

## A PENNY FOR YOUR THOUGHTS – 2

(December, 2005 - February, 2006)

Yesterday I closed the first essay called “A Penny For Your Thoughts,” not knowing when I would begin the next one. Little did I dream that something would happen this morning that I would need to record, but it did. I realize that I am using the “Penny” essays as a diary chronicling the progress of my disease, besides as an outlet for my thoughts. Hence some entries, such as the first one below, may not be pleasant to read. But I don’t know who I am serving with my writings, either, so I want to be as honest as possible. Maybe someone else who has PLS will find these essays some day and be helped by the medical reporting. If a certain entry does not appeal to you, please skip it and move on. With this introduction accomplished, I now take pen in hand (so to speak!) and begin to write.

**Thursday, December 1, 2005.** About 1:00 this morning I was lying in bed awake, my feeding pump chirping softly as it served me my daily portion, the humidifier humming soothingly in the background, when suddenly a little bit of acid reflux came up from my stomach into my mouth. That was not unusual, though it does not happen often. I swallowed and found it to be extremely bitter. The taste seemed to attach itself onto one spot in my throat and would not go away. My reaction was to cough, as though that could dislodge the taste. Instead, all it did was start a bad coughing spell, one of my worst.

In what I call a spell, I cough many times in a row without inhaling. When I absolutely have to inhale, my throat muscles constrict and I make a horrible, loud sound, taking in just enough air to begin coughing again. I have found that relaxing my throat as much as possible reduces the noise and sometimes allows me to draw a deep enough breath to have the one good productive cough I need to break the spell. I have coughed since I was a little girl, but the spells as I have just described them are part of my disease; they started here at Drum Hill.

Usually I swallow whatever mucous I bring up, being unable to expel it. Last night something different happened. After I had been coughing for a while, my mouth began to fill with mucous that felt like it wanted to come out. I did the best I could, using the tissue I was holding. By then my aide had arrived. She raised the head of my hospital bed higher than it had been, asked if I wanted water (forgetting that I may not drink water) and kept me supplied with tissues. Her presence was comforting.

Finally after several coughing and spitting episodes, I looked at the mucous. It seemed to be clear, but it was also streaked with orange. This might have alarmed me, except for two things. The first was that the pulmonologist I saw a couple weeks ago had asked if I ever coughed up blood. I said no, while also tucking away in my mind the fact that this could happen. That fact came in handy last night. The second was a memory that flashed back from childhood. I was in my bed during the night, with Dad by my side, holding a basin. I was coughing up bloody mucous and spitting into the basin. It had happened before!

Mom was good as a nursemaid when we were sick as children, but Dad seemed to work the night shift for us. I was often sick; waking in the night with a fever was not unusual for me. Once when I was about fifteen, and Dad was again on duty, I asked him a question: “Dad, am I a good girl?” “Yes, Verna, you are a good girl,” he said. “Then why am I so often sick?” I wanted to know. “I don’t know,” he replied. Obviously I was seeing chronic illness as a sign of God’s disapproval. Long ago I learned that my physical problems were not punishment from God. One day soon I will be totally healed by my Great Physician. I will never cough again or use a tissue in Heaven!

Finally my coughing subsided, my aide tucked me in and I drifted back to sleep. There was no sign of blood today.

**Sunday, December 11, 2005.** There were two mysteries in my head from my first entry. Did you pick up on them? First, why was the blood orange, not red? Second, why wasn't my aide alarmed? I got my answers at 7:00 this morning when I had another coughing spell, almost as severe as the previous one. I began spitting out mucous again and saw the same orange color. This time the light was better and I could see that the color came from my hands as seen through a wet tissue! As I said, that answered two questions, but it also raised another one: am I so susceptible to suggestion that hearing the doctor's question made me think I would have to cough up blood some day? If so, I must be careful.

**Tuesday, January 24, 2006.** So much time has elapsed and so much has happened since my last entry that I hardly know how to begin this one. I took time off from writing my thoughts to prepare a packet of stories and other writings for our children for Christmas. The centerpiece of that gift was to be six pages of anecdotes from my childhood and that of our children. When I was almost finished with that part of the project, I lost the entire six pages by accidentally hitting the wrong combination of keys. I was devastated! Since then I have heard stories that let me know how common it is to lose not only an article but even the entire contents of a computer! Yes, the stories made me feel better.

