

A PENNY FOR YOUR THOUGHTS – 12

JULY – SEPTEMBER, 2008

The 12th edition of my journal-type essay in which I write about anything I wish, while also recording the progress of my neurological disease, primary lateral sclerosis (PLS).

Saturday, August 2, 2008. At the end of Penny 11, I explained that I was sick much of July, but gave few details. Though it's August now, I'm going to start by recounting some of my memories of July. The first signs of illness came on the last day of June. That morning I told the nurse that my esophagus felt irritated. My exhaling felt and sounded like it was going down a bumpy dirt road rather than down a smooth highway. In addition, my coughing increased, as did my mucous output (clear) and my saliva supply. I avoided contact with the residents in those days and gave thanks for the medical staff who watched over me.

Other symptoms included mild nausea and heartburn, and then fever and diarrhea, which put me to bed for three days. The second week I began to feel better, to the extent that when my daughter Marty asked me on July 11 how I was feeling, I said I was 95% recovered from my illness. THEN – the next morning my low-grade nausea turned into vomiting. The next steps were predictable: vomiting blood, followed by a trip to the ER at Phelps Memorial Hospital. As before, I was put on a suction machine to remove through my tube the rest of the blood in my stomach (a painless procedure). Since blood tests revealed an elevated white cell count, indicating infection, I was admitted to the hospital, where I stayed until Thursday, July 17th.

I'm sure you can imagine the medications, tests and treatments I was given without my describing them. Suffice it to say that I returned to Sky View with a new super-deluxe feeding tube in my stomach, one that is so well designed that I can't imagine it would leak! (The leaking of my previous tube was a product of its design that I learned to work around; it was NOT the reason the doctor replaced it.) The endoscopic procedure used to put the tube in place found two small ulcers in my stomach that were new and discovered that my esophagus "was a mess." Back home I was more tired than usual for several days and, while my stomach was getting used to digesting food again after lying dormant for a few days, mild nausea made me keep a basin nearby, though I did not use it.

And then something happened that I never expected: about a week after my return, I suddenly felt MUCH better than I have felt in a LONG time! I still can't walk, talk, or change positions in bed, but my breathing has improved greatly, my mucous production has declined to almost nothing, and I feel a renewed energy in my body and in my spirit. Whatever the cause or combination of causes, I thank my God and all my caregivers, as well as all who have prayed for me.

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Here is a report I wrote in July. I am including it in this journal because it reveals a lot about life in a nursing home. I can clearly see evidence of God's care in this incident; I hope you can, too.

Tuesday, July 22, 2008.

A report from Verna, 413,

To 4th floor nurse manager; director of nurses; Diane; + whoever needs to know

Re my last 15 hrs.

What an unusual story!

Hassana put me to bed about 8:45 last night (Mon, July 21). Was in a comfortable position on my back, as usual. Cheryl came in about an hr later to give me meds & to hook up my feeding. Was watching TV – all usual.

My USUAL night shift (11-7) routine: Get 2 diaper changes. 1st time (between 1:30 & 3). I am then turned on my right side, toward the door. Usually have turned off TV by then and am dozing, so I give my remote to my aide. OCCASIONALLY I am absorbed in a show and keep remote, turning off the TV when I am ready. My 2nd change is between 5:30 & 7 when I am turned on my left side, toward the windows. (NOTE: Once in a while the night aide, pressed for time, skips my second change. Though I understand that, I don't like it because I usually get up late, since I don't eat lunch. Skipping me makes a long time between changes!) NEVER have I kept TV on all night.

This morning I awoke at 8:15, shockingly refreshed from a VERY good sleep! What's more, I was in SUCH a comfortable position! But wait – What was I doing on my BACK at this time of the day – and WHY WAS MY TV PLAYING??? It didn't take me long to realize that I had not been changed or turned AT ALL during the night! WHY? Surely my deep sleep had something to do with it; I would have rung the bell around 3 if I had been awake. Did my assigned aide, if new to me, think I was still in the hospital? I came back last Thursday.* I was so comfortable that I said nothing, even to the nurse who came in to turn off my feeding machine, which was beeping,** and to give me meds.

