-my-response.html, accessed June 13, 2012.*

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"People… in case you didn't know this or figure it out from the post above… there is no cure, there is no treatment, there are no 'survivors' of this disease to run or walk anywhere for a cure. If you are diagnosed with ALS, you have about a 98% chance that you will be dead within 5 years. Most die within 3 years. A few live for 10 or more years. A FEW. If you are one of them, you probably can't move anything but your eyes, are on a ventilator and have practically unlimited financial resources, holding out hope that someone will figure this out before you have to unplug your vent. These are the stark realities of this disease today…February 25, 2009."

Since my circumstances are considerably different, I am trying to be a little bit more cheerful, positive and helpful. I believe there are cures that have not been studied yet or at least more effective treatments. Medicine is a very complex science, and researchers are very busy people who often do not have time to think, rethink, or learn from people who have conquered neurological diseases. I have more time to rethink ALS/PLS, and my condition requires me to think about my problems many times during every day.

Dudley Clendinen was diagnosed in November 2010 with ALS and died in May 2012 at age 67. He was a former reporter and editorial writer for *The New York Times*. Dudley's many interview recordings with Tom Hall can be found on the *Maryland Morning* website.[6] Based on his life experiences, attending John Hopkins University Hospital ALS Clinic, and/or his reading; he teaches about his ALS problems in detail and his ideas on accepting death gracefully. I got the message in 2004 that I was supposed to accept inevitable death gracefully, but I decided to rebel against the ancient wisdom in a gentlemanly manner and fight it, even though I knew it would be a very embarrassing and very difficult struggle.

[6] Dudley Clendinen and Tom Hall in the WYPR studios, Living with Lou: Dudley Clendinen on a Good, Short Life , *Maryland Morning*, February 21, 2011 at 8:00, http://mdmorn.wordpress.com/2011/02/21/221111/.

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Medication Induced Weakness?

One of the most serious effects of ALS is leg muscle weakness. I have read in the U.S. National Library of Medicine that beta blockers, a medicine that I need to take, has a side effect which is weakness. Common side effects of **Baclofen, a drug commonly prescribed for ALS and PLS,** includes **unusual weakness, especially muscle weakness**. The most commonly observed adverse reactions associated with the use of **Rilutek, commonly prescribed for ALS,** more frequently than placebo treated patients include **decreased lung function and weakness**,

Below are some of many drugs listed in the book titled "Amyotrophic Lateral Sclerosis"[7] for treating the symptoms of ALS not the disease. After the commonly used drugs for ALS are lists of possible drug induced side effects.

AMITRIPTYLINE (or trihexyphenidyl) Side Effects: **weakness**, blurred vision; change in sexual desire or ability; constipation; diarrhea; **dizziness**; drowsiness; dry mouth; headache; loss of appetite; nausea; tiredness; trouble sleeping

ATIVAN Side Effects: drowsiness**, dizziness**, tiredness, **weakness,** dry mouth, diarrhea, constipation, nausea, changes in appetite, restlessness or excitement, difficulty urinating, frequent urination, blurred vision, changes in sex drive or ability

BACLOFEN (or diazepam) Side Effects: **muscle weakness**; back pain; constipation; diarrhea; **dizziness**; drowsiness; fatigue; headache; increased salivation; nausea; vomiting.

BOTOX
DITROPAN (or 4-Diethylaminobut-2-ynyl 2-cyclohexyl-2-hydroxy-2-phenylethanoate) Side Effects: dry mouth, difficulty in urination, constipation, blurred vision, drowsiness and **dizziness**.