Then I wrote many cover letters in preparation for a large mailing of essays, all the while working on Christmas services for December 16 and 23. And then came a day I will never forget: Wednesday, December 21, 2005. That day Marty, George and Janet located the nursing home that they hoped I would eventually move into. In a short time I not only knew they had found the place, but that this was the time to move. After the service on December 23, we decided to aim for Thursday, December 29 to make the change. After that there was certainly no more time to work on essays. Not only did I have to pack, but I had to write a letter of explanation to give to those who regularly attended the worship services.

I did move to Sky View on December 29. (I intend to write a separate essay about the transition.) On January 2 I was ready to begin using my computer, but the only thing I could imagine writing was a reconstruction of "Anecdotes," the essay I had lost. This turned out to be a three week project, which will give you a idea of the snail's pace at which I now type. Yesterday I completed the essay and today I'm writing here. Good night for now. I'll try to write more soon.

**Wednesday, January 25, 2006.** What an unusual day this has been! It is now 4:30 and I have had nine visitors today, seven of whom were here at the same time. Again I identify with my mentor, the apostle Paul. When he was a prisoner in various places, people were allowed to visit him. Though he was alone at times, he also had company. Some brought Paul the things he needed, including encouragement. Others, both believers and unbelievers, came to hear him teach. I'm sure conversions took place in Paul's rooms in the prisons and everyone who visited left with at least something to think about, something that brought them closer to God. From his cells also came much inspired writing, letters both to individuals and groups.

I am not in prison, but I have been confined, both in Drum Hill and Sky View. People kept coming to me in Drum Hill and the same is happening here in Sky View. Leo visits daily and others visit weekly. Local family members come often and the ones at a distance come when they can. Friends from years ago and friends that I made in Drum Hill stop in. I am glad to see each one! My heart's desire is that God's presence be felt in this room and that eternal transactions take place as a result of my being here by God's appointment. I also want the things I write here to be a blessing to others long after I am gone, all for the glory of God. To this end I dedicate myself afresh to my beloved Lord, who has loved me with an everlasting love and won my heart forever with his lovingkindness. Amen.

PS: Two more visitors came Wednesday evening. Yes, it was an unusual day!

**Thursday, January 26, 2006.** Today I would like to write two stories based on things I observed while living in Drum Hill. I could title these stories "Lessons Learned From the Animal Kingdom."

One night I sat for over half an hour watching a beetle-type insect scurry all over my bedroom floor. It was a fascinating show! That insect would run at full speed until it bumped into a barrier, my file cabinets or the wall, for example. I could almost imagine a thought process going on, for instead of continuing to push ahead, it tried moving to the right or left until a path opened up for it to move forward again. I did wonder why it didn't watch where it was going thus avoiding all the head banging! Once the insect disappeared under my closet door. Soon it reappeared; obviously darkness was not what it was seeking.

What I admired was the insect's patience, perseverance and problem solving. Sometimes my walker would catch against an immovable object or my Powerchair would end up in a tight spot and I would feel trapped. Remembering the insect helped me to seek a solution instead of bemoaning my situation. I am still learning as I recall watching that tiny creature run around my floor. It was time well spent.

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For two consecutive days late last fall, migrating Canadian geese stopped for a meal on the grassy slope outside our windows in Drum Hill. One goose caught my attention: the one that was sitting down to eat. Why was it sitting, I wondered. Before long my question was answered. The goose got up and limped painfully to a new spot, where it sat down and resumed eating. The goose had a injured right leg! If I had not seen it move, I might have judged it (to my shame) to be lazy.

People as well as animals have different amounts of energy. For a time I boarded with a woman who had emphysema. Her doctor told her not to do anything standing that she could do sitting and not to do anything sitting that she could do lying down. That dear woman certainly was not lazy! On the second day that the geese were at our outdoor cafeteria, quite a few of them sat down to eat. I can imagine that, with all the flying they had done, some of the geese were tired. Why should they stand to eat when they could sit?

As I continued to watch the lame goose, it suddenly stretched out its right leg, held that position a few seconds and then shook it out before putting it back in place. That goose is doing its physical therapy, I thought in amazement. Though I often think of God as the Great Physician, I had never thought of God as the Great Physical Therapist! So now I had a new name for God as well as a reminder that I, too, needed to work at my physical therapy.

If God takes care of the insects and geese that he made, surely he will take care of us when we are boxed in, tired, stiff and sore. God loves all his creatures, including us!

