

## **Part Nine**

**Friday / 2 January 2009**

I include an interesting series of emails that were provoked by my sending as an attachment **REMF Diary of Dying** to Ron Holz, a Vietnam vet I've known for thirty years or so, and the husband of Diana Holz who was the daycare provider for all of my four children at one time or another. Diana was also a colleague at GRCC during my years there. As Ron mentions in one of his emails, he receives 100% disability from the VA for his PTSD. I never applied for disability through the VA for PTSD because I thought that as a REMF I would not have any chance of having a claim for PTSD accepted by the VA. If I had it to do over again, I would apply, if for no other reason than to get myself in their pipeline. Read the emails, and I'll have a comment or two at the end of the series.

----- Original Message -----

**From:** Ron Holz

**To:** dawillson@earthlink.net

**Sent:** Thursday, January 01, 2009 6:58 PM

**Subject:** Open Talk from Ron Holz "Point Man International "

David: I read your paper work and as always it needs no signature as I can tell your work and love it as always. I just wanted to let you know that I am and have been for several years a member of "Point Man International" a nation wide network of Vietnam Veterans who help all Veterans get through the trauma of war and all the other things that go along with war. I am what the VA calls a 100%, for PTSD and I have 3 Tumors to date, they say A/O, but who knows? I go in every 3 months for biopsy's, so far for some reason unknown to mankind they are non-cancerous, so the wait go on! (Diana tells me I have a reason for surviving Vietnam. Hell I'm not sure I did! We have in our Point Man Group, Veterans who's life goal is to help other Vets in trouble or do their paper work for the VA in a manner in which they understand, and trust me it must be done in a manner they can understand simply! We also have X-claim managers from the VA in our group who know all the inn's and out's of claims. We have gotten claims settled in 24 Hours, and Veterans reimbursed for the money they should not have had to spend out of there own pocket for what our Government caused. I have talked with our claims man and yours is a slam dunk one week 100% VA Rated claim, and we can correct all the typical screw ups on your DD-214, this is very important for your wife also. If you want David I can bring Terry Newby, (the best claims man on the west coast) and my self to your home and we will get you 100% rated ASAP, and stop the spending from your pocket and turn all that over to VA's responsibility, this is what I have been doing for the last 5 years with the help of our

claims writers and my friends also, this would not be the first time we have achieved this. Dave it hurts me to see you or any other Vietnam Veteran hurt plus be pushed around by the Village Idiots at the VA, if you want or need my help ,you got it, we are here and ready to help.

Ron Holz, 4TH.INF.DIV.Grunt 66/67

**From:** dawillson@earthlink.net

**To:** inf4thdivision@msn.com

**Subject:** Re: Open Talk from Ron Holz "Point Man International"

**Date:** Thu, 1 Jan 2009 21:46:46 -0800

Ron,

Thanks for your offer of help in my attempt to get my disability claim approved by the VA. I have no doubt that I have not gone about this process in the most efficient manner. Certainly I have gotten the impression that the folks at the VA struggle to do the simplest things right, such as spelling my name and addressing a letter to me at the address that I submitted to them.

I have an appointment with the Agent Orange Directory doctors coming up soon, as I mentioned in the text you read. I guess I'll wait to see what happens there, and then take stock of my situation and decide whether or not to take you up on your kind offer of help. Maybe I am too much of an idealist, but I still think that any veteran with a physical problem clearly caused by service in Vietnam should get coverage for that problem from the U. S. government just by asking for it. The notion that the VA is looking for every excuse to deny a deserving veteran of coverage, just because he didn't dot an "i" on page 17 of a form, or cross a "t" on page 23 of some government form is too cynical a position for me to take. Maybe in a couple of weeks, I'll be that cynical. I hope not.

Another reason I am going to persist in walking the path I am already on is that much of what I am writing is more than likely to end up being published in the VVA Veteran, and I want to give the VA more rope than I've given them already. If they choose to hang themselves with that rope, that choice makes for a more interesting story. On the other hand, I can't really afford to continue to spend money on medication and chairs etc. at this rate, so I can't let this run on for months and years. Besides, my doctor has as much as told me that with my multiple myeloma being in stage II and of an aggressive form, time is of the essence. So I will try to strike a balance of some sort.

So, in a week or two or three, I may well contact you and ask you to get Terry Newby involved in my claim. I don't want to shut that door. I can't afford to shut that door.

Thanks again for taking the time to read my diary and for your kind words about it and for contacting me. If veterans don't help other veterans, it's likely that nobody will help them.

Yours, David

----- Original Message -----

**From:** Ron Holz

**To:** TERRY NEWBY; Bob Wilson; Thomas Stoddert

**Sent:** Thursday, January 01, 2009 10:22 PM

**Subject:** FW: Open Talk from Ron Holz "Point Man International "

Well I guess we wait, I will be praying that all works out in the end. You know I'm mad as hell, but I think I'm more mad of what happen in Vietnam and to all of us then I am at the VA. Now I do not like how the VA creates it's own nightmares, nor do I care for the conditions of the VA system, I guess right now it boils down to what am I really pissed off about? Is it loosing my friends, is it it the VA, or am I just plain nuts? Hell if I know anymore, see you guys soon, love you all.

Ron

----- Original Message -----

**From:** Terrell Newby

**To:** Ron Holz

**Sent:** Friday, January 02, 2009 9:15 AM

**Subject:** Re: Open Talk from Ron Holz "Point Man International "

Well, Ron, you tried. I just hate to see these guys grind out their lives w/o any consideration for the family they leave behind. The AO Directory is just that ... a directory and a waste of time. All your buddy needs to do is send in a Doctor's statement that he is "terminal" and ask for his claim to be expedited, and off it goes. But should he pass before his claim is adjudicated ... all bets are off, as "the claim dies with the vet". I would love to give him some help, and he can still continue his "journal".

Newbs

Dear Mr. Roosevelt Ward,

Pressure is being brought on me by friends to try a different approach to the VA to get my claim accepted. (see attached). Is it true that if the VA is notified that a veteran has been diagnosed as "terminal" that the claim will be "expedited?" Have you notified the VA that I am terminal? If not, can that be done now? If not, why not? What is the current status of my claim? I am much alarmed by the statements of Terrell Newby, and hope that my claim will soon be settled.

Yours, David A. Willson

I found Terrell Newby's comments annoying, especially his putting the word "journal" in quotes which I chose to interpret as dismissive of the concept, and I didn't find much compassion anywhere in his email. Actually, what I felt from his email was anger. Anger, blame and a dismissive attitude towards my project, the journal I am keeping related to my struggle with the VA and with MM. I felt anger in Ron's emails, too. One of the reasons I have avoided joining groups such as Point Man Ministry is that when I have gone to meetings, often the dominant emotion expressed was anger. I've battled all my life with the issue of anger management, and it continues to be a goal of mine to avoid dealing with folks who are angry. Certainly, I can see that dealing with the VA is frustrating, but what good does it do to be angry about it? Does anger help solve the problems that are inherent in dealing with any bureaucracy? I don't think so. A sense of humor and a rational mind are the best ways to combat the snarl of bureaucracy, in my opinion. Ron says straight out that he's mad as hell, and Terrell Newby's anger is between all of his lines. I'll be interested to find out for myself if the Agent Orange Directory is a waste of time, and I hope that it is not. I resent Newby's conclusion that I lack consideration for the family I am going to leave behind when MM gets me. I believe that I am likely to live long enough to see the VA claim settled. I know this positive attitude is the best attitude for me to have, and I also admit that the attitude comes and goes. I admit to feeling negative and fatalistic from time to time. But I feel so good physically that I can't believe that I don't have at least another year of life to live. Certainly the VA will have coughed up some decision on my disability claim by this time next year. Let's hope so.

### **Friday / 2 January 2009**

We drove down I-5 to Tacoma Group Health for our appointment in the oncology department with Dr. Norman. Much of the time I was driving, I thought about last Friday's appointment which we kept, but which we found out wasn't really an appointment at all. I hoped that we had gotten this one right. Scheduling has always been a nightmare for me, keeping the days, dates and times straight in my mind and on paper. No matter how careful I was, I still got mixed up and showed up for non-existent appointments or was late to real appointments. This is an area I am more dependent on my caregiver,

Michele than any other area. She's a natural with schedules and appointments. No amount of effort on my part, no amount of gritting my teeth, has increased my performance in the scheduling area.

I drove my Ford into the dark, narrow confines of the underground garage and parked. As usually most of the access was blocked by huge SUV's driven by old people. We took the elevator to the third floor and I checked in.