DEPAKOTE
KLONAPIN
LITHOBID

OXYCODONE (an opioid)
Memory loss, constipation, **fatigue**, **dizziness**, nausea, lightheadedness, headache, dry mouth, anxiety, itching, and heavy sweating. It has also been claimed to cause dimness in vision due to miosis. Some patients have also experienced loss of appetite, nervousness, abdominal pain, diarrhea, urine retention, dyspnea, and hiccups

QUININE
ROBINUL

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[7] *Miller, R.G., Gelinas, D., et al, Amyotrophic Lateral Sclerosis, American Academy of Neurology, Demos Medical Publishing, New York, 2005.*

RILUTEK
Weakness, Nausea, Decreased lung function, Headache, Nasal symptoms, Muscle tightness, Abdominal pain, High blood pressure

TRANSDERM
VALIUM
ZANAFLEX (or Tizanidine)) Side Effects: feeling light-headed, fainting, dizziness, slow heart rate; hallucinations, confusion, unusual thoughts or behavior; nausea, stomach pain, low fever, loss of appetite, dark urine, clay-colored stools, jaundice (yellowing of the skin or eyes); or burning or pain when you urinate

ZOLOFT

Falling?

Probably the first common symptom and most serious initial problem with ALS/PLS is the problem of falling. If you review the side effects of the drugs used for relieving the symptoms of ALS, you will see that **dizziness** is a usual side effect.

A team of experts at the University of Erlangen-Nuremberg reached the following conclusions: "In comparison with other fatal diseases, patients with ALS had similar rankings in the coping mechanism of 'rumination', but lower rankings in 'search for social integration', 'defense of fear', 'search for information and communication.' In contrast, 'search for hold in the religion' was of high importance for our ALS patients. In the follow-up examination the importance of 'search for information and communication' increased."[8]

The above observations are not surprising because an ALS casualty's legs will not move unless he consciously makes each move. Every move that one with ALS makes with his legs has to be intellectually considered to avoid falling. To help get information for myself and others with ALS/PLS impelled me to research and write this document.

The literature says that age of commencement of ALS is normally between 35 and 66 years of age. I have often wondered if after the upper age of 66 the data is in error because older people die before going through the lengthy process of diagnosing the problem as ALS or many older people have similar symptoms.

[8] Hecht M, Hillemacher T, Gräsel E, Tigges S, Winterholler M, Heuss D, Hilz MJ, Neundörfer B., Subjective experience and coping in ALS. Amyotrophic Lateral Sclerosis and Other Motor Neuron Disorders, World Federation Neurology Group on Motor Neuron Diseases, Department of Neurology, Centre of Neuromuscular diseases, University of Erlangen-Nuremberg, Schwabachanlage, 6, D-91054 Erlangen, Germany, 3(4):225-231, 2002.

Is ALS and PLS Really a Neurological Problem?

From about age 10 to my late 50s, I regularly ran and leaped across rock covered jagged mountains, streams, and rivers on the rocks without giving it much thought. Occasionally, I would stop on the far side and look back, and wonder how I did that. My automatic ("autonomic" in medical terminology**)** nervous system did the calculations of angles of the rocks, distances, jump velocities, balance, and jump heights one after another in fractions of a second. I do not recall ever falling or getting my feet wet. My automatic nervous system took good care of my safety without my thinking about it.

Later in life, my left knee started becoming painful with arthritis, and due to the pain, my amount of exercise was reduced. My automatic system had to adjust to a weak left leg. Most my weight shifted automatically to my right leg most of the time. I continued playing tennis until 2004. After knee surgery (Oct. 2004) both legs were considerably weaker, but dependence on my right leg increased. I could walk with a stick, but it was painful.

As far as I can see my automatic system is still trying to keep me from falling in the river, but it only has two weak legs to work with. My legs tighten up in dangerous situations. With the safety of a walker, my legs do not get as stiff. My automatic nervous system is still trying to do its job. Treating this as a neurological problem might be incorrect. It seems to me that weakness is my major problem – *maybe* both muscles and nerves decline from lack of use under misguided medical care.

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A Feeding Tube?

The following is an e-mail from a friend dying quickly with ALS.