**Friday, February 10, 2006.** When I came to live at Sky View I looked over the monthly schedule of activities to see what kinds of religious services were offered. Most prominent were Catholic services, held every Sunday and throughout the week. A Shabbat service is held once a month on a Friday afternoon and then there were two others, both listed once a month on Thursday afternoons: Episcopal Service and Christian Service. I decided to visit the latter two in January and found both to be similar communion services, with the Christian service conducted by a Lutheran pastor. Both men gave interesting sermons, enough to make me want to hear them again. Of course I refused communion since I cannot eat bread or drink wine.

Yesterday I attended my second Episcopal service. What a wonderful message the priest gave! First he read a lengthy portion of one of Paul's letters where he says he becomes all things to all people so that he might win some to Christ. Paul was not trying to blend in with others, the priest said, but was looking for some common ground from which to preach the gospel, even if it meant leaving his

comfort zone to do so. My mind and my heart were fully connected as the speaker went on to extol the benefits of believing and spreading the gospel of our Lord Jesus Christ. Communion today, he said, would be bread only and he went around putting a wafer in people's mouths while talking about the body of Christ that was broken for us. I shook my head when he approached me, and he passed me by.

When the service ended, I typed "excellent sermon" on my Lightwriter and drove up front where he could see it. He appreciated the compliment. Then I typed "can't eat bread" so he would know why I had refused communion. Never could I have guessed what happened next! The priest said I could receive communion without taking bread and promptly knelt on the floor beside me and began to pray. I was so stunned and touched that I began to cry. At that moment I felt like I knew what the communion of the saints meant. The priest rose and I truly felt as if I had taken communion. What an experience!

**Saturday, February 11, 2006.** Last year I wrote in another essay my shock when my neurologist talked as if I could survive the whole year. I had just ordered some Mary Kay facial products, enough to last me the rest of my life, I thought. I didn't want to leave behind too many makeup items to be discarded when I died. In December, just before I moved, I ordered more Mary Kay products! My distributor assured me that she delivers to Sky View. Just call when you need more, she said. I tucked away the information in the back of my mind.

Well, a whole year and more has gone by since the doctor's visit I mentioned. The time went so fast! When our son Paul was visiting from California last month, he asked me how long I thought I could reasonably expect to live. A fair question! Paul and I both know that any day could be our last on this earth; that's not what he meant. I told him that since my arrival at Sky View I had signed a DNR form. I had been concerned that having a DNR order might mean that nothing would be done to prevent your death if you were choking, for example. The staff here assured me that all sorts of methods are used to prevent death, but if your heart or breathing stopped despite their efforts, you would not be resuscitated. And so I signed, glad to have that piece of business off my mind. The DNR may shorten my time on earth or it may have no effect at all; I don't know.

On the other hand, my skin, blood and vital signs continue to be good and the feeding tube takes care of my nutrition. I met a woman who has been at Sky View for three years with a neurological disorder. Will I follow her path? I told Paul I felt I could reasonably expect to be here a year from now, but I couldn't predict what my physical condition might be. Mentally I should be alert; whether I can communicate is another story. Looking a year into the future signals a change in my thinking. I will continue, though, taking each day as a fresh start. It's amazing how the days pile up into weeks, the weeks into months and the months into years. Whether I live or die, I am the Lord's. It really doesn't matter to me.

**Monday, February 13, 2006.** Saturday evening and Sunday we had the biggest snow storm our area has had since 1996, with between 16 and 20 inches accumulating by the time it was over. How my situation has changed in the past couple years! This time I could enjoy the beauty of the whitening landscape knowing I was entirely free from the responsibilities that used to come with storms. Churches were closed all around, but even that didn't affect me, as I can no longer attend church services. How well I remember the years when, as pastor, I had to help decide whether or not to cancel services at Community Church! I'm glad others make those decisions now.

**Tuesday, February 14, 2006.** The above story, continued. Here in Sky View there was some adventure to be had related to the storm. The staff that was on duty Saturday afternoon and evening could not get to their homes, nor could fresh staff members arrive. One of my aides was

working for 48 hours before going home Monday morning. I cherish the memory of the half hour that she sat in the dark in my room Sunday night, watching the winter olympics with me, getting some much needed rest. She said she could hardly wait to see her bed. Last night she was back, well rested and ready for duty. I got a new appreciation for health care workers over the weekend. They work long hours on little sleep. God bless them!

