

## A PENNY FOR YOUR THOUGHTS

(October - November, 2005)

At least forty years ago I was riding quietly as a passenger in a car, my mind happily occupied with pleasant thoughts about current happenings, when another person in the car said, "A penny for your thoughts." I readily divulged the subject of my ruminations, assuming the person really wanted to know what was on my mind. After my disclosure, I found myself being scolded for spending too much time thinking about that topic! My reaction, fueled by hurt, was quite childish. I said to myself, "If I am going to be criticized for my thinking, then I will never reveal my thoughts again. I will keep everything inside."

Obviously, I've changed. My essays are full of my thoughts, none more so than DECISIONS, DECISIONS: Facing a Feeding Tube. There I used a diary format, a dated log of my thinking about the tube. Several people, including my daughter MaryBeth, remarked that they liked the diary format and thought it would work well with other topics. Immediately I thought of one entitled Facing a Nursing Home, but decided to go with a catchall title instead, one that I could use as a regular diary, writing about whatever I wished. Now that I have written this introduction, I will go on to my first entry.

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**Saturday, October 8, 2005.** A wonderful thing happened at the Drum Hill worship service last night! My son George, who conducts the service and reads my sermons, had just finished reading what I had written about the love of God, including references to God's everlasting arms. Obviously, George knew there would be a few extra minutes of time at the sermon's end, and he thought of a way to supplement what I had said. Here is my reconstruction of what he did and said:

"I often thought of God's everlasting arms being underneath us when I was holding one of our babies during the night. The baby would be squirming and crying and I would say, 'I'm right here. I've got you. You are safe and I love you.' After a while the baby would settle down and rest in my arms." As he spoke, George cradled his arms in such a way that you could almost see and hear the baby go from rage to rest. Then he continued:

"We are being held in God's arms. And what are we doing? Are we wiggling, fighting, hollering? Or are we resting in those arms, trusting our Father to keep us safe?" I was so pleased with George's extemporaneous talk that, when he was finished, I clapped! George is the perfect interpreter of my words; he also is good with his own.

**Wednesday, Oct. 12, 2005.** I have been thinking a lot about death lately, my own death, that is. Last week I was sick with a fever and congestion. We phoned my doctor who in turn phoned our pharmacy, ordering antibiotics for me. Two nights in a row I had extreme difficulty when I first got into bed, once with coughing and once with breathing. Both times I wondered if I would survive the night. Yesterday I was unusually tired. My physical therapy session was abbreviated as I could barely lift my feet or stay awake. Uncharacteristically, I stayed in bed after the stretching portion of my session so I could take a nap. I remembered the many stories I have heard and read of people who said they were tired, headed to bed for a nap and, in fact, died. I wondered yesterday if I would join their number.

Between the two troubling nights and yesterday, I had an interesting dream that I want to remember. I was standing with several other people in a small room devoid of furniture. Suddenly two men from my past walked in through the doorway, both breaking into friendly grins when they saw me. One was my father, who died in 2000, and the other was Cliff Parent, who died in 2004. Cliff and I

worked together in church for years; he was a family friend, as well. In my dream I observed how well both men looked. They were in their prime, perhaps forty years younger than when they died in old age. Both had a glow of fitness and health about them. They were nicely dressed in sport shirts (Dad's was plaid) and slacks. I thought I knew why they had come. Anxious to share the news, I left that room and entered a larger one where again people were gathered. I told some of them that I thought I would soon be going to Heaven. I had already seen the two men God had sent to help get me ready for the trip.

Yes, it was a dream, but I can't help wondering if it does indeed have meaning for me. If I am to go Home soon, that dream does indeed stir longing in my soul. To be healthy and vigorous – really alive – is so appealing! So is the thought of seeing Dad and Cliff and a host of other family members and friends who are already There. I'm glad I had that dream; glad, too, that I've written it down.

**Monday, October 24, 2005.** Many thoughts are constantly in my head. Finally I might be able to write some of them down. Normally early in the week I am working on the service for Friday. This week's service is already done! George is going to be absent this Friday and Cliff Cullum and Carol Thorne will take his place. To be fair to them, I got their material ready a week in advance. So I feel like I have a whole week to write what I wish! Now let's see ... where shall I begin?