From: D____
To: epenski <epenski@aol.com>
Sent: Sat, Jun 5, 2010 10:22 pm
Subject: Re: Hoping You are OK

"Hi El, I went ahead and got the feeding tube, what a mistake! I had to go on morphine in the hospital I was in so much pain. Last night I got home and was up until 4:00 in the morning we extreme pain in my ribs. I had to go in an ambulance to University of ____ to the ER. Anyway, the "bumper," on the tube was too tight, so they had to loosen it. I'm still in a lot of pain. I'm taking pain pill comparable to Percocet. When I was in the hospital they fed me 4 times throughout the night. They woke me up at 4:00 in the morning. The surgeon that put the tube in is one of top doctors, Dr. _____. I was ready to walk out of the hospital several times, I wish I did. I have to say, though, the formula they give you does give you a lot of energy, just the one day. I'm sleeping downstairs now because I can't bend over. I can get the procedure reversed. I told them I wanted it out today and they told me I would have to wait. The hospital was nice; they let R__ sleep in the same room with me. They starved me for 24 hrs before the procedure and from that point on I haven't gone to the bathroom for bowel movement. I hope I go soon because I usually don't have problems that way. I've missed our correspondence. I went to the ER today, just with socks and when I had to go from the wheelchair to the car, they had to get someone from the hospital to pick me up with R___. My husband forgot my brace and shoes. I only had one visitor in the hospital, my old boyfriend, T____. He looks like Andy Garcia and is so sweet. The formula gives me nausea sometimes. The hospital food was very good, so I stuffed myself with that food and did the formula. They cut my mouth with that endoscope. I was in and out of the operating room and recovery for about 2 hrs. My driver watched our cats on the spur of the moment. I wished I had listened to my inner-self and not got this tube. Anyway, I told them I didn't think I was ready to leave yesterday. Keep your fingers crossed nothing else goes wrong. Miss you! Write soon. L, D____ "

An article titled, Expectations and Outcomes of Gastric Feeding Tubes,[9] states, "*At 3 months, . . . 27% had the feeding tube removed. Patients were impaired in most activities of daily living (ADLs) with little change over time. Medical complications were common: 25% of patients had decubitus ulcers at 3 months, and 24% had at least one episode of pneumonia. . . . Providers and families need better information about the outcomes of this common procedure.*"

[9] *Carey, T.S., Hanson, L., et al, Expectations and Outcomes of Gastric Feeding Tubes, Abstract, The American Journal of Medicine, Volume 119, Issue 6 , Pages 527.e11-527.e16, June 2006.*

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Does Technology Help?

Dr. Elaine Smokewood taught her last year and a half at Oklahoma City University (OKCU) using web cam technology from her home in Augusta, as her voice and mobility were stolen by her ALS. In 2010, she was honored as the Teacher of the Year at OKCU.

"Hi D____, I thought I should pass along this message from Elaine Smokewood, Professor of the Year at her University. Unfortunately, you cannot go to her ALS Clinic, but you might look for another one. El"

_____

Sent: Wed, Jul 28, 2010 3:49 pm
Subject: RE: ALS

"*Hello, El. I am happy to hear from you. I am very glad to know that you are doing so well. I don't know about advice, but I can tell you a little about how I have coped. I am lucky to have access to a wonderful ALS clinic with a wise compassionate neurologist and his team. They have been excellent at seeing I have access to necessary adaptive equipment that improves my quality of life and keeps me as functional as possible as the disease progresses. I have also been lucky to work for a great university which has supported me in remarkable ways. I have sought out alternative medicine practitioners--acupuncturists, healing touch therapists, and others--I think they have helped me sustain my energy. I have relied on my family for emotional and practical support, and turned to psychological counselors to help me come to terms with the huge and sometimes frightening changes in my life. Most importantly, I have sought spiritual direction from gifted, compassionate spiritual guides. This experience offers an amazing opportunity for spiritual growth, one that should be taken advantage of! As you can see, I have turned to a wide variety of resources to ask for help. I used to be someone who was proudly self-sufficient, never asking anyone for help. Now it seems that all I do is ask for help, all the livelong day. No doubt an important lesson for me. I wish you strength as you cope with the challenges you are facing. All my best, Elaine.*"

Dr. Elaine Smokewood died on January 11, 2011 at her home, surrounded by her family. She was born in 1955 and died three and a half years after her diagnosis with ALS.