"I think I may have an appointment at 3:00 with Dr. Norman," I said to the nice lady at the window, as I showed her my Group Health ID card.

"You do have an appointment at 3:00," she said. I sighed in relief. I had been really tense about this. I hadn't gotten this appointment wrong. I paid the \$15.00 co-pay.

Soon we were ushered into a small room to await Dr. Norman. First the nurse took my blood pressure. It was sky high. The nurse said that she'd take it again later and that if it was still that high, she'd consider checking me back into the hospital so I didn't have a stroke. Yikes. I figured that my blood pressure was high because of my anxiety about whether or not I actually had an appointment that day and time. I wasn't anxious about the appointment itself, or about what I might learn or not learn from the doctor. It's always the nuts and bolts of things that freak me out.

Dr. Norman made his entrance. We shook hands. I was seated, but Dr. Norman remained standing for a while. I had a small yellow sheet of paper folded up in the right breast pocket of my shirt with a list of subjects on it that I wanted Dr. Norman to cover during our appointment today. I left it in my pocket and began mentally checking off the subjects as the doctor dealt with them. In about fifteen minutes Dr. Norman had covered all the subjects but one. He'd even brought up the subject of pain and of my need to get more than three or four days of Percocet at a time. He said he'd write a prescription for sixty so that I wouldn't need to fret about running out.

Dr. Norman walked his knuckles down my spine, thumping my vertebrae. I felt no pain, or discomfort. He brought up the need for me to receive pamidronate, a bisphosphate to maintain and strengthen my bones. He had not thought I'd need that medication because my bone scan had been so positive and because of my renal problems, but now that I'd been in the hospital for compressed vertebrae, he rethought that decision.

I brought up the subject of nodes on my lungs, and Dr. Norman pulled up the x-rays and we looked at the pictures of my lungs together. These nodes had been spotted and commented on at St. Clare's Hospital when I was there for a week with my back problems. Dr. Norman mentioned several theories that might explain why I had spots on my lungs, including my thirteen months in S.E. Asia, and we decided to watch them for further developments. Dr. Norman commented that one of the nodes was located deep in the center of one lung, and would present a problem in performing a biopsy. So in a few months more x-rays will be taken and compared to the previous ones.

I remembered, but didn't mention, that my father had come back from World War II, and his weeks of combat on the volcanic island of Iwo Jima with spots on his lungs. He'd had to submit a clean bill of health to the Yakima School District every year before they'd commit to continue his teaching

contract. Every summer my father was tied in knots wondering if he'd have a job in the fall, or if he'd have to look for other employment.

Near the end of the appointment with Dr. Norman, he informed us that as of January 1, 2009, he would be at the Seattle Group Health Monday through Wednesday and at Tacoma Group Health Thursday through Friday. On March 31<sup>st</sup>, 2009, he would be in Seattle full time. How did we wish to handle this? I told Dr. Norman that we were just now getting used to his peculiarities and that adjusting to another new doctor wasn't something I wanted to do at this stage. He volunteered that he was being replaced by a woman doctor who he'd been told was the smartest woman in China. I believed him. I told Dr. Norman that we would be following him to Seattle.

Dr. Norman left the room, and his nurse came back. She took my blood pressure again. She instructed me to not cross my legs this time as such a posture can lead to a higher blood pressure reading. I did as I was instructed and this time my blood pressure was 142/76 which she said was a big improvement. Michele and I then went to the front office and set up appointments. By the time we finished that process, my head was spinning like a top.

My first appointment is Friday January 9<sup>th</sup>, at 11:00 a. m. at the Tacoma Group Health. I'll be receiving pamidromate via an I.V. drip. The process will take 90 minutes. Receiving this stuff will be an adventure, or at least a new experience. I assume that I'll be able to sit in a chair and read during the process of receiving the bone strengthener. Dr. Norman had warned me that there was a chance of renal failure so my kidney function will be monitored during the treatment. It's rare for the treatment to result in heart failure, but knowing that it does sometimes result in this, will give me more to think about during the process.

My second appointment is Monday January 12<sup>th</sup> with the Agent Orange Directory doctors. I've been told repeatedly that this appointment has no connection to the claim I have made to the VA for disability and I've also been told that nothing good will come from the appointment, so I am eager to find out just what will come from contact with the AO doctors.

On Friday January 23<sup>rd</sup>, I must get more blood work done. I count this as my third appointment. I'm eager for that to happen because Dr. Norman told me that my body had responded well to the one cycle of thalidomide, and that my numbers had gone way down. He said that often it took three cycles or more for such a result in a person receiving chemo for MM. Because of the nature of multiple myeloma, I look forward to more good news on January 23<sup>rd</sup> and will allow myself to be hopeful that the numbers will continue to look good.

My fourth appointment is Monday January 26<sup>th</sup> at 3:00 at the Bellevue Group Health with Dr. Chen. I don't feel much of a need to see Dr. Chen, but just about everyone, has told me that I am a fool to not have sought a second opinion about my MM and about the treatment I will receive. Dr. Chen was described to me by the renal specialist I talked with weeks ago as an "aggressive" doctor when dealing with cancer. So it will be interesting to see what that looks and sounds like. After I've seen Dr. Chen, I will be able to say that I have sought and got a second opinion, when I am questioned about that. I predict

that he'll tell me the same stuff that I've heard from Dr. Norman, but maybe he won't. If he does tell me something entirely different, what to do then? I'll cross that bridge if and when I get to it.

My fifth appointment with Dr. Norman is on Monday, February 2<sup>nd</sup> 2009 at 11:00 at the Seattle Group Health. At that time we'll discuss the results of the second cycle of chem. Treatment. I'll want to hear good news, of course, and that news will be in the form of numbers. I've always distrusted numbers, probably as a result of being raised by a father who was a mathematics teacher, but now I am eager to see lower numbers, even though Dr. Norman said that it was hard to know what the numbers mean and how they correlate exactly or at all with the progress I've made against the spreading of my MM.

The numbers relate to the Kappa.Lambda free light chains with ratios (GHC.) These free light chains are being used as a marker of my progress, or so I was told. What does it all mean? To an outsider, it seems like so much mumbo jumbo. So I ask myself, How do I feel? I feel great. Except for the lower back pain which is decreasing each day. I'd like to feel this good right up until the end. Wouldn't everyone? I think that much of how I feel is controlled by me, that I can be a captain of that ship. I resolve to stay positive and to not let anything drag me down for long. If at all.

I should probably also resolve to stay away from as much communication with Vietnam combat vets as possible. Or at least I should pick and choose which of those vets I communicate with. Ron has always been relentlessly negative during the decades I've known him, so it figures that Newby would be cut from the same cloth. Birds of a feather and all that. I do believe that both of them want to help me. Maybe it will come to that, if the VA doesn't help me soon. When I first decided to reach out to the VA to establish eligibility for a disability claim, I told myself to allow them four (4) months for the process to result in my receiving concrete help in the form of a month check from the VA. When the four months are up, then I will take stock and decide whether or not to enlist help from Point Man.

## **Part Ten**

**Sunday / 4 January 2009**

A truth that cannot be disputed is that death, for all of us, is an inevitable consequence. Once born, you will die. You never know when, and you don't want to know. Once you've been told by a doctor that you are living on borrowed time, you can choose your response. A sense of urgency can pervade your actions. Or a sense of resignation, of hopelessness, can paralyze you. I find myself vacillating between the extremes of these two positions. As always in my life, I fail to find anything like a happy medium.

Enhance my peace of mind, or be gone from my life. Eschew anger. Embrace the positive even while up to your ears in bad luck and trouble. The anger and negativity of so many veterans is self-destructive and acts to drive loved ones away, thus lowering the quality of the veteran's life, as well as having a terrible impact on the family in question. There's never a shortage of things to be angry about. There never has been, especially for a sick old veteran. I have files of letters that my great-grandfather Homer wrote to the federal government complaining with great anger about the smallness of his Civil War

pension. I have a file of letters his son, Frank Willson wrote to the federal government complaining bitterly about the same thing, lamenting the plight of the forgotten doughboy. T was ever thus. There never has been a shortage of angry veterans.