At 8:45 it occurred to me that I was VERY wet, so I rang the bell. Soon an aide arrived and asked what I wanted. When I indicated a diaper change, she said she would tell my aide, who, she thought, was busy at the time. When the aide arrived, I was disturbed to find that she was someone who had not taken care of me before, nor had she been told about my care routine. While my aide went to get instructions, I had a talk with myself. My conclusion was that, although her methods may be different from my routines, I would cooperate by letting her do things HER way. As it turned out, I had nothing to worry about! True, there were MAJOR differences, but she was SO competent and SO kind and empathetic that I counted it a PRIVILEGE to be in her care! After I had my Lightwriter on my lap, I asked her name. It is Angel, an aide from the 3rd floor.*** She noticed that my diaper was unusually wet; she also found a bowel movement there.

(Right here I must pause to commend all the aides I have had in more than 2-1/2 years at Sky View: NEVER has ANYONE expressed revulsion at finding a BM to clean up. This is a VERY important part of my feeling comfortable here; I realized early on that I didn't need to feel guilty or apologize for the way my body works at this stage of my life. Thank you SO much!)

Eventually Angel had me all washed, dressed, weighed****, and seated in my chair, with my Lightwriter, TV remote, towel (for drooling), and 2 tissues all in place on my chest and lap. Then I told her what had happened during the night, thus explaining the wet diaper. Her response? "But today's another day, right?" "Right!" I agreed. One of the Bible verses I live by says (emphasis mine): *"THIS is the day that the Lord has made; I WILL rejoice and be glad in it."* That's why I could nod so vigorously to what Angel said.

I am NOT writing this report to get ANYONE in trouble, nor to suggest that there are no other aides like Angel. Rather, (1) I would like to ask that I not be skipped in diaper changes, IF POSSIBLE, and (2) I want to commend Angel to you for her excellent work. NOTE: This isn't the

1st time I have wished I could commend someone officially without making others look bad. Can you think of a way to make this happen?*****

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And now for the REST of the story:

*Only a few weeks later did another probable cause occur to me. I suddenly realized that the night nurse had not come in at 6:00 that morning to give me the two puffs on my puffer. The nurses give assignments to the aides. Perhaps a substitute NURSE thought I was absent and passed the misinformation on. I know my door was closed, too.

**How did the nurse know my machine was beeping, since the door was shut? Shortly after I awoke, there was a knock on my door, and in came my former male aide, the one I have written about several times before. He said he had such a strong feeling the week before that he should come and see me. When I told him the news, he was so glad he hadn't come here and found out I was in the hospital. He heard the beeping and said he couldn't touch the machine, but he COULD inform the nurse. I was impressed by how well he has adjusted to being an EX-employee of Sky View! As my aide, he would have turned off the machine himself; as it is, the nurse came shortly after he left and handled the matter.

***She was probably "floating," a term used when aides leave their regular floors and work where needed for that shift.

****I weighed 144 lbs. I'm recording this for possible future reference. I'm also 5'4".

*****Diane, my social worker in Sky View, told me that if I had someone I wanted to commend, it would not be taken as a condemnation of others. That thought might be stuck in my mind from the past and is binding. I will let God set me free and follow my heart in these matters.

Friday, August 8, 2008. Marty came for a visit last night. Though she couldn't attend our service because of her new job, she said she thought of us while it was going on. I was glad to be there myself, after missing last month. George moderated the service, in the absence of Cliff and Barbara. He was assisted by Leo and Frank, with Earl at the piano and Janet handing out the song sheets. In addition to some other regular attendees from "the outside," Sister Jane was there for the first time. She is a nun that I met in Drum Hill, who became my friend and co-worker in the gospel. Intending to visit me earlier in the day, a series of circumstances kept her from arriving at Sky View until 1:45, just as we were gathering in the living room for the service. As she explained all this to George, Janet and me, we all agreed that she had actually come just in time, as arranged by God! She sat next to me, drinking in the scene. Afterwards, Sister Jane expressed her delight with what she had seen and heard. Isn't God awesome?

