

INTRODUCTION

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On a dark and stormy night in the year 2000, my world changed forever.

Taking what for me is a rare reality break, I am forced to admit that it was a perfectly glorious early summer morning in Northern California, so it wasn't exactly dark, stormy, or night. However, I have always wanted to start a story that way. 'Humor' aside, the sad reality is that my world did indeed change forever on May 30, 2000. Sadder, not a single aspect of that change could ever be considered good in any way, shape, or form. Sadder still is my inability to reverse enough of the changes to restore anything more than a pale image of my previous life. It is my own personal dividing line, my knife's edge. Many things are AS, but few good things are. Most of the good stuff is BS, and in this case, the 'S' stands for 'stroke'.

As I looked up from dressing for work that Tuesday after the long Memorial Day weekend, 5:30AM stared back from the digital clock on top of my armoire. Before I could look away, I felt something strange happen in my head, a weird squirting sensation. I tried to shake it off but my entire right side went slack within a minute and I fell to the bed. As I lay there, several thoughts ran through what was left of my brain. Obviously, it was a stroke and I suspected that medical attention would be kinda nice kinda soon, as in really kinda nice and really kinda soon.

After what felt like an instant later, it dawned on me that the nearest phone was over twenty feet away in another room. It seemed that it might have been on the surface of the moon for all the good it could do me. I am a solitary man most of the time and lived alone, so it probably would be at least a few days before anyone would find me, or more precisely: my remains. I only hoped it would be something other than a vile odor that brought a neighbor or friend. As my eyes closed about a minute after I fell, I was convinced that it would prove to be for the last time.

I was very nearly right.

This was written more than a decade after I started to wake from what became a month-long coma. I was an infant who could not walk, talk, sit up, or feed himself. I wasn't even potty trained! At 51!!!!!!!!!!!! I was little more than a year old when I became toilet trained during my first infancy. In fact, I could do all those things by that age. To have called me "somewhat precocious" would have been an understatement of epic proportions.

Eleven years after The Event, I live alone in my own house and make all my own meals. I do the housekeeping, yard maintenance, and general home repairs. Several times each year, I visit my babies (women aged 41 and 38) 1,500 miles away, go on one or two terrific cruises every year, and seem to find some excuse to take other long distance trips at least twice a year. I stagger around leaning on a cane—sometimes without even using that—after spending a full year confined to a wheelchair. Besides all that, I can tie my own shoes just like a big boy. That and the fact that I wear big boy underpants—most of the time anyway—are proof that I am all growed up, or near enough for government work.

What follows is a nearly random collection of wonderful suggestions, major discoveries, brilliant insights, and self-indulgent moralizing. Truth be told, a few of my modest claims have been called insufferably arrogant; of course, only by the truly misguided. I put that down to simple jealousy on their parts. For your sanity's sake, I hope that I am not the most humble man you will ever meet. In this piece, I have tried my best to offend everyone, but please get back to me if you feel left out. After generally ridiculing your feeble efforts to criticize this masterpiece, in the unlikely event that have a point, I promise to work hard to rectify any such omission in future editions.

Fair warning: if you came here looking for gentle encouragement and careful attention to political correctness, you have come to the wrong place. Here you will be preached to and here you will find blunt language. If either would offend you, there is a simple solution: Stop reading.

I am a winner and find it impossible to resist trying to pull everyone along with me. If pulling doesn't work, whip-and-chair methods and the use of cattle prods are not entirely off the table. I prefer clear and simple terms of self-description over warm and fuzzy ones chosen simply to be politically correct. Others are free to call themselves 'mobility challenged individuals'. In fact, I find myself routinely defending their right to do so.

On the other hand (How can you tell that I am an economist?), I choose to call myself a cripple. I agree with political correctness activists who say that my physical limitations do not define me, but that one word sure describes the way I 'walk' clearly and succinctly.

Speaking of political correctness, some will object to my calling myself a victim. Victim has become a highly-charged and pejorative term these days. I had a stroke. Therefore, I am a victim of stroke, also known as a stroke victim. Unlike many stroke victims—especially the vast majority of poor souls who have ones of the hemorrhagic variety as I did—I survived. Much of the credit for that goes to medical professionals who worked their miracles.

All the rest goes to dumb luck: I was born with a body that heals itself wonderfully. I received the gift of survival. (Some misguided souls would change that to 'undeserved gift', but what do they know?) It had little or nothing to do with my own efforts. That said, I did my part and have prospered since. Even there, my body—with its amazing powers of healing itself—gets the lion's share of the credit.

Therefore, I will freely call myself a stroke victim, and only a stroke survivor to distinguish me from the many victims who do not survive. I have found no word or simple phrase that would clearly and succinctly distinguish me from survivors who do not prosper, especially from those survivors who could have, but did not due to a lack of effort.

The second last caveat is to note that the next course that I take in med school will be my first. The last comes when you remind yourself that advice is seldom worth more than you pay for it. Other than covering my o so ample butt, those are meant to get you to pause before accepting anything you read here. What follows is drawn from one man's experiences perceived through the filters of his own biases, a woeful dearth of training in medicine, and some serious dain bramage.

If you have even the least doubt about the effects—for good or for ill—of any suggestion, consult one or more experts first. By experts, I mean formally trained and externally credentialed ones, for example neurologists for all nerve damage issues, or real MDs for dietary ones. I exclude self-appointed 'experts' in TCM (traditional Chinese Medicine) or other faith healing gobbledygook. More than just trying to reduce my legal exposure, I say this because my intention in writing this thing was to make it easier for others to recover. It is less a case of: "Bruce say. You do." and more of: "Bruce say. You think. You research. You do what works for you."

Hopefully, this has appeased the bottom feeders and they will let me get on with it.

An aside about TCM: I would be more accepting of this particular form of faith healing if someone could explain the huge increase in life expectancy (let alone quality of life) that followed Chinese adoption of Western medicine halfway through the 20<sup>th</sup> Century. This happened long before the Chinese ever became able to feed themselves. It sounds like Viagra works better than powdered Rhino horns.

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#### GENERAL STUFF

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The simple act of waking each day can be a miracle in its own right. Please do your best to treat it as the magical event, the pure exquisite joy, it truly can be. At that point every morning, try to remind yourself that waking means it has already become a very good day. I assume that it will be pretty hard to have a good day when I stop the silly nonsense we call breathing. Job one each day is to wake. The rest is mere detail.

Many say those words, including myself BS, as in 'before stroke' (and not my initials... thanks Mom and Dad). I came so close to the obvious alternative that those words finally came to mean something real to me. Funny that all it took was a crippling stroke to knock some sense into me. Some folks persist in calling me stubborn. Where do they get that?

By the by, speaking about becoming rational, I put out the last cigarette that I will ever consume about twenty minutes before The Event. I keep telling my smoking friends that I found an easy method of quitting smoking.

#### Bruce's Surefire and 'Easy' Way to Quit Smoking

- o Have a crippling stroke,
- o Go into a month-long coma,
- o Stay in the hospital for another two months, and
- o Ta da: you're done!

It is exceedingly strange, but nobody has taken me up on this, even when I remind them that they will sleep through the worst of the withdrawal urges and that my method let me give up a 37-year evil habit the 'easy' way. So, doesn't anyone want to follow my lead? Wimps, all of you!

Keep your sense of ha ha or develop one. Fake it if you have to. It helped to keep things in perspective by making fun of others and myself while I went through my own nightmare. I am the most ridiculous person in the world, except for everyone else, and—as will be obvious as you read further—I am an equal opportunity abuser of all races, both genders, and the disabled or not. OK, especially the not.

There is no alternative to a lifetime of always hard, often lonely, and forever mindlessly painful work to restore only part of what you had before. That's a lie. There is an alternative, but I do not give good curl up and die, not good at all. However, before anyone else can say it, I am fully qualified for mindless tasks. It's a gift.

Be strong or, at least, act as if you are. At the time, someone called me "an arrogant and stubborn son of a female dog", occasionally substituting "illegitimate male offspring" for "son of a female dog". She used more colorful words meaning 'female dog' and 'illegitimate male offspring', but you get the picture. She was offended by my response: "Thank you." I thought she was complimenting me.

I have come back a long, long way. If you are lucky enough to have a body that heals itself even half as quickly and thoroughly as mine did, you may be able to do much the same, but you not only gotta wanna, but also you gotta work at it tirelessly. It would probably help if your attitude proves to be even half as bad as mine was and, as you can no doubt guess, that attitude has not improved one single bit.

You have lost no real friends and no truly close relatives. Some people you had considered friends, even some you considered to be particularly close ones, will turn out to have been little more than acquaintances. Some seemingly close relatives will turn out to have been much more distant than you had thought. I encourage you to do what I did and not focus on those fair weather friends. Find some new ones, but don't forget that you have whole new groups of potential victims at future social gatherings. If you're bored, spend more than a little time with those relatives or hitherto friends who are most uncomfortable with you. Some people are so ignorant that they will act as if they 'think' that strokes are contagious.

When you feel like complaining about how badly life has treated you, think of the many who have been treated worse. At the extreme, are you as badly off as other stroke victims whose only jobs these days are to keep taking their permanent dirt naps? You are just as much a victim as they were, but there is a huge difference: you survived. Will you prosper? No one can tell, but there is one sure way to restore almost nothing: stop working at it. Your improvement may cease someday all on its own, but will screech to a halt soon after you stop trying. Very soon, as in immediately.

We all see poor souls with dread diseases relegated to wheelchairs from which they have little or no chance of ever leaving on two feet. When seeing them, I silently remind myself that my condition is potentially regenerative, not inevitably degenerative. They got rougher deals than I ever did. With barely a twinge of guilt, I feel better about my life. Is that cruel? Yes. Is that simply human? Yes. Does that work? Oh yeah, still does for me.

Being down from time to time is an extremely healthy reaction to the changes you have been going through. In fact, it may be the only rational response. You have gone through some really big changes, and I bet you can't come up with even one that you wouldn't trade away to get back to your old life. Down for a day or two? Healthy. More than a week? Get help and none of that macho stuff guys, and more than a few of you gals. While quiche is still strictly off limits, real men and real women seek help when needed. I did and still do, from time to time.

Set achievable but challenging goals. I can remember lying in my hospital bed barely a week after I woke from my coma. My daughter was telling me that she had become engaged and was planning to marry the following summer. Before I had taken a single step—in fact, before I had even sat up for the first time—I looked up at her and told her that I was going to walk her down the aisle. She smiled what has become her "riiiight Dad" smile, especially as she knew what the prognoses for me were.

What was my expected fate? Even more dire earlier ones had been improved all the way to: "He will remain in a semi-vegetative state for up to a year or two before he dies". A good indication of my mental state at the time was that I could be occupied for hours simply looking at the pictures in *The Big Book of African Animals*.

I leave to you the not very difficult task of guessing whether I made good that promise I made to my baby. What works for me is turning my hopes into promises made to those I never want to disappoint. That has worked for me, but doesn't even hint at what will work for you. My hope is that you can find some way to keep challenging yourself to improve.

The what, how, why, when, and how much of the rehab process seem so obvious to me, but bear restating. The 'what' is improvement. The 'how' is your choice. The 'why' must be obvious. The 'when' and 'how much' limits are defined by your body's powers of healing itself. Where your results fall in the range of possible improvement is totally up to you, meaning that your results will depend primarily on your own efforts. No matter how enticing the thought, I cannot blame others for my failings, especially for not improving when I can.

Unless you are unique, you will face a key question: "Why me?" My answer has been: "Because it was. Deal with it." It's up to you to come up with an answer that works for you. There is no rush, but until you come up with one, expect to keep facing this question and remember that it is fertile ground for down moods or even clinical depression.

Do your best to not treat your caregivers as shabbily as I did. You probably would never guess, but on my best days, I am still described as being something of a curmudgeon. All right, I am still pretty ornery at the best of times. The first year after the stroke, wasn't the best of times, to say the least. I could only hope to improve to the curmudgeon level. I managed to make my paid attendants' lives simply miserable. I was down. They worked for me and paid the price for that privilege.