– Janet said something interesting to me about ten days ago. She was talking about the work each of us has to do and then said, "Your work is to have PLS and that's a hard job!" What a novel thought! I had considered writing to be my work and wondered when it would be ending. I knew that life has value even if you cannot work, that God is interested in our being, not just our doing. But if having PLS is my work, then I want to do it well. I will work until the day I die, even if my work is to just lie in bed and be cared for, and then I will rest.

A bonus to Janet's remark is that now I picture my Mom, lying in her recliner in the nursing home, busy at work having Alzheimer's disease. And she is doing it well! Good for Mom!

– Speaking of nursing homes, that is another thought occupying my mind. This summer my children began looking at nursing homes in the area so they would be prepared if I needed to move into one. "We are looking for a private room where you could continue to write," Marty said. I greeted this well-meaning news with tears. Marty, who doesn't shy away from such things, wanted to know why I was crying. I told her (via my Lightwriter) that there were two reasons:

1. It would mean the end of living with Leo. ("What if you had to leave Ed?" I asked.)
2. It would end the Friday worship services.

She answered the first with a challenge: "We're expecting you to show us how to do it." Believe it or not, that was the right answer. I had showed them how to do many things by God's grace, and would continue to do so.

Marty misunderstood the second. "You will have another ministry in the nursing home," she said. "Look what happened when you came here." I explained that I was not thinking of myself; I was thinking of those who attend. In truth, preparing a service every week is stressful at times. But the stories behind some of the members of our congregation are remarkable. God is so good at bringing people together! They truly look forward to worshipping on Friday nights.

On the other hand, when we started the worship services on the first Friday of May, 2004, I never dreamed they would continue this long. I didn't even expect to live on earth this long! Some Friday we will have our last service. I must prepare for that.

**Wednesday, October 26, 2005.** I just got my hair cut in the Drum Hill beauty parlor. Earlier this year my hair was so thin that I thought I would soon want to wear a wig. After I returned from rehab at the end of June with my new feeding tube, I began having aides to help me with personal care. The first time Avis gave me a shampoo, she remarked that I had such thick hair! I had been noticing that, when I put my hand on the crown of my head, there seemed to be a stubble there, much like what remains in a field after the hay is cut. Could it be that new hair was growing among the old?

I mentioned all this to my sister-in-law Esther and she said, "Protein will do that." Never would I have guessed that my hair had been thinning because I wasn't getting enough protein! I am certainly happy, though, for this unexpected benefit from my tube feedings.

The stubble is gone now. My new hair has grown enough so that Rosa could cut it along with the old this morning. No wigs for me in the foreseeable future!

**Saturday, October 29, 2005.** I'm thinking of my brother Harold just now. He would have turned seventy today if he still lived on earth. Instead he is "in a land where we'll never grow old," to borrow a phrase from a song Johnny Cash sings on a CD Marty loaned me. Johnny is There, too, come to think of it. I wonder if he and Harold have met?

– I'm also wondering what to do about health checkups. I used to go to various doctors for routine examinations, but now getting me to the doctor isn't as simple as it used to be. And that's not all:

1. The progression of my disease makes some exams and procedures almost impossible. The last time I was at the dentist, just over a year ago, I had a traumatic time getting into the chair and even more trauma trying to keep my mouth open and having all those instruments in it. My mouth doesn't open like it used to. When I had my last eye examination this spring, I realized that I could not read the eye chart, since I can't talk. I also could not control my eyelids enough to hold them open for the tests. I decided then that as long as I can see, I will keep the glasses I have and skip the exams.

2. If routine doctor visits and tests did find something wrong, would I want to undergo surgery or drastic treatments with my body already compromised by PLS? And if the answer is no, why have the tests? I have not had my annual mammogram for over two years. The same is true of my sinus and dermatology checkups. I cannot imagine how difficult decisions like these must be for people without a personal relationship with our Lord Jesus. I don't want to neglect my body, but I need to prioritize: what must I take care of immediately and what can I let go?

**Saturday, November 5, 2005.** I have been thinking for some time about crying as a way of talking for those who cannot speak. An incident that happened two days ago will illustrate what I mean.