I wrote the above words shortly after I stood looking out my front window at a snowstorm. I had no idea that a snowstorm was expected this evening. I didn't watch the news and weather today so that's probably the reason for my ignorance. I am home alone this evening because my primary caregiver, Michele, took my daughter to Mercer Island for her lacrosse practice. Nobody, including me, thought I was up to the trip. I stayed home to listen to the blues and to begin a new project, which will have me rereading all the Jack Liffey novels written by John Shannon. I checked on line for a list of Jack Liffey novels and found that there are two recently published novels that I don't have, *The Dark Streets* and *The Devils of Bakersfield*. I need to order those so they can take their place on the shelf with the eight earlier novels. And so I can read them once I have finished rereading the previous eight. It will take me a long while to reread those eight, especially if the 150 mgs of thalidomide I am taking daily causes my vision to go double and blurry.

During this time of my life, I feel the need of a project even more strongly than I did during my well years. But I've always been a project kind of a guy. Upon reflection, I think that committing to this project is an attempt on my part to take control of my future, to make more of a future happen for me. Certainly, I tell myself that I'll live long enough to reread the novels and read the two new ones.

I had a long chat with my mother-in-law on the phone just last evening, when we were talking about the death of my father-in-law from lung cancer. It was his goal, his vision, almost a mania for him, to live long enough to attend his 50<sup>th</sup> high school reunion. He, through strength of raw will, did so, and then he died a couple of weeks later. My 50<sup>th</sup> high school reunion is not until 2010, and too far away to provide an urgent motivation for me to fixate on, so I must invent a project that suits me. This John Shannon/Jack Liffey project will propel me along for a few weeks or months, at which time I'll find another. This project is a natural for me, as (among many other things) I am a Vietnam War bibliographer, and the Jack Liffey books relate strongly to that war.

Of course, I also want to stay alive to be with my family, but that's such an emotional and complex need that something more concrete and measurable works better for day to day, week by week motivation. Why am I so contemplative and inward looking today? Because yesterday I was convinced that I was just a couple of days away from being healed to the point of almost being normal. I thought that soon I could abandon night time occupation of my Zero Gravity chair and resume sleeping in the marital bed with my lovely wife.

Yesterday I tried doing a few small chores, and I did them successfully. No pain, no jolts to my sensitive vertebrae. I carried two empty wine bottles out the back door, across the lawn, through the gate and I dropped them into the recycling bin. I didn't bend over to do so, so they plummeted with a crash into the bin. Mission accomplished, as our leader has said. I made it back into the house safely, dodging piles of snow, no harm done.

Today I woke up feeling great. No twinges, no pain. I had to go to the bathroom. That process did not go so well. When I attempted to arise from my sitting position on the toilet, spasms of pain shot through my spine, and I also felt pain in the muscles of my right chest, an area which has often given me trouble in the past. My Levis and my boxer shorts were down around my ankles and they might as well have been in Wyoming. Sweat stood out in drops on my forehead. I had to call to Michele, my caregiver, to come and help me. She had to pull up my boxers and my pants. Then I was able to button them up and cinch tight my belt. I couldn't have begun to get the boxers and the Levis up by myself. That simple act was beyond me.

Now, hours later, I feel better but I am suspicious of my slightest move. Since that attack of spasms, I've been mostly confined to my Zero Gravity chair. If I am very careful, I can get out of the chair, shuffle across the floor of the family room, leverage myself up the one step onto the kitchen floor, and shuffle into the bathroom to relieve myself. I can shuffle into the computer room to check messages, but I don't even consider sitting down to spend any real time emailing or working on the **REMF Diary of Dying**. Perhaps in a day or two.

I've already called my friend Steve C. and cancelled our scheduled lunch at Shari's tomorrow. I am worried about the forms I've filled out to send to TIAA CREF to withdraw \$12,000 from my pension fund to help pay for some of the expenses accrued by me since I was diagnosed with multiple myeloma a few weeks ago. Our Visa card is overloaded with the cost of the thalidomide, and the Zero Gravity chair, which is currently the only place in the house where I am comfortable enough to sleep.

The new edition of the TIAA CREF forms seems to require that I take the forms to my local branch of the Bank of America and have a banker verify my savings account as belonging to me, and that TIAA CREF can send the money I am withdrawing to that account. TIAA CREF should know by now that that savings account is mine, as I've been withdrawing money from my pension fund into that savings account for years.

First thing in the morning I am going to call my TIAA-CREF rep and ask that rep if that is the intent and requirement of this new edition of forms. Also I will ask about the dates. My wife has to sign a spousal consent form, but can her consent form be dated after the date I put on my forms or what? Every year I agonize about that. One year we got the dates in the wrong order, and we got the forms sent back to us, and we had to do the whole thing over again. "Those are the rules." Of course I can find nothing at all in the many pages of instructions that addresses this date thing. That doesn't mean it isn't in there, only that I have failed to spot it. I view this date thing as a landmine, just waiting for me to step on it. It's set up to explode the innocent and the ignorant.

I will tell whomever I talk to that I recently had surgery on my spine, and that a trip to the bank in this snow and ice could prove the end of me, but I'll do it if I must, as we desperately need the money. Every time I request withdrawal forms from TIAA CREF, they are different from the previous set, and the requirements are more elaborate and Byzantine and inexplicable. When I bring this up with the TIAA

CREF rep, they always tell me that these changes are for my own protection and for the protection of our country. As if I am going to use the money for terroristic purposes.

I always respond, more like you want to protect me from getting my money. Ha ha, the rep grudgingly replies. TIAA CREF reps seem short on a sense of humor. Or maybe I am not funny. I can feel my sense of humor drying up too. But the day must not come that my sense of humor is totally drained away because only a sense of humor is going to defuse my anger and allow me to enjoy what remains of my life.

### **Monday / 5 January 2009**

I called the TIAA-CREF rep concerning their new requirement that I must go to my local branch of The Bank of America and have a banker verify that I am actually the person who has the numbered savings account that I list as mine on the forms, the savings account that I am requesting that \$12,000 (minus \$2,000 for the U.S. government) be deposited in. I had a long conversation with the TIAA CREF rep, who put me on hold for a long time while she verified that there was no way around this new requirement.

Every year for eight years, I've withdrawn money from this pension fund account and had it deposited in this same savings account. A trip to my bank was never required. Now that I am in great pain from multiple myeloma and from the chemo, and am hardly able to walk more than a few steps without taking a breather, TIAA-CREF comes up with an additional hurdle I have to jump to get my money. As the rep says, it's a step that was added to protect me and my money.

I told her that it seemed to me to be a step designed to protect me from my money. This is a comment I will make more than once. I asked her, "If I was requesting you to deposit the money in my checking account, would I need to go to the bank and get this form signed by my banker?"

"No, you wouldn't. Only when the money is going into a savings account."

"Explain that to me. That seems arbitrary and makes no sense to me."

She gave me a long, long explanation which boiled down to four words. "Those are the rules." Okay, I'll jump through that hoop. More like I'll shuffle through the hoop the best I can. When I explained my physical condition to the rep, she said that it sounded as though the time had come for me to give my wife power of attorney. Probably true. What stops me? Well, when my father gave power of attorney to my mother and when my father-in-law gave power of attorney to my mother-in-law, they only had months to live. I'd like to think I've got years ahead of me, but I might be kidding myself about that. Giving Michele power of attorney is the sensible thing to do, but the negative symbolism of that act is powerful.

Michele and I went to the bank. I drove. I looked mighty scruffy, and I didn't bother to exchange my sheepskin slippers for street shoes. Too painful to contemplate. I did drag a comb through my hair. I parked my Ford in the handicapped space right in front of the bank and painfully dragged myself out of the Ford. In a few minutes I was standing in the snow and slush. The trick would be to get into the bank

without falling down. I did it, with great help from Michele. We went to the island in the front of the bank where you go to get help from a personal banker. We had a long wait before we got a banker to help us.

She read the form and asked, "Where is your statement?"

"Statement, what statement?"

"Your pension fund statement, so you can prove that you have a TIAA CREF account."

"No, that's not what you are supposed to do. You are supposed to witness that I am the guy who belongs to the savings account that the TIAA CREF withdrawal is going to be deposited in."

"No, no I must have a statement that shows you have a TIAA CREF account."

I could see that we were not going to get anywhere with this banker, so we jumped to a different banker. Same story from her, but she had the bright idea that I could pull up my TIAA CREF account online and she could verify the account that way. With great pain and shaky fingers, I eventually did so.

Our personal banker scrutinized the statement, and complained that there was no account number. I about lost it then. Standing on that hard bank floor, leaning over the low desk, was not putting me in a good frame of mind. It was like torture. Finally she agreed to sign without finding an account number. We mentioned that we needed the spousal form notarized. She said she'd be happy to do that. I was getting more and more unsteady on my feet. She then offered to fax the forms for us to TIAA CREF. Okay.