All but one caregiver were nicer, so I was shockingly mean to them. I repaid their unrelenting kindness and support with surliness, their cheerfulness with anger.

No one knows your body and what is happening to it better than you, but puleeeese don't make others guess. Tell them in advance what you're going to do and why, so they have an opportunity to object before the fact. Do your best to remember that almost everyone will really try to help. You are responsible to tell them when their attempts intrude on your path to recovery or even put you at risk.

My favorite example of this last thought is what can happen when I am pushing open a spring-loaded door. Some people will reach around me to 'help' by pushing it 'for' me without warning. With the pressure released suddenly, I usually stumble and have even fallen.

When that used to happen, I went to one of two extremes: I would either bark at the offending person or shut up completely. Later, I became better at expressing my dismay. Phrases like; "I wish you had asked before you pushed. I wasn't expecting it and almost fell." come to what passes for my mind these days.

Pick your doctors with care. My selection criteria are just that: mine. Since that by itself should make them perfect for everyone else, here they are:

Primary care physicians can be the most difficult to find. Two dirty little secrets of the Canadian health care system are that family doctors are very hard to find and they are ironclad gatekeepers of access to specialists, even more than their brethren in HMOs here in the States. Here, primary care physicians seem plentiful, but good ones can be just as hard to find as finding any in the Great White North.

In my never humble opinion, what makes a family doctor a good one? Obviously, they need to be medically competent, but good communication skills are at least as important. You will probably need frequent check-ups, so effective communication skills take on a whole new importance.

By the way, Medicare pays for my annual physicals and quarterly checkups including full blood tests, while their publications state clearly that they won't cover either. It helps to be a major sickie. Americans, I thank each and every one of you for all those Medicare premiums and special thanks go out to Californians for buying me supplementary health insurance of a quality about which mere mortals can only dream.

You will probably need to see a neurologist and maybe even a neurosurgeon on a regular basis. You have gone to a whole new level of financial burden on your health plan. For these hyper specialists, I want somebody with the ink literally drying on their diplomas.

My current neurologist received his specialist designation late in 2003. I first saw him barely a year later. Why so new? Three reasons: First, his training was fresher (half of all medical training becomes obsolete in five years or less, and I have it on good authority that it is even faster for the neurosciences). Second, he didn't have time to develop much of the God Complex that infects many physicians but almost every specialist (according to my current neurologist, his peers could be the worst group for this). Third, he was very trainable.

In Sacramento, my neurologist was a foreign-born Arab fresh out of training whom I started seeing soon after 9-11, so I found it very easy to make appointments, if you know what I mean. Competence trumps bias every day with me, and it didn't hurt that he was a nice guy with impressive recent credentials and a real desire to serve his patients. Ergo, he was trainable.

For a physiatrist (physical medicine and rehab specialist) my requirements were much the same as for neurologists. The smell of ink drying on diplomas was a welcome one when I first visited their offices. Rehabilitative medicine has gone through vast changes, many of them in the decade since my stroke. An absolute acid test was whether they saw any time limits to improvement. Limits? Find another.

By the way, a great example of how to get me to smile came when my current physiatrist was administering Botox shots about five years ago. He was doing that to reduce spasticity. Throughout this complex procedure, he constantly checked an assortment of texts and manuals. During a break, I asked him what he was doing with the books. I grinned at his answer, which had to do with it being his first time and he wanted to get it right. I grinned because I realized that I had come to the right place. He felt comfortable showing me his feet of clay. Also, by working from textbooks and the equipment owner's manual, he was more likely to get it right.

Physical, occupational, and speech therapists need one additional qualification. While they must have recent high quality training to hope to be selected for the much sought after position of Bruce's Therapist, it is vital for them to love causing pain. For therapists of all kinds, sadism is an essential quality. Call me a masochist if you must—and you should—but you can't argue with the results.

However, psychiatrists and psychologists are a different story altogether. After technical competence, trust is the most important qualification for choosing a mental health professional and it is hard to define exactly what makes it develop. If you can afford it, do not be at all shy about interviewing several. Obviously, I consider the first visit to any given doctor to be a job interview. Their's. I am considering them for the exalted position as my physician. You may need to pay for interviewing second and third applicants, but try to afford it. While psychologists don't have prescription pads in their desks like psychiatrists do, good ones have links to a tame MD or two.

Try to overcome any inherent bias against shrinks or happy pills, aka anti depressives. I have brain damage. Is it reasonable to expect that my mind remains unaffected when the organ upon which it depends was severely damaged? In other words, how many brain damaged people do you know who are perfectly sane? Ok, no less sane than mere mortals?

Your needs will probably include other specialists and surgeons, and I encourage you to apply some form of the above. One gift of my stroke was to gain an entirely new level of knowledge about medical specializations. I would prefer to have stayed my earlier state of blissful ignorance of the existence of the various flavors of neurosurgeons, if you know what I mean. It's probably overstating things but, for the first five years after, it seemed that I had more medical appointments in a typical month than the total for any ten-year period before my stroke. Many, many more if you include therapy sessions.

Keep a diary of major events and bring it, or a summary, to each visit to a doctor. My memory, or lack thereof, makes this essential for me. Before keeping notes, the only record I had of falls were unexplained bruises on my face, arms, torso, and shins, or lumps on my skull. For falls or seizures, I learned to record dates, times, and circumstances soon after the fact.

I have trained my internist to expect a summary, and I have even trained my neurologist to write his instructions to me and hand them over during visits. Each visit begins with my handing over a written summary. It has always been hard to find good doctors. My solution has been to find promising newcomers and train them. I have found it best to start the training when they are still fresh out of school, meaning before bad habits can set in. I am so very shy. Humble too.

Try to remember that you are the boss. Your doctors work for you and their continuing employment is at your pleasure. Just who has title to whose body? They have been trained—taking my advice, well trained at that—which makes their advice valuable, but it isn't reasonable for them to expect blind obedience to their orders, no matter how little medical training you have. If you let 'em, most doctors will steamroller you, or at least they'll try. Just like you do with car mechanics, treat the advice of medical experts as just that: advice. If you are like me, you don't know anything about car repair and your car is replaceable. I still make all decisions about my car. It does not seem reasonable to give up control of repair decisions for my gem of an irreplaceable body.

By the way, Hollywood types have been very successful at warping public perceptions of comas. They have done their best to convince us that comatose patients are all fully aware of events in the room around them and they show people waking from long comas with cheerful smiles; bright and alert. I have no memories of anything that went on until I woke, and only fragmentary ones of the ensuing several months. From accounts of others, my face showed expressions of agonizing pain during my coma. I deem it a blessing to have no memories from that time.

Hollywood produces dramas and comedies, which are not to be confused with reality. That isn't a criticism of Hollywood, far from it. I enjoy their products, even those pieces of fiction mislabeled as being 'based on real events'.

Following a typical comatose patient through month after month of gradual waking and perpetual anger wouldn't sell many theatre tickets or boxes of popcorn, any more than following him for weeks and weeks in a coma, then usually dying without waking. It wouldn't get any better if they were to add toilet training of adults. The limits to potty humor are not very broad.

What follows is a short piece that led, through many versions over seven or eight years, to the current document. Though it was no more than three years AS when I wrote this, you can see how little my sense of 'humor' has changed.

Twelve gifts of my stroke:

- 1) An understanding of the exquisite joy that comes from waking up each day, and finally learning how just little I deserve that.
- 2) Knowledge of the names and target body parts of medical specialists. For example, without the gift of a stroke, I never would have known what an interventional vascular neurosurgeon was.
- 3) Knowing that all strokes are not caused by the same thing: ischemia versus hemorrhage.
- 4) Being able to spell ischemia and hemorrhage.
- 5) Being able to pronounce ischemia and hemorrhage.
- 6) An appreciation of the joy that can come from the first voluntary movement of a middle finger. However little that movement is, it is a fundamental requirement to being able to give the old one-finger salute.
- 7) A full appreciation of just how primitive medicine is.
- 8) A full appreciation of just how far medicine has come in the last century, decade, and even year. For example, the world would have been spared reading stuff like this without emergency room techniques learned in the decade before my stroke.
- 9) An understanding of just how insidiously malpractice insurance premiums can affect the actions of most physicians. For example, how much they minimize their patients' chances for survival to make it seem a miracle when they do. For example, their gloomy prognoses of the extent of possible recovery. For example, their use of the term 'window of opportunity for recovery' to reduce ongoing expectations.

- 10) A true understanding of just how cruel those can be in terms of affecting the decisions of loved ones of comatose patients and contributing to depression in those patients when they emerge from their comas.
- 11) A real appreciation of the limits to grinding away at rehab. For example, without my body's miraculous power to heal itself, all of my efforts would have been in vain.
- 12) Finally, a better understanding of the term, 'the gift the keeps on giving'. For me, that came from the epilepsy arising from my stroke and the persistence—so far—of some crippling effects.

Oh yeah, an unexpected lucky number 13: Learning to think in terms like 'so far' to account for tiny miracles arising from the long and aching slow process of recovery, and being able to sense those tiny miracles.

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*AFTER YOU GET YOUR PAROLE FROM THE HOSPITAL*

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With any luck, you will get to go home, so it's worth spending a bit of time about that.

It was wildly exciting being carried in my wheelchair up the steps into my little old house in Midtown Sacramento. At the same time, it was one of the scariest events of my miserable existence. It had been three months since I had been home and, quite frankly, I was scared.

One source of my fear was the 24/7 attendant that I had hired, but it took me less than a week to do something about him. He scared me. He was big and gruff. I am small and weak, but obnoxious. I fired him four days later and replaced him with a delightful young lady.

In other words, arriving home was something less than ideal for me. I hope yours goes better, but I outlined one of my experiences to tell you that you need to be able to cope, regardless.

Hopefully, you have a partner, offspring, other close relative, or really good friend who can stay with you for at least a month. The important thing is for them to be willing to let you try to do things for yourself. It won't be easy for them, especially if they love you, but you'll need to convince them of how important it is for them to do just that, to watch you struggle and fail repeatedly.

It would help if you could get your caregiver to take a look at your environment before your return. Have them review the width of doorways, footing traps such as throw rugs, access issues such as the need for ramps or grab bars (or even lifts), and the like.

Do your best to make as few changes as possible, and make as many of those changes as temporary as possible. I know of long-term wheelchair users who continue use temporary wheelchair ramps years after their strokes. Hope springs eternal. When I asked one what she was doing with temporary ramps, five years after the fact, I got what I consider the only good answer: "So, WHEN I get to put the wheelchair away, I can get back to some semblance of my life before."

Any upper stories are probably best left out of bounds for at least a few weeks. When you get more mobile, it will be fun to move back into your real bedroom, but—in the interim—a dining room or family room can act as a reasonable substitute.

Set up a schedule of time off for your caregiver. That will take some of the pressure off for both of you. It won't be easy for them. Hopefully, they care about you, but you want them to care enough to stand back and let you fail. Then ask before they rush in and take care of you. That's asking a lot of a loved one. Breaks will help both of you. Need continuous care? Arrange this with other friends, set up things with a professional caregiver if you can afford it, or seek out volunteer services otherwise. The mutual benefits of the occasional four- or eight-hour break probably will surprise you.

Get some adaptive equipment before you even return home. Go online and search on "handicapped tools" or "adaptive equipment" and the like. The results will show you just how broad the selection is. Don't wait until your return to order the basics. It usually takes a week or more to get things. However, don't buy anything more than the basics for now, but ramps to get past steps and grab bars in your shower should be priorities. For the rest, I recommend that you wait to get home and see how it goes.

Do all formal exercises given to you by your therapists, and do so faithfully. Of course, I did them at least twice a day when told to do them once. I shouldn't recommend my approach to others, but I do. Do them until you cannot stand the pain, and then do a few more reps. They say that I was a regular evening visitor to the therapy gym in the rehab hospital when I was an inpatient there. I would haunt the place long after the staff went home, sometimes—after repeating all the exercises of the day—just longingly staring at the rack of canes while sitting in my wheelchair.

Remember that pain can be your friend. One way or another, it will probably be pretty much a constant companion for the foreseeable future. It warns you that what you are doing is potentially damaging to your body, and that it is getting close to the time to back off. Fairly close anyway.