For over a year I have had a personal trainer (whom I call my physical therapist) come to work with me several times a week. Since both titles have the same initials, I will refer to her as my PT. She has done me a world of good, though some of her stretching has involved enough pain to make me cry out in protest or to bring tears to my eyes. She always responds, either by changing the movement slightly or at least with a sympathetic "I know."

On Thursday, at the end of my hour long session, I got out of bed and stood with my walker, ready to get into my Powerchair, parked less than a yard away. The problem was that I was not centered in the walker; I was over to the right, hence didn't feel safe. My feet simply would not move at all, much less to the left where I wanted them to go. The next plan was to move the walker to the right so I would be centered. But I couldn't budge the walker at all because my PT was standing on my right, holding on to my arm. I felt completely helpless, unable to follow my PT's patient instruction to weight shift and lift, AND unable to talk! That's when I started to cry.

My PT began asking me questions, which I could not answer. Trying to do so only made me cry louder. What I was trying to say with my noises was that I was in distress, and that message came through. But I had no way of communicating what was wrong. My husband, who was in the next room, thought the PT was hurting me with her stretching! Finally I was able to get to my chair and sit down. My crying stopped immediately. Now seated, I could use my Lightwriter to type out to her what I have already told you.

Since then I have been thinking about how babies and toddlers communicate through crying before they are able to express themselves with words. A particularly poignant incident came to mind from the year my family lived in a furnished, rented cottage in Sebring, Florida. I was fourteen years old, Harold was twelve and Bobby was about eighteen months old at the time. Mom laid Bobby on the brown leather sofa to change his diaper. Unlike his usual compliant behavior, this time he screamed and wiggled through the whole procedure. We should have known something was wrong, but we didn't. Instead, we tried to get him to lie still and be quiet. When Mom lifted him up, she saw tiny red ants scurrying about. Now we knew why he was crying: he was being bitten by ants! The remorse we felt burned itself into my memory and remains to this day.

Yes, tears are a way of talking, for babies and for people like me.

**Friday, November 11, 2005.** Dreams have always fascinated me. I can't imagine how the mind can come up with such interesting stories while the dreamer is fast asleep. I have been riding in a Powerchair for over a year now, and have yet to be riding one in my dreams. But I have progressed to walkers, at least. Sometimes I dream I am walking normally and then will realize what I am doing. "Oh, my goodness!" I think. "I forgot to bring my walker!"

The creativity of some of my dreams is illustrated by one I had a few days ago. I was "driving" up to a restaurant in my walker. There are many kinds of walkers, but this was mine: two wheels in front and two straight legs in the back. I came to a parking space near the front door, intending to leave my walker there while I went into the restaurant. The parking space was on a slight incline, so I thought I should put the brakes on the walker before leaving it. Someone noticed that I was getting frustrated and asked what was the matter. "I can't find the brakes," I explained. "When I want the walker to stop, I just press down on the back legs, but there has to be another kind of brake on here somewhere for parking on an incline."

End of dream, but not end of fascination. How did that dream happen?? I know I never saw or even thought of a walker parked in a parking lot!

**Friday, November 18, 2005.** On Monday of this week George and Janet took me to see a pulmonologist for the first time. He seemed to be quite informed about my case, as all my doctors are in the same medical group. Well into the visit, George said something that let the doctor know that we were people of faith. "That will make it easier to bring up my next topic," he said, that topic being end-of-life issues. I was so pleased with his perception! Faith certainly should make a difference, especially when the subject is death.

The doctor wanted to know how I felt about ventilators. "If my body is dying, let me go," I typed. But he wanted more than that. My understanding of what he said next was that even now, if an emergency arose and some health care workers put me on a ventilator, it would not be temporary; my condition is such that I would have to stay on the machine, perhaps for years. Since neither a ventilator nor a tracheotomy appeals to me, he strongly suggested that I sign a Do Not Resuscitate form right away. "Or you could take this form home and think about it," he said. I chose the latter. Janet thinks the doctor was talking about being prepared for "down the line"; I think his concern was more immediate.

Currently I am not having critical breathing problems. My other doctors suggested this visit so everything would be in place for a need that is sure to come. Now I know that just as my ability to swallow, cough, clear my throat, and blow my nose has already been impaired, so my breathing power will diminish as the PLS progresses in my brain.