When we were leaving the bank, I somehow caught one of my slippers on the edge of a bank chair and almost fell to the floor, but I caught myself. Pain shot through my body, but we got this task done.

I told Michele that when we got home, the first thing I'd do would be to call TIAA CREF and find out what the bank was supposed to do with the form.

We got home, parked the car on the lawn, and I carefully made my way through the accumulation of snow to my front porch and into my house. I went to my computer, pulled up the phone number of TIAA CREF and called the rep. In our short conversation, the rep assured me that the form was clear that all the banker was supposed to do was to verify that I have a savings account at their bank and that I am who I am. They are not supposed to ask anything about my TIAA CREF account and they certainly are not supposed to require that they see and examine my TIAA CREF statement. The rep said several times that the form clearly explains the role the bank is supposed to play. I told her that the form wasn't clear enough for Bank of America bankers. The rep said she'd communicate my complaint to her supervisor. Right. And next year, if I am so lucky, I'll be going through all of this same stuff again, plus whatever new stuff they dream up between now and then.

## **Tuesday / 6 January 2009**

When I was up and down during the night to use the bathroom and to take my medication, I soon realized that my mobility was reduced considerably by the pain spasms I got when I put any weight on my left leg. The pain was strong enough to make me think twice about doing anything to provoke it. I ended

up stranded on a tall stool in the kitchen, unable or unwilling to go anywhere. Michele set me up with a telephone, and a piece of paper to write on, my John Shannon novel, *Concrete River*, and my Group Health number, just in case Group Health called in response to the message I left earlier at Dr. Norman's office informing him that the pain from my spine had returned and that I was basically immobilized by it. He's suggested at our most recent appointment that the pain could return, and that if it did, the next step would be for me to have my spine irradiated, as that sometimes reduced pain coming from the spine.

Michele left to go to a medical supplies store, to find a walker for me to use. We hoped that if I had a walker I could shuffle around the house without putting weight on my left leg, as that seemed to be the trigger. I sat on that cold oak stool halfway between the bathroom and my Zero Gravity chair and tried to focus on reading *Concrete River*. I couldn't focus, as my mind kept going back to my situation. As the singer has sung, my mind had a mind of its own. I tried to not think the worst of my situation.

Soon Michele was back with the walker. She placed the contraption, a Two Button Medline Walker, in front of me, and I carefully stood up and placed my weight on the rubber covered handles of the walker. I shuffled away from the stool. No pain. I was able to walk, with the aid of the walker, all the way into my computer room, where I carefully sat down in my chair in front of the computer. No pain. No twinges. Certainly no spasms. Food for thought.

I had mental images of all the doddering oldsters with walkers who I have intersected with through the years. Was I always compassionate and understanding? No, I was not. Do I believe in karma? Do I believe that what goes around comes around? Or do I believe that my being unable to walk without an aid is just the luck of the draw? I don't know. I'll have to think more about this. I know that life is much harder for a person who can't walk. But I also know that millions of people are in this boat, but still lead productive, pleasant lives. I'll have to struggle to get my mind around this new development. Hopefully, this is a temporary setback. After all, just a few days ago, I was able to go to Kent Station with my wife and daughter to see the movie, *Yes Man*. So maybe, in a few more days, I'll be back in that sort of shape. Only time will tell.

I called Dr. Norman's office and left a message informing the doctor that my back pain had taken a turn for the worse and that I was ready to discuss with him the option he mentioned in passing during our most recent office visit. Dr. Norman said that if I experienced increased back pain, I should consider radiation of the spine. The way he said it, it sounded more like "when" than "if." I think that Dr. Norman has a good idea what's in store for me. And none of it is good. This sort of makes Dr. Norman seem like a prophet to me. No details of this treatment were discussed, but I got the impression that radiation is much less invasive than the procedure that was done to my vertebrae. I am eager to move in this direction. I will call Dr. Norman's office again tomorrow if I haven't heard back by noon from Dr. Norman or Vicki, his nurse.

I am getting around great with the aid of the two button walker, but would prefer to be walking unaided with no pain.

## **Later**

After dinner I took my first shower in a couple of days. Having the walker gave me the confidence that I needed to go through the ordeal. Michele was with me every inch of the way. I couldn't reach up to shampoo my hair nor to rinse it, so Michele did that. When I got out of the shower, Michele dried off my legs and feet. They might as well have been in Idaho, they were so inconveniently located. Then I struggled into my clean clothes. Keep in mind that I was hanging onto the walker throughout this process. Michele helped me at every twist and turn.

If I'd doubted what the caregiver role entailed, this shower exercise brought me brutal clarification. During the process, I got close to pain spasms, but times due to my laughing at the silliness of it all. Michele is my caregiver, but I think more of her as my angel of mercy, clad in rose pink cashmere.

Now I am settled in my Zero Gravity chair, listening to Muddy Waters sing "I feel like going home." I am the lucky one. I am home.

## **Part Eleven**

### **Wednesday / 7 January 2009**

I am sitting in my Zero Gravity chair. The wind blew hard all night long and the lights flickered many times, but we didn't lose power. I thought about being stuck in the Zero Gravity chair in the extreme position if the power did go out. That's another bridge I can't cross ahead of time, but it is a worry. I am comfortable in the extreme position, but wouldn't know how to get myself to a standing position without using the lever that's power operated. When I bought the chair at the Relax the Back store, this thought occurred to me, because they had this exact chair available in a manually operated version. But the manually operated chair was somewhat herky-jerky so I opted for this smoothly operating power chair, a chair that's slave to electricity. The wind is still tossing the trees around.

Thinking of my Zero Gravity chair made me think about how quickly it was possible to buy the chair, get it delivered and installed and settle into it. It was the same with the walker, but faster. The commercial establishments devoted to providing products to people with special physical needs respond immediately and they are flexible and dedicated to pleasing the customer.

If only the VA and the Bank of America, had that attitude. It seems impossible to make progress with the VA. There's no way to get a sense of where the claim is at any given time. The process is a mystery. Ideally, the process would be totally transparent, but letters of inquiry are never responded to. Telephoning and email don't result in connecting with anyone who knows or cares what's happening with my claim. Just the opposite of the way that the Relax the Back store operates.

I knew who to call and when I called Mike, he answered the phone and was glad to talk with me. He told me exactly what stage my chair order was in, and precisely when it would be delivered. The VA needs to move in the direction of this model. Group Health is at least moving in that direction. Group Health operates much more like the Relax the Back store than it does like the VA. So that means to me

that the VA could choose a different and better path of communicating with veterans. I have faith that sometime soon I'll have a conversation with Dr. Norman or his nurse Vicky.

**8:45 am**

As I wrote the above words, Vicki called and discussed with me the radiation of my spine that Dr. Norman had proposed at the previous office visit. He's in Seattle today, but Vicki said she'd call him and discuss scheduling this radiation procedure with him. She said this procedure was non-intrusive, more like receiving an x-ray. I can handle that, if I can get there.

**9:15 am**

I'd hardly read one chapter in the second John Shannon/Jack Liffey book, and Vicki called me back. She'd talked to Dr. Norman and he wants me to get moving on this latest development today. I am to go to Tacoma Group Health this afternoon and get my back x-rayed so that Dr. Norman can decide what part of my spine will be treated with the radiation. Okay, I guess I can do that, with the aid of my new walker. This will be an adventure, as I've not ventured out into public with my walker. I haven't tried to get down the front steps either. I looked out at the steps and wished there was a ramp there. That might prove to be the next necessary step, a ramp in front. It'll be an eyesore, but it might be necessary. Or not, if the radiation treatment works and resolves the pain in my spine. I'll have lots to write about when I return from Tacoma.

The chapter of the Jack Liffey book I read had a quote in it about the Vietnam War proving to be the defining event of my generation. Certainly the Vietnam War has defined much of my life, and now it's reaching across the decades to define my dying and death. War has a long reach, and you never shake off its influence.

**Wednesday / 2:40 pm**

I am back from the journey to Tacoma Group Health for x-rays of my spine. Just getting out our front door, down the steps and into the driver's seat of the Ford was an ordeal. I wouldn't have been able to do it, if I didn't have the railing to hang onto. Weeks ago, during the worst snowstorm in Maple Valley's history, my dear friend Guy Libby, came over and measured my front entryway and the door way into the house for railings. He left and returned with materials for installing railings at both entries. The materials he used look as though they were left over from a Dream Home he built. Nothing but first class. He had both railings installed in less time than it takes to tell about it, and he did his usual beautiful work. I've not used the railings in any important way until today, but today they were life savers, both coming and going.