Besides, the other good thing about pain is that it reminds me that I am:

- Still looking at the green side of the sod,
- Not taking a dirt nap just yet,
- Still using up oxygen at a prodigious rate, and
- Irritating all and sundry with my continued existence.

Choose one or more of these platitudes to announce proudly to the world: "You still gotta put up with my antics. I ain't quite dead just yet".

Try to come up with new sources of self-inflicted pain, also known as exercises, but describe them to your therapist before you do them even once. They may be dangerous or may interfere with exercises that your therapist has you doing. Get their advice and then make your own decision. Just who has the title to whose body?

By the by, do not think that your therapist is treating you any worse than they do every other patient. Sadly, you are not that special. A good physical or occupational therapist is an equal opportunity sadist.

After you get your parole from the hospital, your rehab work has only begun. Invest two hours or twenty each day, seven days a week, working on getting things back. Your progress may be slow, and even that pace will slow after a few years, but if you keep on working at it, you should be amazed with the results. In other words, keep getting exhausted on a daily basis. It is a very sound investment.

Ignore any nonsense you hear of there being some sort of window of opportunity for rehab. If there is one, it is two or three decades. Maybe, four. While the pace will surely slow, it doesn't stop, unless you let it. It is unconscionable that people who flatter themselves by claiming to be professionals are allowed to persist with the standard lie of improvement screeching to a halt after six months to a year, two at most.

For whatever reason—and I can think of a doozie—they repeat that mantra, without taking into account its effect on their patients, their patients' loved ones, and insurers. They provide excuses for Medicare and HMOs to abandon patients far too soon.

My favorite example of improvement continuing well beyond the two-year mark is myself. (I bet you didn't see that coming.) I arrived in Florida in late September, 2004, when I was four, measured in stroke years. I had to hurry to catch the fourth hurricane to hit the state that year. They had that much fun with the first three. When I arrived, I used power carts to shop, even in medium-sized stores. Three years later, I didn't use them even when I shopped at a Wal-Mart Super Center.

Even today, I must confess to grinning when I walk past the neat row of powered scooters there, or at other big box stores like the Home Depot, while pushing my shopping cart or even carrying a basket if I only need a few items. Strolling, or my unreasonable facsimile thereof, through a several hundred thousand square foot home improvement store with only a shopping basket is a terrific feeling, 'specially holding the basket with my bad hand, 'specially planning projects around the house for ME to do around MY house.

All too easily, ill-informed opinions about the possible limits to rehabilitation can lead to clinical depression in patients, and even in their loved ones. That pressure can lead to drastic changes: breaking up families or even suicides. I know, for I made my own damn fine attempt at suicide. It happened long before I left my chair, in fact,

only about five months post-Event. As I lay in bed listening to my 24-7 attendant tidying the kitchen, thoughts of improvement ending for all time in as little as a month ran through what was left of my brain. Faced with a lifetime being pretty much bed bound and needing care that I couldn't afford, I made a truly rational decision based on misinformation and disinformation, the only information I had at the time. I took about 50 doses of Phenobarbital and went to bed. I woke a day later in the nut house. My attendant, who suffered my abuse so cheerfully, had taken extraordinary measures and saved my life.

What has changed? After a few days, I recovered from the physical ill effects of the attempt itself and they let me out of the loony bin. Shortly after that, I changed health plan from my HMO to a Preferred Provider Organization, or PPO. My new physicians convinced me that things were wide open in terms of potential improvement. Those real experts included my neurologist, primary care guy, and—most importantly—my physiatrist, the rehab specialist. None was as pitifully ignorant and cruelly self-serving as the HMO doctors who had come up with the bleak prognoses before.

Why do I call them self-serving? How many lawsuits do people start when any improvement is seen as beating the odds? Conversely, any lack of improvement is deemed normal. Destructive profit seeking behavior is not limited to loan sharks, drug pushers, or even lower life forms, like personal injury lawyers. In this country, as in most of the world, doctors are rich self-serving capitalists, and almost all one of them act that way.

By the way, I am also a self-serving capitalist. I just wish I were a rich self-serving capitalist.

It is important to note that you can usually restart therapy after it ends. Like most insurers, all Medicare wants to see is a prescription from an MD and they will usually pay, at least up to their annual limits. After I decide I need more therapy, my docs only seem to need a willingness to retain their sanity for them to write me a 'script. I have started and stopped therapy eight or ten times in the last decade, and I am not done with it yet. When I think I need more, I try to make a case for it to myself by answering one sort of question: What would be the goals, i.e. what are my abilities now and what do I want them to be? After I convince myself, I visit a doctor. Mine have learned to start reaching for their prescription pads as soon as they sense where I am going. Why do they do that? Gutless wimps, all of them. I like gutless wimps of doctors.

Rest after working at it. How much rest is enough? Let no one else tell you what is too much or too little. Listen to your body. It will speak the truth, even to tell you when you are fully rested. What do you do at that point? Up and at it! It is time for more self-inflicted pain.

It turned out that my body was wonderful at healing itself, so doing my assigned exercises and developing new sources of agony let me put my wheelchair away in the cupboard on my first Rebirth Day, the anniversary of my stroke. Trust me, putting that away was the very best Rebirth Day present I could ever have given myself.

Unfortunately, some who work really hard at it never leave their chairs and are the target of criticism by fools ignorant of their medical condition, let alone medicine in general. However, even for those survivors, I believe trying is still good exercise.

Some who leave their chairs do so sooner, some later, and lucky ones never use them. I keep talking about my year to give hope to the many still confined to their own beautiful-ugly, wondrous-awful, liberating-confining devices. Besides which, it is a major source of my abundant personal pride. Though I keep trying to avoid the limelight, there are times I can't. Aw shucks; poor, poor, pitiful me.

I suggest that you don't wait for the pain to subside before walking. It was five years before my unrelenting pain fell off all the way from gawdawful to only agonizing. By then, I had been walking for four years, and walking only made—and still makes—the pain worse.

Speaking of pain, I caution the use of pain killers in all stroke survivors. I am willing to grant exemptions to victims who do not survive. In the most brutal of language, most pain killers have addictive properties and generally become ineffective after chronic use. That can lead to increasingly strong doses or moving to barbiturates or narcotics after a while. For what? As stated before, pain has a number of good properties, including reminding you that you are alive. Since exercise normally increases my pain level, I would need to quit exercising and stay in bed in a drug-induced stupor to be pain free. I decline your kind offer to kill my pain, thank you very much.

Finally, we come to exercising what is left of your brain. Studies have shown that thought processes improve, or decline more slowly with age, when individuals keep challenging themselves mentally. Each and every day, I do all three crossword puzzles in the local newspaper, along with the other word puzzles there and some I have found online. I can't be sure that it has helped, but it can't hurt. Also, I am back to reading although, truth be told, not as much as before.

A recent update: just before my last cruise, I finished digging out the stump of an orange tree that had died. Its trunk was about a foot in diameter of extremely hard wood. That's 30cm for those using the, unfortunately French, but nearly universal system. I had started this a month earlier and worked at it for an hour or two most days from the first gray light of dawn. Here, at the south end of Tampa Bay, the days get rather warm all too soon, even in October. Of course, the worst thing is the 99.9999999% humidity. I dug it out, cutting major roots when I ran into them, including a couple of six inchers. I did it BY myself!!!!!! I did it FOR myself!!!!!! I won, and my 200 lb prize (the stump) was still sitting atop the dirt pile two weeks later when I returned from a cruise. I got to smile again. The reaction of the landscaper whom I paid to haul it away was priceless. He asked me three separate times during the process if I had really dug it out myself. That let me smile three more times.

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#### BACK TO WORK AND PLAY

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If you return to work, good luck. I hope your experiences will prove better than mine were.

Before going any further, I must admit that it was not really work. My employer was the California government. LOL, sorta. I only mention their name since they pretty much had to leave it up to me whether and when to return, as well as whether and when to pull the pin later. Those with real jobs, i.e. private sector ones or even government ones in saner states, usually do not have those choices. Of course, I needed medical clearance to return to work. Guess how much trouble it was for me to get my docs to make that determination.

While the ADA (the Americans with Disabilities Act) tries to limit discrimination against the disabled, my earlier experience in the private sector as a personnel manager trying to reduce the effects of sexism and racism in the workplace tells me just how easily any such mandate can be thwarted. In plain language, if they don't want you—which is all too likely—they will be rid of you. The only question is how much it will cost. Hopefully, they will mess up and be forced to pay you a bunch of money. The financial burden you will be placing on company's health plan may spur them on to make mistakes. Obviously, I hope it does not come to that but, in a perverse way, those medical bills paid by your health plan may become very valuable to you.

Under the ADA, nothing can be required of you simply because of your disability, and no untoward job action can be based on real or anticipated benefit costs. When asked to submit quarterly medical clearances signed by my doctor, I agreed, but asked who was going to read and file the million forms a year that would be supplied by the quarter of a million state employees, let alone pay for them. That requirement was withdrawn. After getting several emails forwarded to me by my boss' boss that discussed how employers had legally dismissed staff with disabilities, I sent my boss several accounts of massive settlements based on management creating hostile work environments for cripples, aka the physically challenged. For some strange reason, those emails dried up. The copies I had saved in my folders on the department's server disappeared as if by magic shortly after I objected. Those I had already forwarded to my home computer were still around.

Get the message? Your employer's servers are just that: theirs. Your home computer is yours. Do the math.

The boss I talk about had replaced the angry fool who was there in May of 2000, and remained until six months after my return. My new boss was a great guy who did his level best to keep his peers and higher ups off my back.

Even in a Land of Fruits and Nuts government job, I had to fight what seemed to be daily battles, just to keep what I had been able to win back. My responsibilities had been scattered among other people, including a replacement hired while I was away. Few of those duties were returned to me and my replacement was kept on, despite the extreme fiscal crisis at the time and his being an incompetent probationary employee. Especially after my original boss passed him on his probationary period review, I came to realize that they were just putting up with me, isolating me, and doing their level best to rid themselves of me. Fortunately for me, they were no more competent at that than they were at doing most other things.

Two years after my return, I broke my leg (the good one, no less!) at work by getting tangled up with a strongly-sprung restroom door and my cane. That turned out to be the beginning of the end. Nine months later, I pulled the pin, exhausted, demoralized, and bored. In other words, they finally won, but only after running up a huge tab. Californians, those were your tax dollars hard at work.

On a much more positive note, try an old hobby or get a new one. For example, in some cities, there exist activities like adaptive golf. Remember the phrase: It's not what I cannot do, it's what I can. Most of us can still play card games and I think they work best with other people at the table, hint hint. The same goes for any activity requiring interaction with others, but I wouldn't search long for other full body contact stamp collectors.

By the way, do not think that you can hide behind excuses as feeble as you can't shuffle, deal, or hold your cards. I learned to shuffle and deal long before I regained any real use of my bad paw, and used a simple device to hold my cards. The same held true for other activities. I learned to use a computer mouse, sign my name, play golf, put on socks, and do up buttons one-handed with the wrong hand, my left one. I even learned to tie my tie using only the wrong hand.

My stroke affected my right side. Pre-stroke, I had been right-handed. You do the math.

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#### CHANGING THE NEW YOU TO FIT THE WORLD

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Accept the fact that your abilities have changed. Duh! You can sit or lie back and wait for the world to change to fit your new abilities, or learn to adapt yourself to the world. As with everything else, it's your call. If you have been paying any kind of attention, no doubt could remain about which alternative remains my first choice. If I want to have even a vestige of my life before, it is up to me to learn how to get things done in the big bad ol' real world. In my not-so-humble opinion, waiting for the world to change to fit my abilities would be a fool's errand.

Accept that you probably will have problems—at least initially—with short term memory. Make adjustments accordingly. Pre-stroke, I had a very busy job with public hearings, media interviews, seminars, analytical work, writing under strict deadlines, supervising the work of two analysts and the like. The only record I kept of my schedule was in my brain and I didn't miss a trick. Everything changed. If I didn't make a record of everything—appointments and conversations—I could not be assured of remembering anything. On occasion, I couldn't remember even having the conversation, let alone remember the specifics of what transpired. I soon learned to keep a schedule on my computer (starting out with Microsoft Outlook, then Yahoo!'s calendar when I retired, finally Google's when I couldn't control access to my Yahoo! Calendar.) All I needed to do was to establish simple routines to actually remember to check it.