I have not yet signed the DNR. I am puzzled as to why you can't refuse a ventilator without refusing a pat on the back or a manual heart massage as well. Must research this further. Will keep you posted.

**Saturday, November 19, 2005.** I hope to be able to get several thoughts down today, some old, some new.

– Last night we had our second Thanksgiving worship service at Drum Hill. I am totally amazed by that simple statement! Last year we celebrated Thanksgiving two weeks in a row. I thought I might as well use all the resources I had because that would be my last opportunity to use them. In January someone inquired about visiting a service in February. I said yes, but wondered if we would have them that long. Now look! I am busy planning the five weeks before Christmas and the New Year service. Will we actually have them? Only God knows!

On Wednesday Carolyn Burke was here. She is my nurse friend who stops in every week to take my vital signs and check on my health in general. There are many creative ways to serve the Lord! I told Carolyn about my doctors' visits and then added: "I don't expect to be on earth next Thanksgiving." She asked a very perceptive question: "Would you be disappointed if you were?" "No, I wouldn't," I answered. Carolyn then told me that, no matter what happens, she will stay with me to the end. Thank you!

I guess the tension between preparing to die and being productive while here will continue for a while. I must live one day at a time.

– Since I came home from Rehab with a feeding tube at the end of June, I have had a succession of aides to help me with personal care. We hire them through an agency for twelve hour shifts every night (8 PM to 8 AM) and for four hour shifts (8 AM to noon) five days a week. The other two mornings my friend Vallie Turner comes to help me. Janet spends two afternoons a week here, more if needed. My husband Leo works his schedule around my care the rest of the week. Leo has had to curtail many of his favorite activities to take care of me and I appreciate that. In fact, I appreciate all my caregivers!

I have written before about having difficulty with a story Jesus told in Luke 17 about servants: *Suppose one of you had a servant plowing or looking after the sheep. Would he say to the servant when he comes in from the field, "Come along now and sit down to eat"? Would he not rather say, "Prepare my supper, get yourself ready and wait on me while I eat and drink; after that you may eat and drink"? Would he thank the servant because he did what he was told to do? (17:7-9).*

Through the years I've had many thoughts on this scenario (all having to do with the master's being an able-bodied man, come to think of it!), such as: Why wouldn't the master get his own supper? Why wouldn't the two eat together? Why wouldn't the master say Thank You, even if the task were on the servant's job description? It's funny how being in my condition throws a different light on the subject. Perhaps the master was not physically able to get his own supper! That does not answer the other questions, though.

Sometimes an aide will not only work the overnight shift but also stay for the morning shift as well, 16 hours in all. Such was the case a few months ago. I was lying in bed thinking I should get up and go to the bathroom, for which I needed the aide's help. But I knew she was in the kitchen eating the

hot breakfast sandwich and drinking the coffee that Leo had so kindly bought for her at our local deli. *What would you have done?* I waited for what I thought was a reasonable amount of time to let her eat in peace and then rang the bell. She came to my door and said, "I will come as soon as I finish my breakfast, okay?" and she was gone. *What would you have felt? And what would you have done?* I was flabbergasted! I laid there, glad that I had a diaper on, and tried to make sense of my racing thoughts – which included the story from Luke. I thought: Didn't we hire you to take care of me? Shouldn't my needs come before your desires? But I did nothing except wait until she was ready to come. I have done a lot of waiting in my life. It's good to know how to wait.

I still can't understand the thought of not thanking servants. I regret that I am physically unable to say Thank You. I nod or smile my approval the best I can and occasionally type a note of appreciation, for I truly am grateful for all the help I get, no matter who gives it to me.

**Monday, November 21, 2005.** How happy I am to have this format for writing random thoughts! Something happened last night that I have now processed in my mind. Writing it down will help my family and perhaps others. It concerns Thanksgiving Day dinner.

MaryBeth and Charles, with their two young sons John and Graham, are coming from Massachusetts Thursday morning to spend a couple days with us. I didn't care what plans my family made for dinner that day because I knew I would not be going. Then Leo told me that MaryBeth wanted to eat in the Private Dining Room at Drum Hill so I could be there. Now I was involved after all!