I drove us down I-5 in a rain that left much of the roadway covered with sheets of water, but we got to Tacoma Group Health with no problems, and parked in the underground garage. There was no handicapped parking space anywhere near the elevator, so we parked at the far end of the garage, and I laboriously and painfully extracted myself from the car, and placed myself in front of the walker. The two

button walker made by Medline. I shuffled along in my sheepskin slippers, as I hadn't wanted to put myself to the trouble to change into street shoes, and soon we were in the elevator headed for floor 2.

We got to floor 2, offloaded from the elevator with much clatter of the walker and immediately noticed the huge crowd in the waiting area for x-rays. I checked in and resigned myself to an hour's long wait. I'd barely settled in when my name was called. Michele set up my walker, which she had folded so it wouldn't be in the way, and I shuffled up to the front and was ushered back by the tech guy to the x-ray area. He was the same guy who has taken many x-rays of me these past few months. He recognized me and we chatted. I didn't have to lie down on the x-ray table, but just having the x-rays taken while I was standing was not easy for me. I could feel myself going downhill, just a result of the process. Getting my jacket back on at the end of the process caused me to grab for the walker to keep from falling down. I found myself hoping that radiating my spine would perform a miracle and keep me ambulatory. I actually thought of this as the beginning of the end. I chided myself, reminding myself that my mother has used a walker off and on for at least ten years, and my mother is still amongst the living. I shouldn't see things as symbols, but just as what they are, aids, aids that can be stored when no longer needed.

I rejoined Michele in the waiting area, and we went back to the elevator and headed down to the basement. We fumbled around a bit before we found our car, but soon we were loaded up, me as the driver again. I wondered how I'd feel behind the wheel after going through the x-ray process, but I felt normal there, so was confident to drive home, in the rain. I did it, but was thrilled to get back home. I used the railing installed by Guy Libby to lever myself up the front stairs where my walker awaited me. I grabbed the walker and shuffled myself back into my house. My reward for this adventure, successfully pursued, was to be a sardine sandwich with green onions and mustard, served on dill rye, washed down with a lime drink. Lead me to them. Now I just have to wait for a call from Dr. Norman's office to set up the appointment for the radiation treatment of my spine. I expect that call tomorrow morning.

### **3:30 pm**

I got a call from Vicki, Dr. Norman's nurse. The x-rays were already scrutinized by Dr. Norman but told him nothing so I am scheduled for an MRI on Saturday at the Tacoma Group Health. I hope that I won't have worsened so much by then that I won't be able to keep that appointment. As I always say, only time will tell. I don't look forward to the process of the MRI. That will be like torture to get on that table and sent into that machine.

## **Part Twelve**

### **Thursday / 8 January 2009**

No call today from the doctors who are supposed to be setting up a consult appointment with me to determine if I am a favorable subject for having my spine treated with radiation. I hope that I am a favorable subject, but the MRI that I am having done on Saturday will partly determine what they think about that. So maybe I am putting the cart before the horse. I understand why I am doing that. It's the

pain of the back spasms I am now suffering from, and I do mean suffering. Neither the Percocet nor the muscle relaxers seem to reduce the pain in the slightest. Any little thing can set off a spasm, and I do mean any little thing. I have been a prisoner in my Zero Gravity chair much of this day, and that time was relieved only by my visitor, Jim L. who was kind enough to visit me today and sit with me while my lovely wife and caregiver, Michele, was gone for a couple of hours to visit with her mother. We talked about our boyhood camping and hunting experiences with our fathers and politics and the course of my disease. It was a pleasant relief from my bibliographic project of rereading all the Jack Liffey novels of John Shannon.

Michele needs to get out of the house more, so that she doesn't end up suffering from the caregiver syndrome of being trapped in a house with sick, demanding old person. Mostly I have been brooding off and on today about tomorrow's 11:00 appointment at Group Health in Tacoma for a 90-minute IV drip of bone strengthener. I am not sure that I am up to the automobile trip to Tacoma, and to the trek from the parking garage into the building where I receive the treatment. A couple of weeks ago that would have been duck soup, but now it will seem like the Bataan Death March. I suspect I'll be fretting about this appointment from now until it actually happens. And once it happens, and I survive it, then I'll begin to brood about Saturday's appointment in the same building for an MRI. An MRI is not a pleasant experience in the best of times, and this is far from the best of times. I suspect that this isn't the worst of times, not yet.

### **Friday / 9 January 2009**

Early this morning Michele took Allie to the airport so she could catch her flight to Palm Springs with her lacrosse team for the Sandstorm Tournament in Palm Desert. Then Michele rushed back home and helped me get ready for our trip to the Tacoma Group Health for my 90 minutes on an IV receiving bone strengthener. I did get from the house to Michele's Honda, but couldn't have done it without the use of the rail that Guy Libby installed by our front stairs. I used my upper body strength to lower myself down the stairs to the waiting Medline two-button walker, and then put my weight on the walker, caught my breath and shuffled to the car. Getting my big body into the car without provoking another spasm of pain was a trick but I did it. Michele did a great job of driving us out of our neighborhood, but the chuckholes in our gravel road hit me hard a couple of times.

We got to the parking garage under the Group Health facility and Michele parked, but wasn't able to park anywhere near the door to the elevators, so I carefully got out of the Honda, and used the walker to walk the entire length of the underground garage, and I did make it to the elevators without an incident or a serious spasm. We went up one floor in the elevator, checked in and Michele paid the \$15 co-pay. Then we waited a bit, and we were ushered into a small room where two little old ladies were waiting to be attached to IV's for their treatments. I ended up sitting on a hard, uncomfortable chair for most of two hours waiting to be hooked up to receive the bone strengthener. The person on duty admitted that I was overlooked somehow. Eventually I got hooked up and I read a *People* Magazine and got the details of the

death of John Travolta's son Jett. No matter how much fame and money a person has, a person is not given a pass on tragedy. I also dozed a bit, and thought what passes for great thoughts. I couldn't avoid hearing conversation in the room as well. One of the little old ladies was there with her son, and then spent a lot of time talking about cats and squirrels. She has a project going at her home where she's trying to teach the cats and squirrels to live together in harmony. Good luck to her with that.

Finally my treatment was over, and we had to face getting me out of the chair and back out into Michele's car. When we got to the car in the garage, we discovered that another car had parked so close to the right side of Michele's car that there was no way for me to get into the passenger side, so Michele backed her car out, and blocked the traffic in both directions for a few minutes while I struggled to get into the vehicle without falling over. Not an easy task. But I made it. My time in that uncomfortable chair had made my back especially sensitive, so every speed bump Michele hit on the way out was agony, but we paid our \$2 and got back out on Tacoma's streets and headed for the freeway onramp. Soon we were on I-5 and headed for home. I felt that I'd accomplished a lot, just getting through the treatment. I felt no different, and felt nothing at all during the IV drip treatment. I haven't read up on what I am supposed to feel, so have no idea what I missed. I do feel I wasn't up to driving today. I have too many different chemicals in my body, and too much pain in my back for me to trust my driving skills. Perhaps driving is now a thing of the past of me. Or maybe this is just a temporary setback.

### **Saturday / 10 January 2009**

The mail brought me two letters today, one from Group Health informing me that I have been referred to a consulting doctor at Tacoma Radiation Oncology Center to determine if I am a suitable subject for radiation therapy. I hope they determine that I am a fit subject, and I further hope that the radiation therapy eliminates my pain because I am having trouble coping with the pain in my back and legs. As I've said many times, I don't mind dyin' but I hate the pain and suffering that goes along with the process.

The second letter was from the Department of Veteran Affairs. I expected it to be a letter of denial, but it was not. The letter was properly addressed, and got both my name and address right. The letter informed me that my application is still being processed, and they apologize for the delay. They go on to say that I will be notified when they complete the processing. If I need to contact them, I must use the numbers and letters in the upper right hand corner of the letter. My name is still listed there as "D.A. Wilso." No second "l" and no final "n." Disconcerting but I am sure the federal government has their reasons. Even so, I am annoyed. I predict that my letter of denial will arrive in a month or two. And there will not be any personal touch to the letter, just the usual impersonal boiler plate stuff.

Today I had an appointment at the Tacoma Group Health at 4:45 for an MRI. This MRI is one of the hoops I must jump through to become eligible for radiation therapy on my spine. I was in too much pain to drive today, so Michele did those honors. She's a great driver, and a saint walking this earth, but I am the world's worst passenger. I suspect that all the meds I am taking make me even jumpier than I am

normally. Michele drives with panache. I am a slowpoke, stodgy driver so I was terrified all the way down to Tacoma and all the way back.