Just like other issues with short-term memory, taking medications can be a challenge, even beyond learning how to swallow again. I soon learned to set up simple routines to remember things, using four-a-day weekly pill boxes. The four daily slots let me set up my initial seven medications, since they ranged from four times a day to once in the early AM or before bed. Now that I am down to a single med, I have two-a-day weekly pillboxes. My anti-convulsive (anti seizure med) has an effective half-life of 14 hours, so I take it twice a day.

Overnight, I keep the weekly pillbox on my dining table beside the empty pocket single dose box. In the morning, I load my evening dose in the daily pillbox and put it into my pants pocket. Then, I take that day's morning dose, leaving the little doors open. In the evening, after I take the dose from the pillbox in my pants pocket, I put it beside the weekly box if I am at home, or in my shirt pocket if I am out.

I would love to tell you that I remember every dose, but cannot. However, my simple routine has limited that to three or four times a year, down from three or four times a week.

If you are still in your chair, recognize that you only have one bad leg. Immediately, put this document down, remove the foot rest for your good side, put it in the cupboard, and leave it there. You can rest your good foot on your bad one for the few times you allow yourself to be pushed by others, but set a goal of never letting yourself be pushed, even when you are in a hurry. Solution? Start getting ready sooner and learn how to move the 'blessed' thing.

Learn how to roll in a straight line using your one good foot and hand. Start slowly and then work up to doing more. Heck, I started off with great instant success: the first time I tried, I went at least a foot, maybe two, and not in a cir-

cle. OK, but only part of one. I relied almost completely on a heel-to-toe pulling motion of my good leg and foot. My hand and arm pretty much went along for the ride. Others rely on the arm and hand as much as their lower limbs, or the upper pretty much to the exclusion of the lower. Whatever your therapists may say, the best way is simply the one that works best for you.

Go to stores with either narrow aisles or long walks. Wal-Mart Supercenters were great. They had both, being colossal and they used to be set up in awful ways for the handicapped. Unfortunately, I have observed a disturbing trend with them. Aisles are getting more open and store employees have started to offer way too much help. I will have to find new places to shop.

By the way, if you're looking for fun, find a store manager and complain about one particularly bad access situation. Sensing a major chain store manager's discomfort, and knowing how well trained they must be in the implications of the Americans with Disabilities Act, is indeed fun: nasty fun, but fun anyway. If you get one who is not intimidated, politely ask to see their boss. I have nothing but time, so I go up the food chain until I find some poor soul whom I can abuse. Doing that at the local Wal-Mart meant that they stopped using the marked off spaces that run alongside parking spots for the handicapped as assembly points for storing shopping carts.

Besides which, some store management types have resorted to bribes to quiet me, especially at national retail chains. Got 10% off four major appliances from Lowe's that way. Got a free pizza from Papa John's and, poof, a month later a parking space for the handicapped appeared where there had been none before in a parking lot not even owned by them. After I saw that, I visited to thank them in person and bought pizza only from them. My waistline shows just how often that is, or was, anyway.

That opens up the important topic of exercise, food consumption, and weight. It is controversial, but my theory (I am busily writing this up for submission to *The New England Journal of Medicine*) is that, if calories consumed are greater than calories burned, weight goes up. That flies in the face of fad diets, even good ones like Atkins or South Beach. Do not get me wrong. I have nothing against good fad diets. Any approach that controls weight is positive in this land of growing flab.

About 2,500 calories a day works for the typical active male, 2,000 for a woman. However, no sane person would call my lifestyle active. I do work out for two hours a day, including 30 minutes on the treadmill where I walk a mile, and not only do all housework, but most basic home maintenance as well.

However, I spend at least four hours on the computer and the same veg'ing on the couch. After two hours at the gym, I can count on the same taking a nap. I am that tired. Among stroke survivors/victims, I am considered active. If I were normal, whatever that is, my picture would appear beside the word 'sedentary' in the dictionary. For me, consuming 1,500 calories a day, i.e. 60% of normal, is the maximum to not gain weight. Pre stroke, I was obese at 5'8" and 205 pounds. Still 5'8" (darn), but I maxed out well over 230! Only by going on a very severe diet (as in 1,200 calories per day) have I brought that below 200. In fact, I was 186 by last weighing, almost the 185 not seen since 1995, possibly on my way to the 175 that I haven't seen since my twenties. I ignore an all too brief period in 2000.

My point, other than to do some 'rare' boasting, is to emphasize just how quickly the weight can sneak up, especially if you are in a wheelchair. I came home from three months of exquisite hospital cuisine at 175. Over the next five years, I regained nearly 60 of the 30 pounds I lost there, and 60 of 30 isn't a typo.

As my weight went higher, mobility became more of a struggle, which tended to lead to a more sedentary lifestyle, which added more weight, and so on. I'm sure that you appreciate the growing struggle as it became impossible to stand for long or walk very far. It finally dawned on me to adjust my diet, a difficult thing to do, not only since eating is one way to fill empty hours, but also is one of the few pleasures of life left to me. I am trying to lose a bunch of weight in my late 50s, very late 50s, in fact the end of the sorry decade that began with *The Day My World Changed Forever*. In May, I was eleven in stroke years; last October, I turned fifty-thirteen in mere mortal years.

So, my recommendation is to look at this issue frankly, make some hard decisions, confirm these with your doctors, then make them happen.

If you want the blubber, go for it. You are in the right place and you have a great excuse, 'specially if you are in a wheelchair. However, if your goal is even to maintain your weight, a major reduction in food intake may be essential. As with most other things, those of you in wheelchairs will need to do more to keep from becoming what I call puddles of flesh. It would astound me to see a morbidly obese person walk away from their chair. Those are very harsh words but harsh doesn't mean untrue.

When you feel up to it, take a roll or a stagger on sidewalks. The roads work in the 'burbs where there aren't sidewalks but traffic is slight. Where there are sidewalks, not all intersections have them cut. Don't try to roll over the precipice. It is dangerous, he says after trying more than a few lip stands.

Rant starts.

Isn't it amazing how they can build gently sloping ramps for cars, but not for wheelchairs? Doesn't anyone take into account people leaning on canes who have to walk across a ramp? They wouldn't make a four legged—ok, they are tires—car go across a ramp any more than they would make a car with a 300 hp motor go up a 1:3 slope, or over even a 2-inch curb. Every year in this country, billions are spent to remove bumps or cracks of less than an inch on roadways.

Even a liberal bastion (Sacramento) of Lotus Land (Kaleefornya) had to be forced by the courts to allocate even a small portion of its road repair budget to fixing its unbelievably substandard sidewalks. Throughout an extended fiscal crisis, the city paid scum-sucking bottom feeders (I apologize to catfish, I mean the other scum-sucking bottom feeders: lawyers) to lose appeals all the way to the California Supreme Court, no less.

Rant ends.

Emphasize using your bad hand as soon as you get even limited motion of it. When it is time to do simple tasks, (eating, brushing teeth, showering, and putting dishes away are good examples) grab your belt or waistband behind your back with your good hand. If you're in the wheelchair, sit on your good hand. Then do as much of the task as you can with your bad one, and don't quit easily. They call this 'forced use' in the literature, and suppliers have all kinds of wonderful equipment to replace the simple action of grabbing your belt or sitting on your paw.

It won't be all that easy to do the first few (like the first hundred or hundred thousand) times that you do this, and your good hand will constantly try to join the party, but persist. If you can't keep that sneaky good hand from joining in, then it's time to look into more sophisticated equipment, like looping a string loosely around your waist knotted with a second loose loop around your good wrist. Remember, the point isn't to bind the blessed thing, just to remind yourself when it starts to join the fray.

If you catch your good hand still trying to sneak in and take a plate down, put the plate back on the shelf and struggle doing it with your bad one. You are permitted to discipline your good hand for being naughty. The results continue to amaze me.

If you are in a wheelchair, grab the edge of the kitchen sink with your good hand and pull yourself to your feet, involving your bad hand as much as possible. I stood for at least thirty seconds when I did this for the first time before my legs shook so violently that I plopped back into my chair. An hour later, I repeated the exercise, and ten times the next day. By the next week, I had ventured almost all the way around the kitchen. Of course, I never did this while alone. I had my attendant hold on to my wheelchair with the brakes set. Try to remember the sink rim when (not if) you fall later. If you can drag your sorry butt over to reach it, it's simply wonderful.

Practice getting back on your feet after a fall. Of course, only attempt this when you are not alone. Ease yourself to the floor, then struggle to your feet. Be safe, but be brave. Treat asking for help as admitting failure, humiliating failure. When you master this at the rehab clinic, start doing it at home, then in public, including outdoors. Don't stop until you can get to your feet in the middle of a lawn, i.e. on soft uneven ground without anything more than your cane to steady yourself. Or, in the middle of a concrete patio. Accept that learning to walk means falling. Learning how to fall and then rise again is an essential part of walking and ain't such a bad metaphor for life in general.

As soon as you can; walk, walk, and walk. Then walk again. The first time that I walked to work, it took a mere two hours to walk the five blocks and only two hours back home. I napped for an hour at lunchtime and at least two

when I returned home. It took me a total of 'only' four hours to commute ten blocks. Two years later, I was up to a lap and a half around Capitol Park in Sacramento, and the trip took no more than an hour. I turned a two-hour five-block walk with two falls into 1½ miles in an hour with rare falls.

The first day that I walked to work, I put the power wheelchair into the closet. Two months later, I donated it to the Children's Hospital when its siren call of "Use me, I could make things so much easier" became too loud to ignore.

Swimming is wonderful exercise for most stroke survivors. However, it is a great example of how personalized each stroke can be in its effects. A significant impact of mine has been to lose resistance to the effects of low water temperature.

It wasn't even six months before I tried for the first time. The YMCA in Sacramento has a public therapy pool kept at a steady 90 degrees with a sling on a hoist to help individuals like me to enter the pool. It was simply a disaster. The very warm water felt stone cold. I never left the sling and had them pull my shivering body within 30 seconds of entry, meaning at least 29 seconds after I wanted.

I have tried repeatedly since, with little change. So, this ex-lifeguard from the Great White North with many new layers of blubber had to find other ways of building flexible strength.

The moral of this story for you? Don't assume that your experience will even faintly resemble mine. Find a public pool—ideally starting with a therapy one—or join a health club with a more private one and try swimming. It is almost always the best exercise, being extremely low impact and aerobic when done properly.

Not surprisingly, I have another caution: do not try this alone. In fact, have someone who is a strong swimmer and well trained in rescue techniques around you at all times, especially initially. If you have your own pool, that's great, but safety concerns lend themselves to considering more public settings, again, at least at first.

Practice picking up the many things you will drop. Have a bowl of dimes or thin poker chips available to spill on the table. Force yourself to pick 'em up with your bad paw. When that's easy, spill 'em on a hard surfaced floor and pick them up while sitting. When that becomes easy, stand and lean against the wall to pick them up. Later, spill them away from the wall, all the while using only your bad hand.

Make others back off and let you do any task you are even remotely able to do or simply want to be able to do someday. Hopefully you can tell them in more polite ways than I did, but do it in any way you must. "Let me do that for you, we're in a hurry" could be answered with: "I will catch up with you. I have to do this for myself".

If they don't listen, and I found listening to be rare, after they pick up an object and hand it to you, open your hand and drop it again right in front of them. Then pick it up yourself. When a 'helpful' person does up a button, remove it and do it up yourself. There's nothing more important for your rehab than this, even exercises given to you by your personal terrorist (PT) or omygawdthathurts therapist (OT). Get others to back off and let YOU force YOURSELF to do things for YOURSELF.