There all kinds on new creative technology available: electric wheel chairs, lifts, electric chairs that stand one up, sensors to implant in the brain, amplifiers, and many more,[10] but **one should consider the consequences of power outages and have concern whether such devices accelerate weakness.**

[10] Muscular Dystrophy Association – USA, Tucson, Arizona

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Weakness from Space Travel is Similar to ALS/PLS

Astronauts can move around in spacecraft with little muscle use. In a zero gravity environment, muscles rapidly weaken drastically due to the lack of use just as one gets from using a wheel chair or bed. Some astronauts have great difficulty standing and walking on return from space.

"Rehabilitating U.S. crew members to preflight status following flights on the Russian Mir Space Station required longer than six months for full functional recovery of some of the . . . crew members."[11]

The following is from "Science Clarified, Space-Stations, Space-Medicine"[12]

"In a weightless environment, muscles, like bones, atrophy from lack of use. Within the orbiting space stations, astronauts are able to move around by softly pushing against walls with a finger or toe and are able to move large loads without breaking a sweat. In 1982 Soviet cosmonauts returned from a 211-day mission on Salyut in obviously debilitated conditions. According to W. David Compton and Charles D. Benson in their book Living and Working in Space: A History of Skylab , 'Although they had exercised daily, their muscles were so flabby that they were barely able to walk for a week, and for several weeks afterwards required intensive rehabilitation.'

"Human muscle is of three types: smooth, cardiac, and skeletal. It is the effects of weightlessness on skeletal muscles, those that make movement of the whole body possible, that most concern space medicine specialists.

"The bulk of skeletal muscles affected by gravity are located in the lower body. These are constantly under stress in order to keep the body upright. Other muscles also work against gravity—for example, those in the upper arms, shoulders, and back that are used for lifting and moving objects. These muscles, while used constantly on Earth, are hardly used in orbit, where even heavy objects float. When these muscles are not used, they atrophy. ***Muscle atrophy of 5 to 10 percent can occur by just eight days into a flight****. Although muscle atrophy does eventually taper off over time, by the time astronauts have fully adapted to weightlessness, a large portion of muscle mass has been lost."*

[11] Chauvin, B. A.S. Shepherd, M. E. Guilliams, T Taddeo, Rehabilitation after International Space Station Flights, Wyle Laboratories and NASA-Johnson Space Center, Houston, Texas.

[12] Science Clarified, Space-Stations, Space-Medicine, http://www.scienceclarified.com/scitech/Space-Stations/Space-Medicine.html, accessed 6/14/2012.

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*"Experience has shown that all those returning to Earth following extended stays in space have difficulty standing or maintaining their posture. Astronauts also have coordination and walking problems until they are able to retrain their muscles to work against gravity. American astronaut John Blaha, who served on Mir, told fellow astronaut and author Jerry M. Linenger that when he returned from space, he had to be carried off the shuttle on a stretcher. Blaha went on to say that his muscles were so weak that '**there was no way I could move. I felt like I weighed a thousand pounds. I could not even lift my arm, let alone stand up and walk. No way**.'"*

A conclusions reached by the University of Saskatchewan on exercise effects on ALS were that "The only studies detected were too small to determine to what extent strengthening exercises for people with ALS are beneficial, or whether exercise is harmful. . . . More research is needed."[13]

I have found that exercise is very helpful for PLS if one stays below the level of fatigue where one's muscles start temperately tightening up. Thus, the ALS patient has to be in charge of his exercise routine. Studies have shown that immobility has a negative effect on nerves and psychology.[14]

Expectations often determine outcomes. It is expected that astronauts will return to good health, but it is expected that ALS sufferers will die quickly.