Michele had her car radio tuned to a golden oldies station and they played Carla Thomas singing "Gee Whiz." I gave Michele my usual lecture on the background of the song and the singer, and I mentioned she was the daughter of Rufus Thomas. After I did that I had a thought. I thought about how much I'll miss lecturing Michele and Allie when I am dead. Then I had a further thought. I won't miss that at all, as I'll be dead. I won't miss anything. It's hard to not be sad about that.

We got to Tacoma Group Health. The last couple of miles of roadway seemed to be mostly chuckholes and potholes, and we hit every one of them. The infrastructure of this country has gone to hell. The underground garage was closed, so Michele dropped me off in front of Group Health with my trusty walker. I slowly made my way to the 2<sup>nd</sup> floor and checked in for the MRI. Michele showed up just as I was handed a two-page form to fill out. I signed at the bottom of the form and Michele did all the rest, occasionally asking me a question. All the usual stuff was included in the questionnaire. Not one thing was new.

The waiting area was almost empty of customers, so soon my name was called. Michele and I went with the technician, parked our valuables in a locker and I then confronted the metal table that I had to lie down on, back to the table. My head had to be fit into a notch. Getting onto the table and arranging myself to suit the technician was exceedingly painful, but once I was all laid out, I only felt minimal discomfort. I was told to not move, and that the process would take about thirty minutes. I zoned out, sort of hypnotizing myself, and the thirty minutes, broken up by the buzzing and clicking of the machine and the disembodied voice of the technician, passed quickly. Then came the moment I dreaded, the time when I had to get myself off the table and back on my feet. I did it, but felt terrible every second of the process. I won't say I felt pain in every bone of my body, but if the pain missed a couple of them, I don't know their names.

There was no painless way to do it, so I sort of tucked and rolled, sat on the edge of the metal table, and stood up, clutching my walker. Michele and I retrieved our valuables and took the freight elevator down. Michele took off to get the car, and the technician stayed with me until I was near the front entrance where Michele pulled up her Honda CR-V to load me in. I did not feel good. I said to Michele, "I hope this MRI results in my getting the radiation therapy, and I hope that treatment works miracles."

Only time will tell. Michele drove us home, and I was eager to get there as I was parched. I wanted to drink many bottles of cold water. I drank one. The trap is that when I drink lots of cold water, then I must soon urinate, and the bathroom is a long painful slog for me from my Zero Gravity chair.

I tried working on answering some emails, but my legs, especially my right leg was in such pain, that I couldn't concentrate, so gave up the effort. Maybe tomorrow I'll feel better. The Percocet and the muscle relaxers don't seem to be helping me much these days. I need to have a conversation with Dr. Norman about that, or perhaps I need a referral to a doctor who specializes in the relief of pain. Something needs to be done.

The sooner the better.

Tomorrow afternoon I have my much delayed Agent Orange Directory appointment. I've been warned by everyone to not expect much from this appointment, but I can't help but hope that I will at least get some information about what to do next to try to get the VA pay for my chemo protocols. I have a vision of Michele pushing me down miles of hallways in a wheelchair and then nothing much happening on the other end. But I will go through the motions of faith, and consider that the VA really is an agency that wants to help me, but that the agency is just so unwieldy that they stumble over each other and their red tape trying to help. I don't want to think that an evil heart beats at the center of the VA. Maybe in a few weeks, I will feel differently.

### **Part Thirteen**

**Monday / 12 January 2009**

Today's big expedition was to the Seattle VA Hospital for a 2:00 appointment with the Agent Orange Directory doctor. We left Maple Valley at 1:00, and Michele was driving because I no longer had the faith in myself necessary to pilot the car that far. Maybe I could make it to the bank and back, but even a trip that short seemed beyond me. I don't know if it's the chemo or the multiple myeloma or just me, but every minute I am a passenger while Michele is driving, I am consumed by stark terror. My body goes rigid and I try to find something substantial to hang onto, but there really isn't anything like that available in the interior of the Honda CR-V.

Because my body is rigid with fear, every bump and every chuckhole the Honda hits causes pain in my lower back and in both legs. We made it alive to the front of the Seattle VA Hospital, but there was no place to pull in to get me out. The driveway that accesses the front entrance is entirely walled off by portable chain link fences. I assume this protection is setup due to fear of terrorist attack, but I don't really know for sure. What I do know is that the entrance to the VA Hospital is almost impossible to get to, whether by design or by accident. Michele dropped me and my walker off on the curb, a block or so from the entrance, and I struggled in the rain to navigate with the help of my walker, the rough pavement and broken sidewalk, while Michele looked for a parking space.

I waited inside the front door for Michele for about ten minutes. It was now 1:55. Many other vets also waited inside the door, most of them with walkers, canes or in wheelchairs. From where I was sitting I could see a large poster of a line drawing of an old vet, down on his luck. The caption of the poster read something like this, "You served your country, now we are here to serve you." Right. Michele showed up, all aflutter, to tell me that she couldn't find a parking space of any sort, not even an illegal one, so she was going to have to wait in the valet parking line. She told me to go ahead and make my way to Building 1, Room 122, to keep my appointment with the Agent Orange Directory doctor. I headed off down the seemingly endless hallways, toward my destination. I had my choice of stairs or ramps, so I took the ramps which were slippery but easier to deal with than the stairs. I actually passed a couple of ancient vets with canes, who were moving more slowly than I.

I got to Building 1, Room 122, and I checked in with the secretary at the window. Michele soon showed up, and we sat down and waited for my name to be called. Soon it was called, by the doctor himself, Dr. Peterson. I shuffled back to his tiny office and sat down on the examining table. Michele sat in the only chair. The first comment that Dr. Peterson made was that he could see we shared the same tailor. He gestured at the trademark name on my navy blue shirt. Carhart. Dr. Peterson had on a brown plaid Carhart shirt. I made some comment about how comfortable the shirt is. Then Dr. Peterson asked me a lot of questions. Some of his questions related to whether I'd served in Vietnam in the Army, where in Vietnam I'd been stationed, were my children born with any defects, have I had any diseases surgeries, etc? I've addressed all of these issues previously in the many forms that I've filled out and submitted to the VA,

I tried to figure out why the duplication. I guessed that it's due either to lack of coordination between different departments in the VA, or that they are trying to trip me up, so they compare my answers at different times and in different places and then call me to account on any inconsistencies. The process seems needlessly mysterious and confused.

I asked Dr. Peterson what process we had to go through to get the VA to pay for the chemo medication that I have been prescribed for my multiple myeloma. He said that this was the process. Dr. Peterson tapped my knees with a little hammer and asked me to go AHHHH while he looked down my throat. He listened to me breathe in and out. I had the thought that he's not going to learn anything about my multiple myeloma with these techniques, so why is he doing this stuff?

When the doctor asked me where I'd been stationed in Vietnam, I told him I'd been stationed near Saigon for the first part of my tour of duty and for the last part of my tour I'd been stationed at Long Binh. He didn't ask me anything about travel around Vietnam, which I did in my role as a stenographer for the Inspector General. He also asked me if I'd worked outside my MOS, and I said no, that I'd worked only as a stenographer. Dr. Peterson didn't ask me about duties I performed at the company level such as guard duty, shit burning detail, filling sandbags and so on. I was surprised he didn't ask about that stuff, but it didn't occur to me then to volunteer that information. He mentioned in passing that his son had recently been diagnosed with MS and that the VA was paying for his very expensive medication.

Dr. Peterson's manner was mostly brusque and matter of fact. The thing that kept sticking in my mind throughout the short examination was that I have already been diagnosed by Group Health doctors as having multiple myeloma, and I am currently receiving the recommended chemo therapy as treatment for the MM, so why am I being talked to as though nothing is known about me and my condition? Is that a method or ploy that VA personnel use to dissuade vets from completing the process or what?

At some point during the examination, Dr. Peterson asked me if the thalidomide I took each night helped me get a good night's sleep. I could hardly stand such a question. I said, "Not really." I told him that I took the stuff each night to combat the MM and that had nothing to do with a good night's sleep. I wonder where that question came from and what he was getting at. His question just seemed silly to me. Another question that Dr. Peterson asked me that seemed totally off the wall was if I'd been getting my

regular flu shots. He asked the question as though he had no doubt that I was. When I told him, no, I never get flu shots, he seemed nonplussed, but made no comment.