During part of her visit Thursday evening, I asked my daughter if she would give me a "facial": I wanted her to wash my face and then rub lotion onto it. She removed my glasses, gladly complied with my wishes, and put the glasses back in place. What a shock I had then! My vision was all blurry, no matter what section of my trifocals I looked through! I could think of two possible causes: either Marty got lotion all over the lenses (unlikely), or I was allergic to something in the lotion that was affecting my eyes. When I told her, she removed my glasses to wipe the smudges off them (her first thought, too). She held them up to the light, took a good

look, walked over to my desk, and then said with mock seriousness, “Oh! Did you want me to put YOUR glasses on you?)

How we laughed when we realized that she had put HER glasses on me! That is, MARTY laughed heartily; I did the best I could with what remains of my laugh mechanism. I really miss the ability to respond well to my keen sense of humor, which remains intact. I have often heard the term “to die laughing.” I wonder if that’s possible? Wouldn’t that be an interesting way to enter Heaven? Once there, the laughing could continue unhindered by disabilities! How good that would feel!

Monday, August 11, 2008. 50 years ago today, in Huntsville, Alabama, Leo and I became first time parents, when I gave birth to a son, whom we named George Thomas. Within eight years he was big brother to two brothers and two sisters, David, MaryBeth, Marty and Paul. We rejoiced at their births and we rejoice in them still! I have pictured George leading his siblings into their teens and then out of them into their 20s. When they were all safely there, he led them into their 30s – and then their 40s. Today he’s again on the move, preparing the way for them to enter their 50s. Wow! Our family is scattered across the country and we now span three generations, but what keeps us together, while also setting us free, is the eternal love of God that transcends space and time.

Saturday, August 23, 2008. I have been watching some of the Olympic events that have been taking place in China these past two weeks. It’s amazing what the human body can do with a combination of training and determination! During this time I watched two movies from my video tape collection that are based on true stories about the Olympics: *Cool Runnings* and *Chariots of Fire*. When I mentioned *Cool Runnings* to my son David recently, he told me an amusing story. While he was recovering at home from surgery a few years ago, he and his wife Dana decided to watch that movie. However, they soon had to eject the tape because it was too funny! Every time David laughed heartily, his incision site hurt! I, too, find the movie to be SO humorous, but it also has substance; it addresses some valuable life lessons in a way that moves me deeply.

When I find a movie I like, I enjoy watching it again and again. I remember the first film I watched repeatedly in the theaters; it was *Chariots of Fire*. The time was early in the 1980’s; when our daughter MaryBeth was a student at the university in Binghamton, NY. On a visit to her, I was thrilled to find that *Chariots of Fire* was playing at the local theater. Although I had already seen the movie three times, I told MaryBeth that there was nothing I’d rather do that evening than to accompany her to the theater for her first viewing of the film. We both equally enjoyed our experience!

Sunday, August 31, 2008. Today I finished writing a new essay titled *God Will Take Care Of You*. This is only the second essay I have written this year, besides the Penny journals. When I was in the hospital last month, I had plenty of time to think about all sorts of things. My conclusion was that my essay writing as a project was just about over, and I didn’t mind at all! Only one topic remained to be addressed, as far as I knew, and that is my thoughts on Abraham that I have been pondering for more than a year. Then came the energy surge that I mentioned before. For the August service, I introduced several old hymns that we had not used before, including God Will Take Care of You. Then I wrote a meditation to go with the hymn. After the

service more thoughts on the subject filled my mind until I saw not only the possibilities for a new essay, but one I could use for our September sermon! And now it's done! Amazing.

Monday, September 1, 2008. Labor Day is here already! How time flies! MaryBeth and her husband Charles, with their two sons, were here for a couple days over the weekend. MaryBeth, a gifted writer, is helping me with some writing projects that are more than I can handle. How I appreciate those who help me do what I cannot do! Thank you!