When you can't find a public toilet for the handicapped, use one for mere mortals if you can. When I couldn't do even that, I had a towel for modesty and a portable urinal handy. They make them for women too. Urinals, that is. I'm not sure, but I suspect that most towels are not gender specific. On a more serious note, I found that portable urinals designed for female use were much better to use before I left my chair. I went home for a #2. Do not be embarrassed when, not if, you have an 'accident'. Try to hum a tune while remembering those worse off when that happens. That helped me pass the time as I made my grand exit in soggy pants.

By the way, a handicapped toilet can't work any better than a handicapped parking space can park a car. It is you, and not the toilet or parking space, that is handicapped.

When you are done and happen to be on a toilet with no grab bar, turn as far as possible to your good side and either grab the pipe if there is one, or put your good hand flat on the top of the tank. Place your feet as close as you can to the toilet and as much of your weight as you can over your knees. Push. Though I have to be careful and sometimes have to really work at it, it has been amazing how many times I have come to my feet in the absence of grab bars.

Men, what do I do when I am ready to wipe myself after a bowel movement? I stay sitting, grab a small piece of toilet paper, open my knees, and wipe. Thoroughly and repeatedly. Rashes down there are painful and hard to make go away. I addressed this to men since few women need, or should need, training on wiping themselves while sitting.

Join an online community of survivors. A good one is strokesurvivors on Yahoo!, but there are many others. More about this later under Resources.

Shop around for live stroke support groups. Find one or more where you feel comfortable. Follow leads listed in the national stroke groups sites (see 'Resources' below) and call local hospitals, including rehab ones. These meetings are great for many reasons, but two stand out. They continue to show me that I am not alone, and they can be great sources of information, both at meetings with guest speakers and those where we just sit around sharing. An extra reason for me has been the self-esteem arising from being asked to guide sessions dealing with travel, and you can imagine just how desperately I need new sources of self-esteem.

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#### *CHANGING THE WORLD TO FIT THE NEW YOU*

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I include this section only grudgingly. After ten years of struggling on my own, I started to accept the notion that not every change that I force on the world is altogether bad. In fact, some are good... at least on a temporary basis. Letting others do things for me is the best example of this. At first, I needed to rely on my doctors and nurses for simple survival. As time went by, I needed less and less of that and chose to learn how to start to make my own efforts, and eventually to rely only on my own efforts. My recovery depended on it and I prospered. In the last year, I have started to let others do things for me, from time to time. With one exception, I can tolerate that only about once or twice a week. It must be redundant, but a pretty woman's help is pretty much acceptable pretty often, as in pretty much all the time. Call me shallow. I mean it. Call me shallow.

Get rid of throw rugs and doormats in your home; be it an apartment, house, trailer, or cardboard box. Ladies, please try to not throw out your husband, lover, or both, with other doormats. If you can afford it at all, consider replacing wall-to-wall carpeting with smooth flooring. Hardwood is far more durable and looks nicer, but laminate usually has more give to it. Wheelchairs don't roll very well over carpet and it is very hard to catch your toe on smooth flooring. Two years ago, I had all the carpet in my house replaced with laminate and I have fallen rarely at home since, which is a big improvement for me. The bruises I have earned by falling on laminate are more shallow and heal faster than the trophies I have won by falling on hardwood in stores or other homes.

Get what I call a picker upper: a wand with a claw at the end. There wasn't anything better to help pick up things when I was in the (ugh!) wheelchair or before I could bend over while standing. As soon as I could, I gave up that aid. At first, I leaned against doorways to pick up things with my good hand. Now, using only my bad hand, I'm able to pick up things as thin as dimes in the middle of a room and extract socks from the back of the dryer drum. I looked longingly at platforms when I replaced my dryer a couple of years ago, but decided that would make things too easy. Curses, foiled again!

If you are permanently stuck in a chair and can afford it at all, get the interior doorways in your home widened to at least 32", preferably to 36". The latter is the ADA guideline but, in my opinion, 32" is ample for access in a normal size wheelchair around a private home. However, exterior doorways of 42" are a delight. Again, if your budget allows, consider as wide as is feasible and with as gentle door closers as you can afford. Closers that work slowly, but surely, can be extremely useful... if not today, then in the coming years.

If you suspect or even hope that you may get out of your chair someday, don't do it, especially if you value the trim of your doorways. Kinda helps getting outta da chair when you start bashing into dem doorways. Apartment dwellers with high security deposits take note. Keeping things fragile encourages you to leave the comfort and security of the chair.

Self-styled professionals have no better track record of predicting whether you will ever get out of your chair than economists do of predicting recessions. I know, being both an economist and one for whom prognoses were made as stupid as what my loved ones were told at the end of May 2000: "Get to town quickly, he WILL die soon." Barely a week later and without any apology, that was changed to, "He'll probably die soon, but in the unlikely

event that he lives, he will linger for a year or two in a semi-vegetative state before he dies." Forecasts made about this economist were miserably (or should that be 'gloriously'?) wrong. Irony sure is ironic, eh?

Set up your kitchen with everything on the counter or at the front edge of the lower cabinets if you are chair-bound, adding lower shelves in the upper cabinets when you can stand, however briefly. Consider removing cupboard doors if you can even nearly touch the front edge of a shelf with the fingertips of your bad hand. If you keep doing your exercises, your reach and balance should improve. Obviously, you won't have as many things available, so be selective. However, a well set up kitchen will let you tell others to quit being so 'helpful'. One measure of my success is that all the cupboard doors are back on, and I use all the shelves in my kitchen.

Prepare your own meals, even if you don't live alone and have no history of doing that. It is such good therapy to make a meal with your own hand or hands and you will have a bunch more time around the house than you ever did before. Don't have a clue what to do and live with somebody else? Sit them down in the kitchen and let them help by talking you through it. Of course, few spouses would be happy to just sit back and let you fail, but try to train them to do just that. Dining on one's culinary disasters was a fine tradition while I was growing up and—treated right—could lend itself to amusing moments with your partner.

When you are wheeling yourself or staggering around stores like a Supercenter or mobility aid specialty store, look for helpful aids for one-handed food preparation, but only if there is no voluntary motion in your bad hand. Like clamps to hold veggies or fruits when you want to cut or peel them. Amazing how few things need peeling when it is a big deal to do so. Healthier, too. However, switch hands at the first perceptible motion of the fingers of your bad hand. Grab your belt behind your back with your good one and... You know the drill. In other words, keep using the one-handed tools, even after you get motion in your bad hand, just change hands.

Use the Internet to find stuff. I just searched using the keywords 'handicapped tools' and got 20,100,000 hits.

Keep a box of mobility and other aids that that you don't need any more. I have two such boxes and every time I look at them, a big grin spreads across my mug. I think you know why.

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#### *BENEFIT INCOME AND HEALTH INSURANCE ISSUES*

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For those not already receiving regular Social Security benefits, visit the Social Security website ([socialsecurity.gov](http://socialsecurity.gov)) and then go to an office at your earliest convenience, as in before a week goes by. Social Security Disability Income (SSDI) won't start until at least six months into your disability, but don't wait, even if you plan to return to work. If anyone hasn't said it to you before: plans change and some plans are changed in spite of the planners, if you know what I mean.

When approved, SSDI will start the latter of the end of a six-month waiting period following disability and the date you actually apply. I don't think my way will work for many, since it seemed to be based on my ability to charm those of the female persuasion, but I still did my homework. By the time I visited their office, I had already checked out their website, learned many of the ins and outs from online support groups, drafted an application, and collected all the required supporting material.

I make an issue of this since Social Security is renowned for rejecting pretty much every claim, most more than once. Another legitimate criticism of them is how long it takes them to process claims, including appeals. The growth industry of self-styled 'SSDI advocates', proves it. Lawyers are not exactly famous for being all round nice guys. That they want to be involved means that there is a bunch of money in representing claimants. Since the only money available is from retroactive payments—the feds have no history of paying punitive damages—the value of the typical claim cannot pay for all the TV ads we see. One can only conclude that there must be many such cases.

Putting aside the draft I had made of the application and about half the supporting documentation that I had gathered, I took the rest into their office, arriving before it opened. When my number was called, I asked how one should apply for SSDI. The clerk waved her hand vaguely at the forms rack to show me where the apps were, but I stood there acting confused, which was not exactly a stretch at the time. In response to my reaction, she (women, gotta love 'em) offered to help me fill it in, to which I agreed, indicating that I had real difficulty printing clearly and

of a size small enough to fit in the boxes. Since I would have had to use my left hand at the time, that was true, but ignored the existence of a typewriter at home.

When she finished doing my work for me, I asked what came next. After no more than a moment's hesitation, she indicated that I should go back to the waiting area and someone would see me within the hour.

While her cryptic comment surprised me, what else did I have to do? I waited no more than twenty minutes before being ushered into a back office, whereupon I had the interview for which most applicants wait at least two months. No more than two hours from the time I first hobbled into the main office, I was on my way home knowing that all I needed to do was go home and mail in the stuff I had left behind so deliberately.

I came back a week later to drop off the stuff that I could have mailed. A week after that, my phone rang. It was the interviewer telling me that my claim was approved to start on time, meaning after six months of disability. I don't really know, but it seemed obvious that my claim got some very personal attention. Kinda helps to have a goofy smile. Further proof that once you can fake sincerity, you've got it made. Of course, my success may have had something to do with being prepared and being flexible. Nah, must be my gorgeous smile. BTW, I really do take reality breaks, but do my best to keep them rare and brief.

As indicated earlier, do not become discouraged when your first application for SSDI is rejected. Treat that as a first rejection and appeal their decision. At that point, or at least by the time you make your second appeal, consider hiring a bottom feeder to represent your interests. Since a growing number of law firms advertise their expertise in and success rates for SSDI appeals, they gotta have some expertise in this area. Lawyers want to be sued even less than their typical victims do.

I became eligible for Medicare two years later. I don't remember actually even applying for it. Check [medicare.gov](http://medicare.gov) to see. If I didn't have my group medical plan and my income were lower, I would have needed to bridge the gap with Medicaid, called MediCal in California. For those in sane states, meaning the other 49, you will need to check your state government website. For computer illiterates in the crowd, consult the state government section of the blues pages of your phone directories.

I have two other sources of income. One is a disability pension from my employment, the other is the single thing that I did to prepare for something like what happened to me; LTD or long term disability insurance. I mention them only to brag... ok, there's another reason. Before much time goes by, sit and try to think, or what passes for thinking these days, about income sources. Only after I did that did I remember my 401K and pension plan with the State, but I checked out my eligibility for Canadian pensions as well. I lived and worked there until age 40, so I will get my Canada Pension Plan (CPP) and even a portion of their Old Age Security (OAS) pension when I hit 65. I could have got some CPP as young as age 60, discounted pretty much the same way as Social Security does for regular benefits. I know that I am not eligible for any disability pensions from Canada: having checked this out on official websites, followed by confirming phone calls.

The lesson here is to stop and try to think of all possible income sources and don't dismiss any until you've checked them out, first on an official website and then by telephone or office visits. Try not to assume anything. If I had, I wouldn't have learned about my Canadian OAS and CPP eligibility which will be worth hundreds of dollars a month after I WILL reach age 65.

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#### GENERAL TRAVEL STUFF

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During the first seven years after moving to Florida, I went on a baker's dozen cruises and visited my kids in Ontario well over 20 times. I flew back and forth to Sacramento four times (the Governator couldn't seem to do anything without my help), stopping off in Lost Wages on three of those trips. At the start of cruises, I have flown to Rome, Los Angeles, Barcelona, Copenhagen, Rio de Janeiro, and Acapulco. At the end of cruises, I flew home from Barcelona, Athens, London, Rio, and Santiago. I drove from the Tampa area to Atlanta and back for a stroke support group meeting and the Miami area four times for cruises. However, there was a trip to LA when I was still living in Sacramento of which I am most proud. It was made shortly after I 'fired' my full-time attendant.

Note that my attendant was a willing participant in her own firing. Bless her; she was that much into helping me with my recovery in spite of my treatment of her. She knew how important that step would be to give me the

space to keep getting better. Did I really push her away when I was ready to climb into the shower one day? A gorgeous woman who wanted to wash my naked body? I can be sooooo foolish some times.