Dr. Peterson finished up his part of the exam and told us that next I was to subject myself to blood work, x-rays and an EKG. I wouldn't have minded the blood work, even though I am anemic and just had blood work done three days ago at Group Health, and I guess the EKG would have been okay with me, but the notion of more x-rays was anathema to me. I had a complete series of x-rays done of my spine at Group Health just a few days ago, and the pain of that process was still fresh in my mind. I raised the question with the doctor of whether it was necessary to duplicate tests that were done at Group Health recently. I am not certain what I was told about that, but I got the impression that the tests at the VA were a package deal, all or nothing.

We proposed to Dr. Peterson and Leigh Hayes that we use Leigh Hayes' computer to pull up the Group Health records that pertained to the required tests, and print them out right this minute, so that the Agent Orange Directory would have the records today. Leigh Hayes checked with her supervisor and then told us that VA rules prohibited doing that. Our option appeared to be for us to go home and print up the Group Health records and then mail them to Leigh Hayes. I didn't follow this logic, but I didn't want to be x-rayed again as I was already in so much pain from this trip to the VA Hospital that I wasn't thinking straight. Just contemplating the trip back out of the deep, dark recesses of the hospital, to get back to the front curb made me shake and shudder. Could they have put the Agent Orange Office any further from the front entrance? Probably not. Does it do any good for me to think the office is located where it is due to a plot or a conspiracy on the part of the VA to make this process of getting on the Agent Orange Directory list as difficult as possible? No, that mindset doesn't help. Dr. Peterson himself sort of raised this issue when he asked me if I'd made a claim against the VA for disability due to my MM. I told him that I'd filed such a claim months ago. He commented that he was the doctor who I would see for that evaluation, and he wondered why that test couldn't have been lumped in with this one. I told him that I didn't know why. The process continues to be a mystery to me. Leigh Hayes gave us a list of what we should retrieve from the Group Health records and mail to her.

Almost immediately upon leaving the Agent Orange Directory Office, it occurred to me that I was making a mistake to not subject myself to the VA's own blood work, EKG and x-rays. But I just didn't want to go through the pain of more x-rays. I figured I'd be kept waiting for an hour or two, and I was already in so much pain, I could hardly stand it. I was due for my Percocet and the muscle relaxers at 2:30 and it was already past 2:30. Both meds were at home. Where else would they be? I found myself trying to gauge where Dr. Peterson stood on my case. He was a hard man to read. I hoped that the fact that we both were wearing Carhart shirts would produce some sense of shared destiny, and that might tip the balance in whatever decision he made about me. Yes, I was clutching at straws.

Michele and I retraced our steps back to the VA Hospital entrance, where Michele retrieved her Honda from the valet. There was no convenient place for them to park the car due to the anti-terrorist precautions so I had to navigate through a lot of broken, rough sidewalk and struggle with my walker.

Every inch of the way I kept thinking I was making a mistake by not being a good soldier and allowing the VA to duplicate those tests. If we lived in a rational world the VA personnel wouldn't want to waste time and money doing tests that have been done over and over at Group Health. And what's up with a VA rule that doesn't allow them to print out test results from Group Health?

Michele said that the process seemed full of paranoia and assumptions that I (or any vet) was trying to put something over on the VA, trying to get something we hadn't earned or didn't deserve. I saw a glimmer of that when Dr. Peterson asked me when I went into the Army (January 1966) and when I'd gotten out of the Army (October 1967.) If you do the math, that's only 21 months, not the full 24 months that make up a two-year enlistment. His body language indicated that he had a problem with that, but he didn't ask me to explain, and I didn't volunteer that I'd extended my tour of duty in Vietnam by a month and a half so that I'd get an early out when I returned to the States.

Dr. Peterson did ask me what I did when I got home. I told him that I'd gone to graduate school and received an MLS, and then taken a job as a librarian. He asked me where I'd worked, and I told him that I'd worked at Green River Community College for 30 years. All the time he was asking me this stuff, my mind was racing, trying to figure out what that had to do with my being on a list that I'd been exposed to Agent Orange while serving in Vietnam. I guess I could see that his questions about whether my children were born physically normal were pertinent, but my being a librarian didn't seem to have anything to do with anything.

Michele theorized that his questions about my parents' health and the health of my siblings were meant to expose a familial tendency to cancer, thus discrediting my connecting my exposure to AO in Vietnam to my MM, so perhaps these other questions had a similar goal. Do I think Michele is overreaching in her suspicions about the questions? Probably not. Certainly the process feels unfriendly and discrediting to me, carefully (or carelessly) designed to deny this vet the money and care he seeks. This is an exclusionary process, not an inclusionary one, protective of the VA, not of the hapless veteran with MM or any other AO related cancer.

So, with my head whirling with all the above stuff and more, we headed home on I-5. It was a terrible, painful trip. I don't know if that was due to my meds having worn off, or the feeling of impotence that the interview with Dr. Peterson left me with. Oh, that mention of impotence reminds me that Dr. Peterson also asked me, after first asking me about urinary and bowel incontinence, about whether I was capable of an erection. That's another question that didn't seem necessary to the AO Directory process. That question makes me think that the doctor had no concept of what sort of pain I am in, that he thinks that I am up to such a passionate frolic. I have failed to communicate to him how much pain I am in. I tried. When he asked me about the pain and what I was taking for it, I told him that I was taking Percocet and that the Percocet wasn't making a dent in the pain. He then mentioned all sorts of other and better and more powerful methods of dealing with my pain, none of which have been made available to me.

Anyhow, the trip home was a nightmare. Every time we changed lanes, every time brake lights flashed in front of us, I was convinced we were goners. I am always a jumpy passenger at best, but I was

really freaked out during this trip home. Beyond the pale. I feel badly for Michele who as my caregiver is trapped behind the wheel carefully transporting me from appointment to appointment, but unless I am knocked out with morphine or some other powerful pain killer, I am going to be a first-class pain as a passenger. No matter how hard I try to take control of my worst instincts, I fail in the battle of mind over matter, and find myself letting out with involuntary cries, cries that anticipate a painful and fiery death in an auto collision, cries that the driver must find disconcerting and annoying, or even maddening in the extreme.

But we made it home, alive if not well. I immediately removed myself to my Zero Gravity chair, and Michele brought me cold water and my meds. I sat in my chair and thought that I should have stayed at the VA Hospital and gone through whatever tests the VA doctors wanted me to go through, but at that moment, I couldn't stand the notion of more tests.

### **Later the same day at 3:30 pm**

When we got home we picked up the mail. Nothing from the VA. There was a phone message from Dr. Wang's office, the Tacoma Radiology Center, asking us to call Stephanie and set up an appointment for a consult. Michele called her and set up an appointment for 20 January, Tuesday, with Dr. Wang. Dr. Wang will discuss treatment options with me. The options weren't mentioned, but should include radiating my spine in an attempt to reduce or eliminate the pain in my back. We'll find out when we meet with the doctor. Meanwhile, we can just stew and conjecture.

### **Tuesday / 13 January 2009**

Thank God, this is a day that I don't have to go anywhere. I don't have to haul myself out the front door, down the front steps and into Michele's Honda. I've spent the day reflecting on yesterday, and urging Michele to find me some stronger pain relief. Michele called Vicki in Dr. Norman's office and requested that she talk to Dr. Norman about a prescription for something stronger than the Percoset. Vicki said she'd look into the possibility of that. Michele also asked her to round up the records that Leigh Hayes wants for stage two of the process of getting me on the Agent Orange Directory list. She'll work on that.

The scene that kept going through my mind about my experience yesterday at the Seattle Veterans' Hospital is of Tom Cruise in the role of Ron Kovic in that great movie directed by Oliver Stone, *Born on the Fourth of July*. Tom Cruise was robbed when he didn't get the Academy Award for his portrayal of Kovic. The particular scene that's stuck in my mind is where Cruise as Ron Kovic is receiving physical therapy to walk again, and it's obvious to everyone but him that his legs will never work again. He has a totally gung ho, positive, can-do attitude, but then he falls and we hear bones break, or think we do, and then the next scene is of him marooned in a hospital bed in the most squalid room that a VA hospital can provide, all hope gone. He knows, and we all know, he's never going to walk again. What now? It's hard for me to not identify with that moment of truth, but is it my moment of truth? I'll know better

once I've met with the doctors about the possibility of radiating my spine, and maybe I'll know for sure once the radiation process has begun. Will it be one treatment, a series of treatments? I haven't got a clue. The magical mystery tour continues. I guess that the only way to get questions answered it to live through the process. And become an authority the hard way.