One of my nurses mentioned that she liked the color combination I was wearing. I smiled and thought of Betty, the aide who has dressed me 4 or 5 times a week for more than a year. She takes pride in seeing to it that my pants, shirt, socks and shoes are all coordinated, and I appreciate that. As I see her pleasure, I have often been reminded of the pleasure I got from dressing my dolls when I was a child ...

In particular, I think of Mary Ann, a heavy cardboard paper doll with a part I could insert into her feet, allowing her to stand upright. I remember how this doll became mine. Mom and Dad had an insurance man who visited them regularly to talk business. My brother and I loved his visits, for when he was ready to leave, he would give each of us a quarter – a FORTUNE for a child in the early 1940s! In 1941, when I was eight years old, Mom took us uptown to our Ben Franklin 5 & 10 cent store to spend some of our fortune. I saw and fell in love with a set of sturdy pre-named paper dolls at 15 cents each. I chose Mary Ann and took her home, eager to cut out her pretty paper clothing and begin playing with her.

The next year our family moved to a farm for what turned out to be a ten-month stay. In my bedroom was a window that faced the road down which we walked on our way to and from the school bus stop. Each day I would dress Mary Ann and stand her on the windowsill facing outward, as if she were looking for me. On my return from school I was so happy when I got my first glimpse of my doll! I still remember several of the paper outfits that came with Mary Ann!

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My friend Paul Pinsker died at Sky View, where he had lived less than two weeks, on Sunday, September 7, 2008. He was 96. His service was on Tuesday, the 9th at 12 noon. Between the asterisks is the tribute I wrote for Paul at his daughter-in-law's request. She read it at the service, with me at her side. I used my journal style of writing because I wanted to insert it into this Penny essay as well.

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A TRIBUTE TO PAUL PINSKER

Saturday, September 6, 2008. What a surprising day this has been! My regular aides at Sky View nursing home usually come around noon to begin getting me up for the day. But today a substitute aide arrived at 10:00 and asked if I was ready to get up. Eagerly, I said yes, and began planning what I would do with the extra hours in my chair. About 10 minutes later, my husband came in with a message for me: "Paul is dying. Richard and Marilyn are here. Join us if you are able." Leo knew I had issues to consider, the main one being that my disease has taken control of my emotions. But as I considered my options, I quickly understood that GOD had arranged for my getting up early, knowing I had an appointment to keep. Of COURSE I would go, and God would be with me.

I took the elevator from the fourth floor, where I live, to the fifth and entered room 519 shortly before 11:00. Richard told his father that both Leo and Verna were here and Paul, weak as he was, said, "I can't think of a better combination." Not long after that, he stopped communicating with words. But love doesn't ALWAYS need words. Love swirled all around that room, binding us together and wrapping itself around Paul. I stayed for four hours; the others, much longer.

During that time, Richard asked Leo if he would speak at Paul's service. Then Marilyn asked me if I would write a tribute to her father-in-law; if so, she would read it for me. That was quite a challenge! And now, from the many memories I have of Paul, I will select a few to share with you.

Leo and I moved into Drum Hill Senior Living Community in January, 2004, a couple months after Paul arrived there. Almost immediately we found ourselves sitting together, by assignment, at table 3 in the dining room. As we spent an hour or more at the table twice daily, a friendship formed between us FAR too strong for DEATH to conquer. Our mealtime encounters soon enlarged to pleasant visits at various places in Drum Hill, including in his apartment. Before long, on one such occasion, we met Richard and Marilyn, much to our delight. Eventually Paul also met every one of our five children and their families as well, and they mutually enjoyed each other. Love is elastic; it expands easily to take others in and then holds them close to the heart – forever!