My visit was almost eight months after The Event and was to the UCLA Med Center to get a second opinion about the need for additional brain surgery. Took an airport shuttle to SMF (Sacramento airport), cab from LAX (Los Angeles airport) to the UCLA Med Center arriving well before my assigned appointment time, cab back to LAX, and home from SMF by shuttle.

Victory! Especially since I had made the reservations myself, travelled by myself, and done it all while confined to the chair. How did I make this one a success and most trips since?

I started slowly and worked up to doing more. The trip that I just talked about was not my first. Within a month of getting out of the hospital, there was a hopelessly bad bus trip to Reno (three hours from Sacramento). Then, a horrid trip from Sacramento to L.A., then a bad trip to St. Thomas, then the trip above, then a good—but not great—one to Toronto, then...

That I describe any trip to the Caribbean in negative terms is a powerful indicator of my condition at the time. I had been to the same island on my third honeymoon and had given it a different rating. Of course, my new wife was 22 and I was 44 at the time, which might have had some effect on the rating.

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#### DRIVING AGAIN

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As northern North Americans, i.e. as Canajins and Mercns, we cherish our freedom of mobility. Losing that can just grind away at us. The urge to drive our vehicles, particularly if we have been doing that for three or more decades, can trump any rational thoughts about risk.

Despite those natural feelings, try hard to approach starting to drive again with great caution. In California, there was no set period before one could apply to have a health-related driving suspension lifted, though they use a rule of thumb of three months. The legendary efficiency of the California DMV makes that a de facto one-year minimum. I waited until the two-year mark before I even applied.

Do not be fooled by the fact that you have kept your driving privileges, if that is the case. I imagine myself standing beside a ball of crumpled steel with a young family crushed inside, crushed by my actions. I hope that is sufficiently vivid to give my fellow stroke victims pause before they just get in their cars and start driving, suspended license or not. That vision might explain why I waited two years to apply and didn't follow up on my application for over a year.

Visual acuity is the first major consideration. One thing that our bodies do amazingly well is to compensate for many deficits, and our minds are great at disguising—especially to ourselves—those our bodies can't. You may be unaware of or gloss over even major vision problems. Those can cause accidents under the strain of that most complex of tasks: driving. Even before I applied for reinstatement, I had my eyes examined in detail by an ophthalmologist. I encourage everyone to do so, even survivors who keep their driving privileges.

Why an ophthalmologist and not just an optometrist? The former needs an undergraduate degree, followed by four years of med school, then at least two years of internship and residency, then at least two years of specialization. The latter needs an undergraduate degree and up to four years of specialized training. In my book, twelve or more years of rigorous training and ruthless selection processes beat no more than eight of tough, but far less rigorous, winnowing.

Right or left side neglect is another. Unlike some stroke victims, I can see across a normal field of view, though I tend to ignore what is happening to my right. To control the effects of this right side neglect, I have trained myself to be deliberate in looking over my right shoulder once every minute or two, and—when pulling through an intersection—I move my head to look to the right, move it to the left, then to the right again. In other words, I do not just glance. I find actually turning my head works better. I follow much the same process when I change lanes.

Learning to cope with gross or subtle changes to your body or mind is the biggie. By definition, you are brain damaged. Depending on the location and extent of injury, you will have deficits, be they significant or mild, be they physical or mental. There is an ever-increasing variety of adaptive equipment designed to compensate for most

physical issues. Each of these has a learning curve for true mastery, so give yourself time. Even though I used no adaptive equipment at the time and had driven for over 35 years, I took eight or ten driving lessons to sharpen my skills with my new body. That was eight or ten more lessons than I had taken before I got my license at 16.

More about adaptive equipment: If your stroke, like mine, affects your right side, there exist things like left foot accelerators and extensions for wiper controls. For left affected side types, extending the turn signal lever to the right of the steering wheel may be essential.

For either side, suicide knobs that stick out from the steering wheel can assist you to have very secure one-handed steering. Regardless, unless your leg, foot, hand, and arm all come back completely, you'll have driven a manual transmission for the last time.

These are not the only kinds of equipment available; the Internet is a great source of information, as are your therapists and the staff in a store dedicated to mobility equipment.

Who pays for these things? Not Medicare and no private insurance plan of which I am aware. You can get some of these installed in new cars at the manufacturer's cost, within strict limits of both of time and money. Check each manufacturer's web site to find out how this works, then go to shops that install these things. Those mobility equipment specialty shops can provide the knowhow about which equipment will work how well on which vehicle and they can provide the expertise in the paperwork required for various manufacturers. Only after all that, start to look at cars.

Make your first driving trips brief and don't be alone. You have a new body controlled by a bramaged dain. Be kind to yourself while being critical of your behavior. I am sure that you can hazard a pretty good guess of just how modest I am. Does the word 'not' come to mind? However, I willingly subjected myself to the humiliation of giving up after a mile or two when I attempted to drive too soon. A couple of months later, I drove to the hospital rehab clinic, about a three-mile trip. A month after that, to Reno and back, 130 mi. each way.

Think about your vehicle. Can you even get into the driver's seat? Would grab handles help? Is there excellent visibility all around? Remember the young family entombed in their car and that you have lost a bunch of your ability.

As a passenger, you can take some simple steps to make things go more smoothly:

- o Start getting ready much sooner than you may suspect that you will need. When I went on my first road trip, my best shower to rolling out the door time had been about an hour, so I started the process 90 minutes early.
- o Think about wearing adult diapers if you don't think you can wait 30 minutes from the first urge. I wore them and still do from time to time, though I wear big boy pants over them.
- o Take whatever time you need to get comfortable before the wheels start to roll. Imagine yourself sitting in any position for twice the anticipated duration of the trip.
- o If you depend on it, don't forget your wheelchair or other mobility aid. That may sound trite until you remember that it can mean far more to you than it possibly could to your driver and other passengers.

Interestingly enough, when I took the road test to get my license reinstated, the examiner seemed to pay little heed to my actual driving. Instead, he engaged me in a vigorous conversation. I didn't realize what he was doing until much later. He was attempting to see if I would let myself be distracted. He seemed convinced by my never looking at him while the car was moving and asking for a moment's silence at a couple of critical stages, like when merging with traffic from a freeway on ramp. The car radio was silent for the test and, even today, is never on while I drive. Ever the harshest critic of myself, I can get distracted or lulled to sleep far too easily.

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#### FLYING AND CRUISING

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Plan, plan, plan, and then: plan again. I have an Excel workbook called 'checklist' and, before I do anything else, I find the worksheet for my last trip of the same type, and copy it. The result is a framework for the itinerary, packing list, hotels, cruise details, etc. for the new trip. It has all the phone numbers, confirmation/reservation codes, re-

minders about stopping the flow of newspapers and mail, suitcase contents list, ad nauseum. Not a nerd like me? Using paper, pencil, and ruler is not nearly as easy, but you will probably appreciate the investment.

By the by, the first thing I do is to change the font color to red on the new worksheet. Then, as I make each correction, like changing airlines, after I enter the new details, I turn that portion black. It's my way of keeping things as simple as I need to these days, particularly with my feeble memory.

Use Internet travel agents or traditional ones. For me, that has been Expedia, Travelocity, Priceline, Cruises Only, and others. If I were computer illiterate, I would use a carbon-based unit (i.e. a real live travel agent) even if it costs a bit more. I check out possible itineraries and general seat or cabin availability, and then call an agent to discuss my special needs. This has worked especially well for cruises. The agent contacts the airlines, cruise companies, hotels, etc. for you and tells them what you need. I write each agent's name as they come on the phone, and am not particularly subtle when doing so.

Call the airport or dockside parking authority directly well before you leave town, after getting their number from the general one for the airport or cruise line. Ask what the parking rules are for the handicapped. Is it free anywhere, for all types of disabilities, and for all durations? At TPA (Tampa airport) short term parking is free for at least four weeks (I have done exactly that) for those with hand controls or left foot accelerators for the driver. In other words, there is tangible evidence of major mobility problems of the driver. It was the same at the Ft. Lauderdale port for cruise ships.

Other disabled persons, whether driving or not? Spaces are reserved for the handicapped who, I understand, pay full price, including the extra for short term versus long term. Check local rules before you leave home. I only know what they are at TPA and were at SRQ (Sarasota-Bradenton airport) several years ago, and claim no knowledge of other airports. Even if I were to fly from SRQ again, I would call days before I left town.

When you make your reservation, identify that you will be in a wheelchair, if that will be the case. I have an utter distaste for those awful things. When I put mine away in the cupboard, I swore I wouldn't use one ever again. I still plop my butt into one at airports. Why? As soon as I could, I tried walking. However, the combination of transfer times being so short, distances between gates so great, crowds of distracted people hurrying to catch flights who tend to kick out the tip of my cane, and the need to get off any airplane last, followed by needing to board the next one first; all make walking in airports seem a distant possibility... so far. I almost never use the word 'never' when talking about my abilities, or lack thereof.

Cruise ships have the best equipped facilities for the handicapped I have ever seen. Wide aisles around beds, roll-in/roll-out showers, and emergency call buttons with chains attached are just a few of their amenities. However, each ship only has a few of these cabins and they are often reserved by (un)surprisingly agile passengers, so: plan, plan, plan... then plan again. Of course, I have used only cruise lines that call on U.S. ports. That makes them subject to ADA regulations. Check with the disabled passenger department of your cruise line well before you book.

Reserve an aisle seat on flights. Consider changing your itinerary if one isn't available. The airlines sometimes hold accessible seats for the handicapped, but don't rely on that if you can. I think some of the problem with seating for the disabled is caused by self-described handicapped people who seem to undergo miracle cures when it comes time to deplane. Why an aisle seat? The bother of having people climb over you is totally wiped out by the speed (ok, the relative speed) of getting to restrooms yourself. Besides, they are way easier to get into or, more accurately, less difficult.

An hour or two after you make your reservation online, call the airline to see if bulkhead seats are available, but don't be too disappointed if they can't release them until you actually get to the airport. Why a bulkhead row? Generally, these are much more accessible and are much closer to the front of the plane. When my seat in stee-rage makes it closer, I freely use the restroom in first class without anything being said, sometimes not long after the announcement that it is for the exclusive use of first class passengers. In other words, I exploit my handicap. Who is going to pick on the cripple?

Watch travel to otherwise civilized countries. America has its well-deserved reputation for our national sport of abusing the poor, but takes first place in guaranteeing access for the disabled. In other words, as bad as it is here, it is worse everywhere else. Do not expect treatment as you would here, even in hotels operated by American chains.

I was shocked in Copenhagen to see steps to enter most every store, few curbs cut at intersections, woeful conditions at tourist attractions, and—most disappointingly—my hotel room for the disabled had 18 inch paths around the bed, a six inch step at the bathroom door, and a 20 inch high bathtub with knife edges. The only concession for the disabled was a single horizontal eight-inch grab bar on the wall just above the soap dish in the middle of the tub. In their ongoing effort to make access difficult, the hotel had no shower chairs. Before I arrived, I fully expected Scandinavian countries to be the best. To say the least, they fell a tad short.

Just to prove to you that I am still trying to figure things out, last November, I tried a new cruise line: Costa. It was a seven-day Mediterranean cruise out of Civitavecchia (the port for Rome) and I planned to stay in Rome for the four days after the cruise. I cut it short on the third day of the cruise and flew home from Barcelona. Why did I abort this rather expensive holiday? First, I flew to Rome, which was an uneventful trip. Then things fell apart. For the first time in over a dozen cruises, I left the ship early. I was knocked over three times in two days, once by a crew member who tried to rush past me to get on as I got off a passenger elevator. He looked at me lying in the doorway and rushed off. Few of the announcements for activities were in English, despite there being a thousand passengers from the U.S., Canada, and Britain, not counting those for whom English is their second language, i.e. most of the ship in total.

Even getting to Rome's port city (Civitavecchia) was an expensive adventure. I had to take a cab (for 'only' €160 + tip) because the Italian rail system refused to accommodate my mobility scooter. It seemed that they needed 24 hours' notice. For all my compulsive planning, I was ill prepared and paid the price. The return airfare was nominal compared to the pain and boredom that I was avoiding. Some fine day, Europeans will get it, meaning they will start to become inclusive of their disabled population.