### **Same day, Later**

Michele got a call from Vicki, Dr. Norman's nurse, that the doctor had prescribed a more powerful medication for my pain, and that Michele could pick up the prescription at the pharmacy at the Tacoma Group Health. Michele was told that the prescription couldn't be filled at the Federal Way Group Health pharmacy because it was a narcotic. Also, Vicki said that if Michele brought her the list that we got from Leigh Hayes at the VA Hospital telling what records the Agent Orange Directory needs to put me on their list, she'll get what they have together to be sent along to the VA. Michele drove down to Tacoma and got the prescription. I stayed home in my Zero Gravity chair. When Michele got there, the prescription wasn't ready yet, so she had to wait, but eventually her name was called and she got the pills. She also gave the list to Vicki to work on. When Michele got home, I took one of the pills, and waited for the results. The pill bottle said I could take one or two every four hours, "as needed for pain." These do the trick. The name of the stuff is hydromorphone. I'll have to look that name up on line to see what's in this stuff. I think that two of them would put me beyond cloud nine. I might take two of them at bed time. Chair time, that is. It's great to not have to expect a spasm of pain at the slightest movement. Michele is my angel of mercy. I worried the whole time she was gone that something bad might have happened to her. If she were snuffed out in a car accident on I-5, what would I do? Michele is my life line.

### **Part Fourteen**

#### **Wednesday / 14 January 2009**

I had no appointments yesterday, and I have no appointments today, and none scheduled for tomorrow, so I have had the time and energy to reflect some on how the multiple myeloma has impacted me and how I live my life.

I lack the easy mobility to do the things I used to do as a matter of course throughout my day. I can with some difficulty, but always with a few pain spasms, find CD's and replace ones in my CD changer that I've tired of, but I've dragged my feet at then refiling those CD's I am done with, the result being a great messy stack of CD's on the top of my changer. I need to address that issue, but I hate to expend that much energy going back and forth using my walker between the changer and the cases I have my CD's stored in. Of course, I have hundreds of CD's stored in cases and places that I can't reach at all in my current state, so one result of my infirmity is that I am listening to CD's easy to reach, many of which I have not listened to in years, or in some cases may have never listened to. That's a good outcome of my situation.

I have a couple of plastic tubs on the floor of the family room in which I have placed lots of stuff that I'm currently interested in. I shoved this stuff into these tubs around Thanksgiving time to get the clutter out of the way. But now, because these tubs are on the floor, they may as well be in Idaho, as I can't get down to them. I can't bend, and I dare not go down on my hands and knees, both for fear of provoking pain spasms in my lower back and of not being able to get back up again. I can try to supervise my long suffering wife, Michele, and have her attempt to retrieve an item I think might be in the tubs, or perhaps dragoon Allie to the same task, but I hate to use up their energy and time in such a pursuit, as it's possible, even likely that the item I want isn't in either of those two tubs.

My mania for constantly neatening up the house must go unfulfilled. I am not straightening the pillows on the sofas, I'm not picking up dirty cups and saucers and putting them in the dishwasher, nor am I scooting in the oak stools at the kitchen counter, lining them up just so, but am leaving them all higglety pigglety, the way they sit without my obsessive attention. I am not rotating Allie's various colonies left around the house, back into her cluttered bedroom, so piles of her shoes sit here and there in the kitchen. I am careful to not entangle my feet in them when I laboriously shuffle my way from my Zero Gravity chair in the family room to the chair in front of the computer, but I must leave the clutter lie.

Yesterday, when Joaquin was visiting us, he and Michele and Allie finally dealt with the Christmas clutter in the living room. The first thing to go was the Christmas tree. Michele and Joaquin had much difficulty getting the tree out of the stand and out of the house. They've never been involved in this chore. So they had no experience to draw upon. That's my fault, of course. In the past, for 16 Christmases, I was always the one who removed the tree from the house. Michele and Allie would have readied it by taking all the lights and decorations off, but I would remove it from the stand, and finesse it out the front door and drag it to a place in the back yard near our little barn. I would always do this when I (and the terriers) were the only ones home. The terriers would hide in Allie's room for the duration.

After I got the tree out of the house, I'd replace all the furniture where it had been before being moved to make room for the ten foot tree in the corner. I'd put the framed posters back on the wall in their special places. Then I'd get out the vacuum cleaner and vacuum up the needles dropped on the rugs and the oak floor. Michele and Joaquin and Allie did all of the above this year, except for vacuuming. The vacuum cleaner isn't functioning these days. I suspect that there's a jam that could be easily removed by me. I'm the only one who has ever dealt with the various problems of upkeep on the vacuum cleaner, and I have no idea how to verbally direct Michele or Joaquin in how or what to do to make the obstinate thing work well again. That frustrates me, as my condition frustrates me in all other areas where I can no longer function as I always have. I look around the house and wish I could wave a wand and be what I was not so long ago. Just waving the wand would likely provoke spasms of pain in my lower back.

This brings me to the dead bunnies. Dumb bunnies for sure. For whatever reason, bunnies are attracted to the small fenced back yard that is the exclusive domain of our two terriers, Sweetie and Toby. Since my multiple myeloma has had a big impact on my mobility, two dead bunnies have turned up in that yard. The first one I was barely able to deal with. I had not yet become totally dependent on my walker, so

I was able to scoop up the dead bunny with a shovel and toss him over the fence into our woods. A week or so later, another dead bunny made an appearance. Michele had to deal with that one. She postponed and agonized at length, but finally she got a bag and a shovel and got the bunny into the bag and too it to our garbage can. The entire operation made her shudder and shake with revulsion but she did it. I would rather have done it, but I couldn't.

Things have changed around here. Things had to change in response to my physical changes, but change doesn't come easy. The division of labor in our house has come to an end. All of the tasks and chores that were my province have fallen to Michele, or perhaps to Allie. Of course, many of the things I used to do were unnecessary things, things fueled by my obsessive compulsive nature. Those are the hardest things for me to witness being left unattended to, because they attach to my core nature. But I have to come to terms, at least externally, with my not doing those things, with them just piling up. I think of a story my mother has told me about the few weeks after my father's death from brain cancer twenty three years ago.

She was putting away in the closet some dress shirts of my father's, and she noticed that some striped shirts had gotten mixed in with the white shirts, and some short sleeved shirts had got mixed in with the long sleeved shirts. She started to reclassify them according to my father's dictates, but then she caught herself, and realized that there was no further need for her to be a slave to this rigorous order. In fact there was no longer a need to even keep the shirts at all. They could be donated to the Goodwill. She felt a sense of being liberated, a sense of freedom. I can visualize my young widow feeling similar feelings at a later date, perhaps mixed with some sense of loss.

Of course, I am not quite dead yet. I have no idea when that event will happen, nor do I want to know, but I did foresee the time (now) that I'd be limited in my mobility, so that's why this past year I tried to get many loose ends wrapped up before it was too late for me. Maybe I'll get my old normal mobility back, as a result of the radiation treatment of my spine or as a result of the IV'd bone strengthening process, but I am still glad that I made many trips to Aaron Brothers Framing to get my Vietnam War artifacts framed and shadow boxed, to create what Allie has labeled "a shrine" to myself and my military career of twenty one months. Now such activity would be beyond me, and I'd not want to delegate such a task to anyone else. The directions would be too complex and arcane and arbitrary for anyone to understand. I am a guy who likes things done a certain way, so I preferred to do those things myself. I never have liked being waited upon. But for now such a life is forced on me by circumstances, and I must put on a happy face and be as good as I can be about the situation so I don't distress my loved ones who are doing such a great job of attending to my needs and waiting on me hand and foot. It's a tough situation for all concerned.

It is quite a stretch for me, but also for the others. Maybe I'll grow some as a human being. Maybe. But what I really want is to be the way I used to be. I keep thinking of Thomas Wolfe's novel, *You Can't Go Home Again*, and I realize the truth of that title. Okay, I know what he's getting at, but I am still hopeful for major positive changes being brought about in my mobility and in the elimination or reduction

of the pain that holds me captive. My consult with the radiation doctors isn't for another week, so I must find hidden reserves of patience. Patience is a virtue, I've been told, but it's a virtue I've always had in short supply. I want to get started with the radiation. I don't want to wait. Delayed gratification is supposed to be the key to success as a member of the educated middle class, but it's a key that has eluded me all these years. I've always felt that anything worth having is worth having right now, this second. Perhaps not having things that way will bring me closer to attaining wisdom. I am waiting.