Paul had the largest working vocabulary of anyone I have ever known; I was sure he was a retired college professor. How he laughed at the thought! When I found out his remarkable education was from observing life and reading, I admired him all the more. While he was conversant on so many subjects, he also remained a student, paying close attention to what others had to say. Paul was able to admit his error when subsequent information proved him to be wrong, another quality I admire. At Sky View I keep current with national and world affairs through television, thanks to Paul's influence. And that's not all! I remember when I read to him the first essay I wrote in Drum Hill. He liked it, but said it was too wordy. I edited it and found he was right: it WAS better when tightened. That was some of the best advice on writing I have ever received!

I must also mention Paul's keen sense of humor. His running commentary about the things he saw was SO funny that it became difficult for me to handle. At first he liked my laughter so much that he wished he could bottle some of it so he could hear it whenever he wanted to. I knew that my laughter was already abnormal due to my brain disease, a fact that he came to understand in time. When I progressed to the point where hearty laughing produced coughing spells, he tried to curtail his comedic comments for my sake, a sacrifice I appreciated.

Now I feel as if I am the one who has captured some of PAUL's essence – that is, his spirit – and by doing so, he will be with me always. Don't worry – you can do the same, for thus it is with things of the spirit: no one person or group can capture all of it. There's always some left over!

Sunday, September 7, 2008. Today I was again in the process of getting up when, about 11:30, Leo came in. He checked on my status, and then brought in Richard and Marilyn who delivered the news that Paul had died peacefully at 10:00. I was at peace, too. There is a time to be born and a time to die.

I will conclude my tribute with a poem that I wrote in August. In honor of the times Paul and I spent together listening to music, I named it "A Parting Song." Leo read it to him several weeks ago.

A PARTING SONG

We will meet again,
Although I don't know when.
I also don't know where,
Whether here or There.
But I can let you go,
For deep inside I know
It's part of God's good plan
That we will meet again!

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Tuesday, September 9, 2008. Sunday and Monday were busy days for all of us. I had a tribute to write, which I finished and printed about 6:00 Monday. In addition, I agreed to attend Paul's service if arrangements could be made on such short notice. George came here Sunday evening to help us. He called my friend Carolyn who – God bless her! – gladly agreed both to handle the transportation details and to go with me to the funeral home, even though she had to change her schedule to do so. George came back Monday evening to pick up my tribute, which he emailed to Marilyn and Richard.

Everything went so well this morning! Without rushing at all, Carolyn and I got on the Paratransit bus for the seven mile ride to the funeral home. Leo, Richard and Marilyn met us at the door and escorted us inside. What wonderful people we met there! Love was swirling all around those rooms, too! A rabbi spoke first at the service, then Richard, then Leo, and finally Marilyn and I. Our combined talks worked together well to present a comprehensive picture of a man who was truly unique. What a privilege it has been having him as a friend!

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Friday, September 12, 2008. I have been doing a lot of "eating" these past two months. (For those of you new to my Penny essays, "eating" is my way of expressing a deliberate attempt to imagine that I am eating. I savor every mouthful, and have no trouble chewing or swallowing.) It all began when I was in the hospital in July. For several days, while my stomach was healing, the only food I had was included in the endless bags of water that entered my body through my veins. As has happened before during hospital stays, I craved ginger ale; also as before, one small serving back at Sky View satisfied that craving.

But the "eating" continues to this day. I can't seem to get enough! I used to enjoy going to Wendy's and ordering a plain baked potato and a serving of chili. I would cut the soft potato into bite size pieces, pour the chili on top, and eat both together. What a meal! I have often "eaten" this potato-chili combination in the past couple weeks, including right now. I suppose this phase will end, as it has before, and I will go back to ignoring food. I wonder how others with feeding tubes handle the absence of oral eating? If you have some tips, please tell me!

Tuesday, September 16, 2008. Alvin died Sunday morning. He was a 4th floor resident who lived two doors from me on the same side of the street (hall). Most of us were surprised by the news, for Alvin did not appear to be sick. True, he used a wheelchair due to the effects of a stroke he suffered years ago, but he didn't just sit and bemoan his fate. Instead, he used his good arm and leg to propel himself all over Sky View. Alvin was interested in everything and everybody, and everywhere he went he was a Presence, with a capital P. He had a booming voice, a sharp mind, and a ready smile. A few months ago he was elected president of our resident council. And he was already growing his white beard for a role he enjoyed playing annually: that of Santa Claus for our Christmas festivities.