The country in second place for treatment of the disabled is Canada, but be careful. Don't let a Canadian hear you say that, but don't assume anything. The adage of plan, plan, plan, then plan again applies. When you make hotel reservations there, not only try to reserve a room for the handicapped, but also find out what that means, just like you do in America, eh?

Watch travel to the rest of the world. I found laughable conditions in Dakar, but what do you expect in a country that measures annual economic output per person well below \$1,000? Providing for the disabled is an expensive proposition.

Of course, there are some surprises. In extremely poor Tallinn, Estonia: sidewalks, the vast majority of store entrances, and hotels in the oldest part of a very old city were models of accessibility. In St. Petersburg, it was just the opposite: almost no provision except for those of the two working leg variety in a city that had to be almost completely rebuilt after the Great Patriotic War. Even there, I found an exception. After I climbed at least 20 steep stone steps without a handrail to get in, Hermitage Museum staff members were so politely insistent that I chose to relent and sit in a wheelchair provided by the museum. I did get them to back off with their offer of providing somebody to push me for my tour of this astounding site. By the end of my four-hour tour—about a hundred less than it deserves—I was cursing myself roundly for this last decision. My leg was that dead tired.

When going to an airport, consider taking a cab from home or from nearby parking lots. These days, you can't drop off your bags at curbside check in, then go off and park your vehicle. Using an airport shuttle service can make sense, if there is one. However, don't be shy about asking to be dropped off at the terminal when others drive, or paying the surprisingly little extra for valet parking where it is available. I caught myself passing on valet parking because it would cost \$5 on a trip that the air fare alone cost one hundred times as much. All I can say is, "Doh!" in my best Homer Simpson voice.

When packing, minimize your baggage, especially if you're travelling alone. Nothing more than having to schlep your own bags once should convince you of the merits of minimizing.

Ladies, please do not be offended, but travel more as the typical man would. Seventy pounds of baggage for a three-day trip seems a tad excessive. Try scraping by with a meager sixty-five. I am not asking you to cut down the Imelda Marcos Memorial Shoe Collection in your closet, but doubt that you will need more shoes than the number of days that you will be away.

Men, you may need to break down and pack a second of your three-pair shoe collection. There may be formal occasions where your ratty running shoes would be inappropriate. For those, pack your dressy sneakers.

Plan to get to your gate at least an hour earlier than recommended, especially if you want a bulkhead row seat. If you don't end up needing the extra time, airports have a bunch of distractions. Watch airport seating, though. I can get into any seat, but have no hope of getting out of some without major assistance. Leaning against large flower pots and 'renting' a seat in a restaurant or bar are good alternatives, as is asking the gate attendant for a normal chair. Buying one soda an hour is usually enough to rent a seat in a restaurant, but that may add to your bathroom needs.

Speaking of which, before you go to the gate, visit the restroom, especially if you have been soaking up sodas in restaurants. That may sound trite until you realize that your next visit may be an hour after you preboard. It must sound outrageous, but consider wearing adult diapers when you fly. I still do.

Despite hydration being so important for your body's healing, try to limit other fluid consumption for the period from at least a couple of hours before you leave for the airport until you arrive at your final destination.

Soon after your gate agents arrive, tell them that you are there, especially if you are in a wheelchair. They can't do their job, like tagging your chair with a so-called gate tag, if you don't do your part. Remember, most of them really want to help. If they don't, they need to appear as if they do to satisfy their management. All airlines fear the ADA (Americans with Disabilities Act).

Remember, the ADA is federal law. Just like cruise operators whose ships call at American ports, airlines fall under federal jurisdiction. You do the math.

Think about using a wheelchair in airports, even if you don't use them in town. Airlines and cruise operators make them available for embarking and debarking, so you don't need to burden yourself by bringing your own. Imagine changing flights in Atlanta. It is not unusual for gates to be well over half a mile apart and sometimes over a mile. Stopovers can be as brief as 40 minutes between the scheduled arrival of one flight and departure of a connecting one. It may take a minute or two to get the door open, then five or ten more to empty the plane before you can deplane. They usually start preboarding about 20 minutes prior to departure. In this example, you could have as few as eight minutes to get to your next flight. That's doable in a chair, but it is beyond my abilities to stagger a half-mile or a mile in eight minutes. That is: it's beyond my abilities, yet.

Note that it is best to tell the airline in advance if you want to use one of their wheelchairs. While they won't exactly have one waiting for you as you park your car, one will be waiting—with someone to push it—at every stop on the way, including at the end of your trip... as long as it is a North American carrier. Pull up your reservation online or call the airline a couple of days before you leave and review your reservation, especially extra services like wheelchairs.

Warning: either boarding or leaving cruise ships can involve walking half a mile or more. Although usually far less constrained by time than in airports, often this in crowded conditions and over a variety of terrain conditions.

You can bring your own powered wheelchair on any flight. However, they are hassles, must be checked in well before your flight, and may incur additional airline charges. A mobility scooter or folding manual wheelchair can be rolled to the door of the airplane, then 'gate checked'. Gate checked items are first out of the hold and put just outside the plane in the jetway. At worst, they will be at the top of the ramp. Any removable foot rest or seat cushion should be carried on board with you, unless you want to make unplanned donations of them, if you know what I mean. Don't be shy about asking cabin crew to carry these to your seat and stowing them for you.

It may not come as a surprise to hear of differences between how my scooter was treated by an American carrier (Delta) and a European one (Air France). It highlights the differences in how disabled travelers are accommodated by American or Canadian airlines and abused by their European cousins. Outbound, I flew Delta from Tampa (TPA) to Atlanta (ATL), had a two-hour layover, then non-stop to Rome (FCO). I gate checked my scooter in TPA and it was waiting for me at the top of the ramp at ATL. I used it for the next 90 minutes in ATL, then gate checked it again. Seamlessly, it appeared at the top of the ramp in FCO.

On the return, Air France initially rejected it altogether (despite my reservation clearly showing it) and then grudgingly relented and accepted it as checked baggage. They did provide (grudgingly) a manual wheelchair to use, though they failed to offer to have anyone push it. When I arrived in Paris (CDG), no wheelchair greeted me. They got me one after 20 minutes, but again failed to provide me with any help pushing it. I made it on my own to the Delta flight, and then my worries were over. In ATL, my scooter appeared in the luggage area in US Customs and they had no problem with my gate checking it from there. Back home at TPA, it awaited me in the jetway just outside the plane.

All this should indicate why I consider America to be in first place when it comes to being inclusive. In my experience, Europeans seem to 'think' that disabled people should just stay at home.

Powered wheelchairs and scooters can be rented almost anywhere, including on cruise ships. They are expensive and a hassle to rent, but are definitely a treat. Consider renting one for all or a part of your vacation. If you want one, pre reserving them is pretty much essential. Call the folks at your cruise line who handle disability issues. They can set you up, or tell you where to go, or whom to call.

Check anything more than small purses or books, even luggage that could qualify to be carried onto your flight. You will leave the plane last, so your baggage will probably be on the carousel before you, when you arrive at your final destination. These days, connecting legs are all too common, inter flight times short, and gates far apart (how can they keep doing that?). Those are all reasons to leave the baggage handling to, gosh, baggage handlers! Go figger! The fees that most airlines have started to charge for checked bags may seem burdensome, until you check your bags once and feel how liberated you become at stops along the way.

Well before you land, tell your elbow mates that you will be leaving the plane last. Warning them should improve things later.

How much should we tip those who push us around at airports? I ask them who their employer is: the airline, the airport, or themselves. Only if they tell me that they are self-employed (including Sky Caps) do I consider tipping them. How much? No more than \$10 for unusually good service in a major airport, \$5 for typical service, and nothing for anything less. Once, I gave a Sky Cap \$20 when he whisked me to the luggage carousel, then on to my car without a quibble. Of course, that was after 20 hours flying home from Athens to Tampa via long layovers in Paris and Atlanta, all coming after a 27-day cruise and a week in Athens.

On any extended vacation, consider mailing souvenirs back home as you accumulate them. It is surprisingly inexpensive.

Before I leave on a trip, I put several fives in my shirt pocket, since getting one from my wallet would be time consuming while sitting in my chair. The fives are useful for tipping my 'pushers' as well as paying for food, books, etc. when in my chair. Pouches with strings that go over the head are available in many stores, both virtual ones and their brick and mortar cousins. They are great for tickets and ID, and are also places to put those fives if you do not have shirt pockets.

Before travelling to other countries, get local currency in small denominations for each county you will be visiting, or at least some Euros. That can save nasty looks from baggage handlers at, say, Paris de Gaulle airport (CDG). Don't give them such an easy target. Make 'em work at being rude. The French will rise to the challenge every time before you can get outta Dodge and, in my experience, they are equal opportunity abusers. Degree of disability seems not to work its way into their 'thinking'. After all, they are Europeans, so their attitude towards the disabled is unlikely to be up to American standards. However, there is one thing not realized by most Americans: the French are almost as rude to each other as they are to Americans. In my experience, the French seldom bathe, use deodorant, practice effective dental hygiene, or use polite language, even away from tourists.

However, for tipping people at CDG, currency choice has proved to be an issue or not, depending on the airline. When I flew on Delta and American, I used euros to tip my pushers. On Air Chance, it isn't an issue: none have been provided on the three occasions that I have passed through CDG.

Carry your passport as ID, even on domestic trips. Since drivers' license records are kept by each state at varying levels of security, I suspect something like this will become required by the Feds before very long. As intimated previously, security at airports is a federal responsibility.

What about packing medicines? In my pockets, I have critical medicines in original containers from the pharmacy for at least twice the number of days I will be away. Critical medicines do not include pain killers. The only medicine in my pocket is my anti-seizure one. Others go in my suitcase. Pause before you put barbiturates (like Pheno-barbital) or other heavy duty narcotic or nearly narcotic drugs in your pockets or even your suitcase, particularly if your trip is international. If you really need them, a prescription from your doctor may keep you from waiting behind Al Gore in the full body cavity search line for domestic travel or reenacting a certain scene from the movie *Midnight Express* on international trips. Why pockets for ample supplies of critical meds? Twice in my life, my baggage has gone on much better vacations than I ever did.

An update: in December of 2009, I went on a 15-day cruise from Ft. Lauderdale to Valparaiso, Chile. Despite knowing how great cabins for the handicapped were on ships, and my travel agent finding that one was available, I chose a cabin designed for mere mortals. Just like the Sacramento-LA trip mentioned before, one word describes the result: victory. I no longer need one designed for special needs, i.e. cripples. My recovery has progressed that far in the decade since my second infancy, including in its tenth year. Six month window of opportunity for rehab? Yeah, riiiiight.

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#### RESOURCES

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All too easily, we can become housebound. Some of that is simply unavoidable. Energy reserves are limited (read, we tire quickly), we are ashamed of our physical condition, we don't work and our friends do, we have lost many 'friends' and more than a few relatives shun us, etc. As I said before, some fine day, somebody will convince people that strokes aren't contagious.

Some of those reasons are valid, but we can't let them take over our lives, especially the embarrassment thing. I figger that, if anyone needs to be embarrassed, it is them that ain't been tested YET and think—too often expressed using shrill voices—that they know the first blessed thing about me. That group of fools includes those who pity me, those who condemn me, and even most of those who praise me without thinking. I have just this to say to people like that:

"I reject your pity and do not accept your judgments. I am looking for friends and will keep looking, thank you very much."

However, there is an addendum to this rule: pretty women in awe of my accomplishments are always welcome. I'm only taking my own advice about getting back to an old hobby.

Use the Internet, whether you are travelling, looking for assists for daily living (like a picker upper or devices to hold food when you cut them up, etc.), or are just plain bored. All Americans can and should have Internet access. You can spend as little as \$200 for a netbook computer (or about the same for a Color Nook or Amazon's Kindle Fire) and \$10 a month for dial-up access, visit your local library to use free computers with high speed connections, or sit in a McDonald's and hook up with WiFi. Software keeps getting easier to use and hardware is improving at a dizzying pace. Don't have a clue about the new technology? Introductory classes are taught at most libraries and all community colleges, and I suspect that you will encounter other students there. Guys, some of them are women, mostly non-jail bait. Hint, hint.