I have always tried to avoid disappointing people. It never occurred to me to say "No. I cannot come." Instead, I started picturing myself in my power chair having what would be a treat for me: mashed potatoes and gravy or sweet potatoes and cranberry sauce. I wondered if we should take a blender to make the potatoes smoother. But lately I have been having serious coughing and choking spells, some involving food, some not. Maybe it would not be wise to stray from my usual diet now. But I still planned to be there.

It was my understanding that in order to use the Private Dining Room there had to be 8 to 10 people having dinner together. Leo had made the reservation and I didn't know if he had a special dispensation for a small group or not. For me, asking questions is not a simple matter. Knowing at least that there was room, I began to invite others to come. I asked Marty and Ed and told them they could bring guests. I suggested to Leo that he invite Paul, our 93 year old friend from Drum Hill. Janet said that, although they had plans for an evening dinner, she might be able to send a couple males to Drum Hill if we needed them.

And that was it until last evening. Leo told me Marty and Ed were going out for Thanksgiving dinner with another couple. "How many people are going to eat in the dining room?" I typed. "Six," he replied. I had not heard whether Paul had accepted the invitation, so I typed, "Which 6?" He said, "The Dyers are four, and Paul and me." Then he added, "And you, sitting in your chair watching us eat." That last comment stunned me into facing reality.

The truth is I don't want to watch people eat Thanksgiving dinner or any meal, for that matter. It's hard for others to imagine the loss of the ability to eat. I don't appreciate detailed reports about how delicious the ingredients of a certain meal were nor do I like to hear complaints about food. Like Japheth's daughter, I need time to mourn my losses. I have progressed to the point where I can now see the many food ads on TV without becoming upset. The rest will follow, but I don't know when.

With all these thoughts suddenly in my head last night, I began to cry. My aide was startled and asked me what was the matter. Of course, I could not answer that. (Try to imagine also losing your ability to talk!) My response was to cry louder. I cannot control the duration or the intensity of either my crying or my laughter any more. I must have cried off and on for at least a half hour last night,

while also getting ready for bed. Leo and my aide could do nothing but stand by, which is the right thing to do, incidentally. (The worst thing is to tell the person not to cry.)

Now I had more reasons not to go to the dining room: I could not risk crying or laughing spells, and both are likely on that occasion. Add to that the ever present threat of coughing spells and the fact that I drool, cough and yawn without covering my mouth, and break other rules of etiquette, and I think you can see why I do not want to be at the dinner.

Paul, at 93, has had to say No to his family several times lately. "My children have to realize that I am old and cannot keep doing everything I used to do," he says. I agree with him. Likewise my family and friends must realize that I am ill and cannot do everything they might wish I could do. And, by God's grace, they will.

How do I envision Thanksgiving dinner? My family says, "See you later!" and heads for the dining room, leaving me here to do whatever I want. All who are in the dining room – and I now leave that all up to Leo – have a wonderful time laughing and talking together while enjoying their food. Everyone is happy – and thankful.

**Thursday, November 24, 2005.** Today is Thanksgiving Day. Right now the Dyers, Paul Pinsker and Leo are in the Private Dining Room having dinner. Leo, wearing white shirt, dark trousers, bow tie, and an apron I made him a long time ago, is the waiter for the group. You know where I am. All of us are content. I am thankful.

The previous entry did help people understand how I felt. So far Marty, Leo, my aide, Janet, MaryBeth, Charles and a few others have read it. MaryBeth said she hopes that I, in turn, know that they were only trying to include me and hadn't thought of the other issues. I certainly do understand that.

**Sunday, November 27, 2005.** I fell last night for the first time in over fifteen months. I did end up on the floor one time this summer with a different aide but that time I did not fall; rather, I slid to the floor on purpose. It was during the night. I was trying to get out of bed to use the commode, with my aide by my side. When I sat up, I was too close to the edge of the bed and began to slide off. She valiantly tried to get me back onto the bed, but it was not working. Finally I indicated to her that I was going to slide down and, with her help, I did so. I told her to get Leo. With one of them on each side, and my guidance, we got me up with no harm done.