Once Alvin took part in a comedy program by reading jokes and riddles from a book he enjoyed. One of them quickly became a favorite of mine:

Question: How do you repair a broken tomato?

Answer: With tomato paste.

No remembrance of Alvin would be complete without mentioning his love of God and his Christian Science religion. With the zeal of an evangelist, he would seek out those who were willing to listen as he expounded on his favorite topics. He was an inspiration to many, giving them materials to read between his visits. I remember being so impressed with how calm Alvin was when his wife died. He said she had always been with God; now she was simply with God in a different way. Now the same is true of Alvin. Meanwhile, his absence certainly will be felt here at Sky View.

I have given my poem "A Parting Song" to the staff to be used in Alvin's memorial service. When the poem came into my mind five weeks ago, I had all sorts of partings in mind, not only death. For example, I gave a copy to my grandson when he came to say goodbye before returning to college. But now, in quick order, it has been used in Paul Pinsker's memorial service and will be used in Alvin's. God's timing is always right and he certainly has a plan!

Sunday, September 21, 2008. A persistent problem that I had with my telephone ever since I moved into Sky View came to an end this summer in an unexpected way. Rather than having my identity stolen, I had an additional identity thrust upon me, that of Danielle V. Gibbons (not her real name). Several times a week my telephone would ring and, since I can't answer it, a message would be left on my answering machine. Though a few were social in nature, most of Danielle's calls involved confidential business matters.

At first we tried to do the right thing by calling back and reporting the error. In particular, George took on the project of informing people that, instead of Danielle, they had reached his mother in a nursing home. When repeated notifications did not stop the messages, George began deleting them, while I practiced not being annoyed by the calls.

Then this summer Sky View installed another telephone system that gave each of us new phone numbers. Since then, every message left on my answering machine has been for me! I think of Danielle from time to time and wish her well.

Sunday, September 28, 2008. My physical therapist always wears pink uniform tops to work, though they are varied in style and print. Recently she came in with a new one covered with brightly colored flowers. I loved it! And I loved the memory it brought to my mind. Aunt Elsie,

who was actually my mother's aunt, was in her mid-80s when this story took place. Our family, during a visit, drove my parents from their home in Pennsylvania to Maryland to see Aunt Elsie, then a widow. Tall and slim, she was as spry and delightful as always. What a pleasure to be in her company!

Aunt Elsie, wearing a summer dress with a floral print, took a walk with us that warm, sunny day. She also kept us entertained with wonderful stories as we strolled, one of which is as fresh in my mind today as the day she told it more than 30 years ago. She said, "I was taking my afternoon walk last week, wearing this same dress, when I passed a group of teenage boys across the street. I heard one of them say, 'Look at that old lady over there! She looks like a walking flower pot!' " Aunt Elsie paused to chuckle and then added, with fake indignity, "I wouldn't have minded if they had said 'flower GARDEN,' but 'flower POT'!!" And then we all had a hearty laugh with her. What a great response to a comment she could have found offensive! Thank you, Aunt Elsie.

Monday, September 29, 2008. It's time to wind down another Penny essay. Other things are also concluding. I finished listening to an interesting book on CD: *Can't Wait to Get to Heaven* by Fannie Flagg. One of the main characters, Aunt Elner, reminded me so much of Aunt Elsie. The Mets' baseball season ended yesterday as well, with a crushing defeat made doubly sad by the fact that it was the last game ever to be played at Shea Stadium. And summer is ending. I know that fall started officially a week ago, but it still feels and looks like summer. Not for long, though!

As for me, I'm fine. There is little change physically and I continue to enjoy my days, rejoicing in God my Savior. Lord willing, I'll see you in Penny 13!

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