Virtual friendships were my first steps back. I joined online support groups after searching using keywords such as 'stroke support groups'. Some were collective "Why Me?" pity parties, but some of that was good, at least a bit of that was good at the start.

Other groups were so positive that they were laughable. In one group, an individual actually posted a message that she was glad she had had a stroke. That day, I cancelled my membership in that particular group; not so much that she had posted such a message, but that the next ten messages actually supported the nonsensical idea.

The ones that I have stuck with are in between. From groups, I have made more than a few virtual friends, as I call them. I have built my virtual harem.

Particularly good general sites include:

[stroke.org](http://stroke.org) for the National Stroke Association

[strokeassociation.org](http://strokeassociation.org) for the American Stroke Association

[strokefl.org](http://strokefl.org) for the Florida Stroke Association

As stroke survivors, we are 'blessed' with not one but two national associations. Between them, their sites have a bunch of materials and links to other sites. For my money, NSA's is better, but you may (be wrong and) find ASA's to be better. However, my recommendation is to visit both. The Florida one has links to both national ones and many others.

Resources for travel:

[allaboutdisabledtravel.com](http://allaboutdisabledtravel.com) is an excellent site. It has links to a wealth of sites for travel by the disabled.

[barrierfreetravels.com](http://barrierfreetravels.com) can keep you up to speed on changing national and international conditions. In preparing for my last cruise, I ignored their warnings about European rail provisions for cripples and paid the price: thousands of dollars for what ended up becoming a four-day nightmare.

[amazon.com](http://amazon.com) When I searched at the main site using the phrase 'disabled travel', I found not only several books, but also links to things like how to visit Disney parks if you are disabled and a bunch of other information.

If you search using keywords like 'disabled travel', get ready to be inundated, but do it anyway. Commercial ads running down the sides of web pages are also great portals.

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#### CLOSING

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That's all I have: you're on your own now to succeed or fail. You were all along, but may not have realized that fact, or dismissed it as relevant. It is a fact of your life. I hope you decide to make the most of what is left of your body, mind, and life, but accept that falling is part and parcel of walking. Getting vertical again is the real challenge. That makes walking pretty much like everything else in our miserable lives.

Losers say: "I failed" or "I can't".

Winners say: "I didn't succeed. So what? Just get outta my way, I'm taking another run at it. Gotta do this, gotta do it for myself."

My old self passed away a decade ago. He will never return. My new self, while similar, can't do as much as he could but I am not interested in comparing what I was able to do then and cannot do today. The only important things are to wake and to see what trouble I can cause today. Some call that a hobby, real friends accept that I take it on as a job, and it seems that I am pretty good at my job.

My world changed forever at 5:30 AM on May 30, 2000, but not everything changed: I am particularly proud of my good bad attitude.

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#### SUMMARY

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##### General Stuff

- o The simple act of waking each day can be a miracle in its own right.
- o Keep your sense of ha ha or develop one.
- o There is no alternative to a lifetime of always hard, often lonely, and forever mindlessly painful work to restore only part of what you had before.
- o Be strong or, at least, act as if you are.
- o You have lost no real friends and no truly close relatives.
- o When you feel like complaining about how badly life has treated you, think of the many who have been treated worse.

- Keep telling yourself that your condition is potentially regenerative, not inevitably degenerative.
- Being down from time to time is an extremely healthy reaction to the changes you have been going through. In fact, it may be the only rational response.
- Feeling down for more than a week? Get help.
- Set achievable but challenging goals.
- Unless you are unique, you will face a key question: "Why me?"
- Do your best not to treat your caregivers shabbily.
- No one knows your body and what is happening to it better than you, but puleeeese don't make others guess.
- Pick your doctors with care.
- Keep a diary of major events and bring it, or a summary, to each visit to a doctor.
- Try to remember that you are the boss, and resist being steamrolled by doctors and therapists.

#### After you get your parole from the hospital

- Hopefully, you have a partner, offspring, other close relative, or really good friend who can stay with you for at least a month. The important thing is for them to be willing to let you try to do things for yourself.
- It would help if you could get your caregiver to take a look at your environment before your return.
- Do your best to make as few changes as possible, and make as many of those changes as temporary as possible.
- Any upper stories are probably best left out of bounds for at least a few weeks.
- Set up a schedule of time off for your caregiver.
- Get some adaptive equipment before you even return home.

#### Exercise

- Do all formal exercises given to you by your therapists, and do so faithfully.
- Remember that pain can be your friend.
- Try to come up with new sources of self-inflicted pain, also known as exercises, but describe them to your therapist before you do them even once.
- Remember that a good physical or occupational therapist is an equal opportunity sadist.
- After you get your parole from the hospital, your rehab work has only begun.
- Ignore any nonsense you hear of there being some sort of window of opportunity for rehab.
- All too easily, ill-informed opinions about the possible limits to rehabilitation can lead to clinical depression in patients, and even in their loved ones.
- It is important to note that you can usually restart therapy after it ends.
- Rest after working at it.
- Don't wait for the pain to subside before walking. That can take years or the pain will persist for the rest of your life.
- Exercise caution in the use of pain killers.

#### Back to Work and Play

- Remember that there is federal law that says clearly that nothing can be required of you that isn't required of every other employee and real or anticipated benefit costs cannot be the reason for negative job action.
- Accept that your employer WILL try to get rid of you. Try to make that as expensive as you can, as in maximize your severance pay.
- Try an old hobby or get a new one.
- Do not think that you can hide behind excuses as feeble as you can't shuffle, deal, or hold your cards.

#### Changing the new you to fit the world

- Accept the fact that your abilities have changed.
- Accept that you probably will have problems—at least initially—with short term memory.
- Just like other issues with short-term memory, taking medications can be a challenge, even beyond learning how to swallow again.
- If you are still in your chair, recognize that you only have one bad leg.

- Learn how to roll in a straight line using your one good foot and hand.
- Go to stores with either narrow aisles or long walks.
- Surprisingly, there are connections between exercise, food consumption, and weight.
- If you want the blubber, go for it. You are in the right place and you have a great excuse.
- When you feel up to it, take a roll or a stagger on sidewalks.
- Emphasize using your bad hand as soon as you get even limited motion of it. Do as much of any task as you can with your bad one, and don't quit easily.
- If you are in a wheelchair, grab the edge of the kitchen sink with your good hand and pull yourself to your feet, involving your bad hand as much as possible.
- Practice getting back on your feet after a fall.
- As soon as you can; walk, walk, and walk. Then walk again.
- Swimming is wonderful exercise for most stroke survivors.
- Practice picking up the many things you will drop.
- Make others back off and let you do any task you are even remotely able to do or simply want to be able to do someday.
- When you can't find a public toilet for the handicapped, use one for mere mortals if you can.
- Join an online community of survivors.
- Shop around for live stroke support groups.

#### Changing the world to fit the new you

- Get rid of throw rugs and doormats in your home.
- Get a picker upper: a wand with a claw at the end.
- If you are permanently stuck in a chair and can afford it at all, get the interior doorways in your home widened to at least 32", preferably to 36".
- If you suspect or even hope that you may get out of your chair someday, don't do it.
- Self-styled professionals have no better track record of predicting whether you will ever get out of your chair than economists do of predicting recessions.
- Set up your kitchen with everything on the counter or at the front edge of the lower cabinets if you are chair-bound, adding lower shelves in the upper cabinets when you can stand, however briefly.
- Prepare your own meals, even if you don't live alone and have no history of doing that.
- When you are wheeling yourself or staggering around stores look for helpful aids for one-handed food preparation.
- Use the Internet to find stuff.
- Keep a box of mobility and other aids that that you don't need any more.

#### Benefit Income and Health Insurance Issues

- For those not already receiving regular Social Security benefits, visit the Social Security website ([socialsecurity.gov](http://socialsecurity.gov)) and then go to an office at your earliest convenience, as soon as possible.
- When approved, SSDI will start the latter of the end of a six-month waiting period following disability and the date you actually apply.
- Social Security is renowned for rejecting pretty much every claim, most more than once. Another legitimate criticism of them is how long it takes them to process claims, including appeals.
- Do not become discouraged when your first application for SSDI is rejected. Treat that as a first rejection and appeal their decision.
- Check [medicare.gov](http://medicare.gov) to see when you will qualify.
- Stop and try to think of all possible income sources and don't dismiss any until you've checked them out, first on an official website and then by telephone or office visits.

#### Driving again

- Try hard to approach starting to drive again with great caution.
- Do not be fooled by the fact that you have kept your driving privileges, if that is the case.
- Visual acuity is the first major consideration. Get tested by a neuro ophthalmologist.
- Right or left side neglect is a major issue for almost all stroke victims. Loss of field of vision is less common, but may be a death knell for hopes to get your license back.

- Learning to cope with gross or subtle changes to your body or mind is the biggie.
- Talk to your therapists and check out adaptive equipment at a store specializing in disabled equipment and the Internet.
- Make your first driving trips brief and don't be alone.
- Think about your vehicle, as in need for grip handles and similar simple adjustments.

#### Flying and Cruising

- Plan, plan, plan, and then: plan again.
- Use Internet travel agents or traditional ones.
- Call the airport or dockside parking authority directly well before you leave town, after getting their number from the general one for the airport or cruise line.
- When you make your reservation, identify that you will be in a wheelchair, if that will be the case.
- Cruise ships have the best equipped facilities for the handicapped, period.
- Reserve an aisle seat on flights.
- An hour or two after you make your reservation online, call the airline to see if bulkhead seats are available.
- Watch travel to otherwise civilized countries. Europe will probably surprise you in just how far they are behind America in providing access for the disabled.
- The country in second place for treatment of the disabled is Canada, but don't assume anything, eh?
- Watch travel to the rest of the world. Providing for the disabled is an expensive way of doing business.
- When going to an airport, consider taking a cab from home or from nearby parking lots.
- When packing, minimize your baggage, especially if you're travelling alone.
- Plan to get to your gate at least an hour earlier than recommended, especially if you want a bulkhead row seat.
- Before you go to the gate, visit the restroom, especially if you have been soaking up sodas in restaurants.
- Despite hydration being so important for your body's healing, try to limit other fluid consumption for the period from at least a couple of hours before you leave for the airport until you arrive at your final destination.
- Soon after your gate agents arrive, tell them that you are there, especially if you are in a wheelchair.
- Think about using a wheelchair in airports, even if you don't use them in town.
- Note that it is best to tell the airline in advance if you want to use one of their wheelchairs.
- Warning: either boarding or leaving cruise ships can involve walking half a mile or more.
- You can bring your own manual wheelchair to the plane's door and gate check it, as long as it is a Canadian or American airline. Confirm with others.
- Powered wheelchairs and scooters can be rented almost anywhere, including on cruise ships.
- Check anything more than small purses or books, even luggage that could qualify to be carried onto your flight.
- Well before you land, tell your elbow mates that you will be leaving the plane last.
- Consider tipping those who push you around at airports.
- On any extended vacation, consider mailing souvenirs back home as you accumulate them.
- Before leaving on a trip, put several fives in your shirt pocket or over-the-neck ID pouch, since getting one from your wallet would be time consuming while sitting in my chair.
- Before travelling to other countries, get local currency in small denominations for each county you will be visiting, or at least some Euros.
- Carry your passport as ID, even on domestic trips.
- Put critical meds in original pharmacy bottles in your pockets, others in your luggage.

#### Resources

- All too easily, we can become housebound. Some of the reasons are valid, but we can't let them take over our lives.
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- [strokeassociation.org](http://strokeassociation.org) for the American Stroke Association.
- [strokefl.org](http://strokefl.org) for the Florida Stroke Association.
- Resources for travel:
- [allaboutdisabledtravel.com](http://allaboutdisabledtravel.com)
- [barrierfreetravels.com](http://barrierfreetravels.com)
- [amazon.com](http://amazon.com)
- If you search using keywords like 'disabled travel', get ready to be inundated, but do it anyway.
- Commercial ads running down the sides of web pages are also great portals.