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[13] Dalbello-Haas V, Florence JM, Krivickas LS., Therapeutic exercise for people with amyotrophic lateral sclerosis or motor neuron disease, Cochrane Database Systematic Reviews, University of Saskatchewan, School of Physical Therapy, Saskatoon, Saskatchewan, Canada, (2):CD005229, 2008.

[14] Montague, S.E. et al, Physiology for Nursing Practice. Amsterdam: Elsevier, 2005.
Niven, N., The Psychology of Nursing Care. Basingstoke: Palgrave Macmillan, 2006.

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How the Patient Weakness Increases

After an operation, the nurses take away your cane and substitute a wheelchair.

Medical personnel encourage you to use a wheelchair or a motorized cart.

Physical therapists throw you out of treatment if you improve too much or not enough.

Over reaction of family, friends and strangers that are connected to the medical industry is common. They insist that they help when it is not required and after you even say "No."

As soon as you can walk a few feet after an operation, they ship you out.

They insist you go to a rehabilitation hospital where:

1. there is little or no rehabilitation,
2. they insist you use a wheel chair instead of a walker,
3. they insist you call for help when you need to go to the bathroom but frequently never show up when you call
4. wake you up all hours of the night
5. give you very small quantities of nutritious food or no nutritious food
6. give you all kinds of useless drugs whether you want them or not

I have a hard time believing that advancement from PLS to ALS and on to premature death is not partially assisted with excessive use of drugs, poor institutional and home nutrition, and lack of exercise of victims. Stephen Hawking, diagnosed with ALS, has pointed out if you have slurred speech; people automatically assume you are stupid. Also, I have observed that some people also just assume you are deaf, drunk, had a stroke, or **that it is OK to bully you.**

On July 12, 2012, before noon I drank a little water and went to bathroom then I drove to my dentist. After treatment by the dentist and while reaching for my car door handle, due the slope of the ground, my walker fell over, and I fell backwards. I was not hurt. Immediately I knew I had to get off the hot asphalt, but I spent about a half hour lying on hot asphalt in the sun being held down by ill trained medical workers. I finally persuaded them to let me up, help me stand up and get me off the hot asphalt. Then they blocked my every move to get out of the hot midday sun before forcing me into an ambulance. Then I spent an hour strapped down in a parked ambulance blocking traffic, and 6 hours in the Emergency room without seeing a doctor or having any treatment. I was without drinking water and not allowed to use a bathroom until about 9 PM. So I had no water or access to the bathroom for about nine hours. All the while, I was surrounded by many over-reacting medical people who ignored any reasonable request that I made. When I was finally allowed to stand, they pulled and pushed on me without regard of safety or regard to my appeals or my son's requests to let me go.

Anyway, while it was an amusingly stupid, painful, and unbelievably cruel event for me, it might have been lethal for some other elderly people. Nonetheless, I was surprised that I survived and escaped unharmed from a nightmarish situation. I felt great as soon I was free to walk around. I fear that many others have gone through that sort of cruelty. As I write this, I realize I was in the hands of many emergency workers who had no training in handling old, disabled and weak people or how to let them get their balance. The following quote[15] illustrates the outcomes of such thoughtless actions.

"*Creating a learning-oriented culture within hospitals and carried out by charge nurses and leaders at the point of care is a key to patient safety.*

"People go to hospitals to be treated for an illness or for corrective surgery with the expectation they will return home in much better health than when they entered the medical facility.

The reality, though, is that many may never recover or return home. A 2009 study by Hearst newspapers estimated ***the death toll from preventable medical mistakes is nearly 200,000 annually in the United States***."

[15] Boutelle, Clif, Preventable Hospital Deaths Can Be Reduced by Encouraging Error Reporting, Society for Industrial and Organizational Psychology, Inc., Public Relations, 2012.