A whole set of circumstances led to last night's incident. For about two weeks I have had a rash in my right groin. It started small and we (the aides and I) used over-the-counter ointment that I had on hand. Realizing at last that this was not going to cure the rash, I asked Leo on Friday to phone my doctor's nurse. He responded immediately, so Friday evening I had my first application of prescription cream, with the second yesterday morning. During the day I noticed some rash in the left groin. Now I was really concerned.

I suspect that the rash has something to do with my use of diapers. I have no bladder control at all anymore and often am sitting in wet diapers. Mostly that is my choice; going to the toilet is a big production and I don't want to do it every half hour. Sometimes it is because no one is available to go with me to the bathroom. Leo thinks the problem could be alleviated by my taking in less water through my tube. Countering that is the caution several doctors have given me to keep myself well hydrated. I don't know how many ounces would constitute being well hydrated. Should have asked! Also I feel – rightly or wrongly, I don't know – that more water dilutes urine, hence is better for me. Anyway, last night I thought it would be good to sit in the shower and thoroughly cleanse my diaper area with soap and lots of water before applying the second dose of cream for the day. This would not be a full shower, which I take three mornings a week with aides. I typed my plan to my aide and

she agreed. All went well until I was getting out of the shower stall. Even with assistance, I had great difficulty getting to a standing position and onto the walker. My feet were beginning to take tiny steps in the right direction, so my aide turned to get my Powerchair into place. Just then my legs began to give way and I started to sit. I called out but before the aide could reach me, I had let go of the walker and was sitting on the floor. (Now that I'm writing this, I recall a similar incident this summer when a friend was able to quickly move the shower chair under me to prevent a fall.)

The aide called Leo. I assured both that I was not hurt. Then Leo stood in front of me and stood me on my feet. They got me onto the walker and we agreed on a plan to get me in my chair, involving my walking ahead a few feet. A problem arose right away: the wheel of my walker bumped against the leg of the commode and Leo was standing so close behind me that I could not move even half an inch. So I used my language of crying to indicate something was wrong. I tried to motion for Leo to step back, to no avail. How I wished they would have noticed the snagged wheel! I'm sure to them it looked like my feet just wouldn't move. Finally Leo said, "One way or another, you're going to have to get into that chair, and he spun me around and sat me down. It was scary, but it worked. Soon thereafter my feeding was hooked up and I was in bed.

Both of my floor incidents involved Leo's help, as well as that of an aide. I'm thankful they occurred when he was in the apartment and appreciate his help.

During the night, when Leo came in to flush my tube, (something the aides are not allowed by their agency to do), he said, "You have to consider whether you are able to stay here any longer." I know; but I also know something else. When I was in a nursing home for rehab this summer, I was washed by many different aides. Only one washed my genital area thoroughly; that was a day or two before I was discharged. She found a condition that took ten days of a prescription cream to clear up. There and in other nursing homes that I know of, once a week showers are the usual routine. How thorough that bath would be would depend on who was assigned to me that day. Aides and certified nurses' assistants are commonly responsible for ten patients daily. That's a lot! Once I rang a call bell for two hours before someone came. When she arrived, I couldn't use the commode, though I certainly did need my wet diaper changed! But yes, I know a nursing home in the near future is a distinct possibility. May God's will be done.

**Wednesday, November 30, 2005.** "With the Lord day is like a thousand years, and a thousand years are like a day." I see this verse in a different light now than I did before. This year marked the 50th anniversary of my graduating from college. Could 50 years possibly have gone by since we were all together on our college campus? On the other hand, could all that I have experienced since graduation squeeze into just 50 years? It all depends on the point of view I am taking at the moment. Sometimes time flies and sometimes time hangs heavy on our hands. I can look back on 50 years or even the 72 years of my life and assess what they feel like to me. God can look back on a thousand years and say it is like a day and at a day (like the day Jesus was crucified?) and see it as a thousand years.

At Drum Hill I have been considering three months to be a year for me. Thus it seems that I've had a feeding tube for two years, not six months. Knowing that my situation could change drastically at any moment, I do not plan ahead more than three months. That's why I keep writing; I don't know how many "years" I'll be able to do it. I've also decided to end this essay now, subtitled it October - November, 2005. By my new calculation, this diary contains 8 months worth of my thoughts, and that's plenty!

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Verna Kwiatkowski