The other bit of excitement centered around two workers who tried to go home late Sunday morning in a taxi. My room is on the fourth floor of our five story building and faces front, just to the right of the entrance, as you face the building. Down in the driveway my aide and I heard a vehicle spinning its wheels on the ice under the snow that was still falling heavily. The aide looked out and saw two employees getting into a taxi that was obviously stuck. She called two other aides and the three of them couldn't believe what they were seeing. The room was full of their questions: Why did the taxi come down the hill to get them? Why didn't they walk up the hill to meet the driver? Why do they stay in the car? They opened my window and hollered down, "Get out of the car!" And all the while the driver kept spinning the wheels. Even I knew the futility and danger of what he was doing. Finally the workers did exit the taxi; I suppose they met someone else at the top of the hill and got home. The taxi driver would have benefitted from the thinking of the insect I wrote about earlier! Later on, a tow truck got the taxi out of our driveway and I was left with a memory and a story to tell.

**Monday, February 27, 2006.** My mother, Florence Ziegler, is 97 years old today! We sent her a card, though I doubt if anything about this day will register in her mind. Still, I'm glad for this day in 1909 when Annie and Norman Hicks had a baby girl that they named Florence. I'm glad she grew up, met and married my father and eventually had me. I wouldn't exist were it not for my parents. Happy birthday, Mom! And thanks!

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I just reread what I wrote about the snowstorm. I used to call days like that Sunday "found time" – days when regularly scheduled activities were canceled, stores were closed, and there was nothing to do but stay home. I could stay indoors several days in a row and not get "cabin fever." That was all good practice for now, when every day is found time. I was not outdoors from December 29 until February 16, when I was transported by ambulance to Phelps Memorial Hospital to have my feeding tube replaced. That turned into a 24 hour adventure involving my family, a new hospital, new doctors and, eventually, a new feeding tube, one that can be changed at my bedside from now on. For me, going out means leaving my room to ride down the hallways looking at the art work, to visit the day room or to socialize. A really big – and wonderful – excursion consists of going to the first floor to watch the beautiful finches in our newly installed aviary. What a treat!

**Tuesday, February 28, 2006.** Today I want to write about something that has been on my mind for a long time. Literally I'm thinking of how my mind works and wondering if others have the same kind of inner conditions that I have. It's hard for me to understand why people would want to turn on the radio or television set for background noise. I want a quiet atmosphere most of the time, but that's because the inside of me is so noisy!

First of all, for at least the past fifteen years there has been a constant ringing in my left ear. I was told I would have to get used to it, and so I did. Besides that, two more things are always present: music and conversation. The music can be anything from the theme of a TV show to classical music to hymns or Scripture songs. At Drum Hill Leo used to put on a soothing music CD to lull me to sleep when he tucked me in for the night. During that time my inner music was often from those CD's. With effort I can change the music inside me, but I cannot get rid of it.

The conversation may be a replay of one that I actually had with someone or one that I would like to have, complete with visual images. Yes, my mind is full of pictures as well, but they are not noisy. Since I have been writing, the words going around in my mind are likely to be portions of essays. Often before I write a sentence it has been edited mentally several times. The words have no relationship to the music; they are separate entities.

One advantage of having a mind like mine is that I am never bored. I don't remember ever being bored, even when I was doing repetitive work in factories. And I don't fear losing my physical abilities, because then I can focus on and enjoy more the things my mind conjures up. A disadvantage is that the things I am reading or the conversations I am having with visitors have to compete for attention with what is already in my head. In other words, it's hard to concentrate. I cannot imagine clearing my mind to the point of silence; I simply couldn't do it.

I wonder how other people's minds function?

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Since I want to use the "Penny" essays as a way of letting people know my current condition, I will now conclude this second edition three months after I wrote my first entry and two months after moving to Sky View. I am adjusting well to living in a nursing home. Certainly I need this level of care. I do not use my walker at all any more, not even for transfers. My aides use a lift to move me from my bed to a shower chair and, after my toileting, bathing and grooming are complete, to move me from the shower chair to my Powerchair. I go to bed about 10 pm (my choice) and get out of bed about 11 am (the earliest my aide is available). While lying in bed I can watch TV, DVD's and videos. I'm enjoying that.

I can truly say I am happy and content. To God be the glory!

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Verna Kwiatkowski