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A List of Hopeful Developments

- In 2011 Northwestern University Feinberg School of Medicine study claims to have identified a common cause of all forms of ALS.[16] This study provides a common target for drug therapy and shows that all types of ALS are driving into a common river of cellular errors. "This opens up a whole new field for finding an effective treatment for ALS," said senior investigator Teepu Siddique, M.D. "We can now test for drugs that would regulate this protein pathway or optimize it, so it functions as it should in a normal state."
- Eric Edney was warned in 1995 that he had about six months to live. He truly demonstrated that the doctors were wrong. He is still alive. While I got some good guidance several years ago from Eric, I have followed a more challenging and less complex path. Eric has authored two helpful and inspiring books: Eric Edney, Eric Is Winning!!: Beating a Terminal Illness with Nutrition, Avoiding Toxins and Common Sense, Xlibris Corp., Bloomington, IN, 2008, and Eric & Glenna Edney, Surviving Without Your MD, Do Prescription Drugs Ever Cure? Xlibris Corp., Bloomington, IN, 2009.
- There are many scientifically unverified claims on the internet that coconut oil has helped improve people's ALS symptoms. While I am taking coconut oil every day since early 2012, one person cannot verify any medical treatment, but it is a hopefully a sign of that progress may be possible.
- "*Preliminary data reported Jan. 17, 2012, by BrainStorm Cell Therapeutics demonstrate that the biotechnology company's experimental NurOwn stem cell technology has not caused any significant adverse side effects in a phase 1-2 clinical trial in ALS. In addition, clinical follow-up of trial participants indicates that the treatment appears to have improved breathing, swallowing and muscle strength.*"[17]
- More is being discovered about nutrition every day. For more information see http://elsresearchstudies.com/nutrition.htm
- Stephen Hawking was born in 1942 during WWII in England while England was being bombed by the Germans. He was diagnosed with ALS in 1963 and was given 3 years to live, but kept struggling and maintained his positive attitude. He is still alive in 2012, age 70. Hawking is the one the most honored scientists in history and is currently often described as the most brilliant scientist in the world.
- It is very clear that ALS, PLS, and many other health problems are just partially the subconscious that needs a little adjustment. If these problems were better understood, they might be quickly solved by retraining the subconscious without resorting to the harmful use of drugs.
- I am alive, happy, and fairly healthy for a man near 80 because my expectations have always been positive.

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[16] Marla Paul, Major ALS Breakthrough, Researchers discover common cause of all forms of ALS, Northwestern University NewsCenter, Research, Evanston, IL, August 22, 2011, http://www.northwestern.edu/newscenter/stories/2011/08/siddique-als-breakthrough.html

[17] Amy Labbe, Indications of Safety, Efficacy in BrainStorm Stem Cell Trial,MDA/ASLS News Magazine, Jan. 23, 2012, http://alsn.mda.org/news/safety-efficacy-in-brainstorm-stem-cell-trial

Making My Home PLS Friendly

I was having trouble getting out of my bath tub after taking a shower. My plumber consulted me on putting a walk-in shower in place of my bathtub and did not give me a quote, but he told me he would have to tear up the whole bathroom: plumbing, wall tile, sink, and floor tile. That would have been very expensive.

Thereafter, I decided it would be more convenient to cut out part of the bathtub. A large number of people and home repair workers told me that was a crazy idea, but when it was finally done by Thomas Graul and Sheila Richards, it turned out to be a satisfactory and inexpensive solution to the problem.

I have a number of small handles in my home where I have a stair or two or an obstacle to step over. This is shown in the following photograph. My showering soap and shampoo are in convenient dispensers.

I have three Winnie Walkers (Drive Lite Supreme). One is in my automobile; one is in my basement, and one I use constantly. The advantages are that they fold for tight spaces, light in weight for going up and down a few stairs, have big wheels for rough surfaces and brakes and brake locks for going downhill.

I have difficulty with telephones, but I feel I have a responsibility to communicate with victims of ALS and PLS by email at ElsResearch@aol.com. Emails are welcomed.

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