

A PENNY FOR YOUR THOUGHTS – 8

JULY – SEPTEMBER, 2007

Friday, July 6, 2007. Last week when I was finishing the 7th edition of my journal, I mentioned how quickly the days pass for me at Sky View. It was then that I realized that my attitude toward time and my disease has changed. In an earlier edition I said I considered three months to be a year, meaning that every three months I lived with PLS equaled a year I might have lived otherwise. In other words, I saw my life on earth as rapidly drawing to a close. Now I would say I am almost back to real time, where twelve months equal a year. I take that to mean I'm feeling healthier. Also, I've had time to observe what PLS is doing to my body and find that the literature is correct: PLS moves slowly. So I will live and enjoy one day at a time with God and see what happens.

This evening, for the first time, I saw a rainbow from the window of my room! The full arc was visible, from the hills near the river, across the sky and into the tree tops in Croton. The nurse came in to prepare my feeding for the night and found me by the window. When I pointed out the rainbow to her, she said, "Well! That's a sight you don't often see!" She was right, of course. I am glad I had time to watch that beautiful sight until it faded away.

Saturday, July 7, 2007. Alvin's wife died last week. She lived on the 2nd floor here at Sky View, while Alvin lives two doors from me on the 4th floor. Alvin faithfully visited his wife, reading to her daily from the Christian Science devotional that they both enjoyed. I had no idea how he would react to his wife's death, but knew I had to say something to him. Two days later I was sitting in my doorway when Alvin came wheeling by. He stopped and we greeted each other. Then I typed, "I am sorry about your wife." He exuded peace as he replied, "That's very kind of you. But my wife was always with God. Now she's just with God in a different way." (That sounded so much like what Paul said to the Corinthians: "Whether we live or die, we are the Lord's." I've often thought Paul's comment makes death seem like nothing – which is actually correct. Jesus himself taught us that those who believe in him never die!) Then Alvin gave me a copy of a hymn from the Christian Science hymnal. The hymn, too, is peaceful.

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Recently I have developed a technique I call "eating". For just over two years I have been fed through a tube in my stomach. At first I didn't want to be around food or to even hear talk about food, that's how much I missed it. Then I practiced "looking through" the food, trying not to let my brain register the taste treat that I was missing. It is very hard to avoid food in our culture. Have you noticed how many TV ads are about food? And hardly any gathering, even here at Sky View, is complete without the serving of refreshments. My taste buds DO feel deprived at times. Believe it or not, "eating" helps! What I do is eat the food in my mind, allowing all my senses to become involved. I can "eat" any time, any place, as much and as often as I want – without gaining an ounce! I find it interesting that the food I "eat" most often is spaghetti with a thick tomato meat sauce.

My daughter Marty came to visit on Thursday. Apologizing for talking about food, she told me about buying sugar snaps in a NYC farmers' market the day before. She knew that would flood my mind with memories of my dad's vegetable gardens and my mom's cooking, as it did hers. What she did NOT know was that, as she spoke, I "ate" my fill of sugar snaps and oh, they were delicious!

Monday, July 30, 2007. A month and a half have gone by since Leo and I celebrated our 50th wedding anniversary and three weeks have passed since the announcement of that event appeared in our local newspaper, *The Journal News*. Marty first approached me with the thought of an article

back in April. At first I was reluctant. Marty was both patient and persistent in handling the subject with me, tempting me with the thought that people might be inspired by our story. In thinking it over, I found several good reasons for publishing the news:

1. It would give me a chance to publicly acknowledge God as the core of our family.
2. It would bring people who knew us in the past up to date on our family, our activities and our current status.
3. It might let people see that not all residents of nursing homes are sitting around waiting to die.
4. It might get people thinking about the meaning of marriage, including me.

And so, assured by Marty that there was no rush as the article could be submitted after the fact, one day in June I began to write. It occurred to me as I wrote that this was not much different from writing an obituary! I discussed the contents with Leo and then Marty and George edited the piece somewhat to make it fit the newspaper's guidelines for length. Here is the article as it appeared in the paper:

Leo J. and Verna Mae Kwiatkowski Celebrate 50th Anniversary

Leo J. Kwiatkowski, from Taylor, Pennsylvania and Verna M. Ziegler, from Annville, Pennsylvania were united in marriage on June 15, 1957. The two met while in college, he at Lehigh University and she at Millersville State Teachers College, through a regional meeting of InterVarsity Christian Fellowship. A common faith in God through Jesus Christ drew them together; that same faith sustained them through fifty years of marriage and keeps them vital now.

As newlyweds, the couple moved to Huntsville, Alabama where Leo was employed at Redstone Arsenal, first as a civilian and later as a lieutenant in the army. In 1960 the Kwiatkowskis moved to Yorktown where Leo began his career with IBM at the new research laboratory, continuing in marketing, then as a computer programmer until his retirement in 1992.

Leo was active in the community in many ways, including all phases of the Scouts; as an election inspector; and as a Section 1 track official. His voice was often heard as he announced music recitals, served as emcee for the Grange Fair and gave the play by play for Yorktown football games. Leo was, and continues to be, a Bible teacher who has served as visiting speaker in many pulpits.

Verna Mae's work almost always involved some form of teaching, all of which she enjoyed. It began with two years as Miss Ziegler in public elementary schools. She taught accordion and piano lessons at the Carrozza Music Center in Yorktown Heights; led Bible studies, including her Bible Basics seminars; was a religious educator at Pleasantville Cottage School; and was pastor of the Community Church of Yorktown, retiring in 2000.

Not long after that, Verna Mae began to notice signs of a neurological disorder diagnosed as Primary Lateral Sclerosis. The disease has progressed to the point where she can no longer walk or talk. She now lives at Sky View Health Care Center in Croton, where she continues to write, enjoys company, and holds a monthly worship service with the help of friends and family, including Leo.

The Kwiatkowskis have three sons and two daughters: George (Janet) of Yorktown, New York; David (Dana) of Clemmons, North Carolina; MaryBeth (Charles Dyer) of Hamilton, Massachusetts; Marty (Ed Ford) of Yorktown; and Paul (Marita) of Clovis, California. Eleven

grandchildren complete their immediate family: Eric, Evan, Paul, John, Sophia, Andrew, Amy, Amanda, Robert, John and Graham.

Now for some comments about the reasons I gave for writing.

1. All I can say in addition is “to God be the glory!” And I mean that sincerely. Our marriage, like many others, had its ups and downs, but through it all, God’s grace proved to be sufficient for the moment. I cannot praise God enough for bringing us to this point, which, in retrospect, seems to have arrived so quickly!

2. It is impossible to keep in touch with everyone whom at one time we called friends. Personal articles such as this allow people to review old memories (hopefully good ones!), or even to renew contact if they wish. I like to “put the ball in the other person’s court,” to use a tennis analogy. Now we will see what happens. (By the way, for the past three and a half years, since we moved from our house in Yorktown, I have used the name Verna, mostly for simplicity’s sake. For this article I used Verna Mae, as that’s the name people from my past would recognize.)

3. Many people have a real aversion toward nursing homes and vehemently state that they would never live in one. I am not at all embarrassed or upset that I live in a nursing home. And my family certainly has NOT “put me away”! Rather, I cooperated with them by moving into a place that was equipped to give me the physical care I need. I hope the article shows that at Sky View I continue to be the same person I have always been. If you find that hard to believe, come and see!

4. If a husband and wife are no longer able to live in the same house, is that the end of their marriage? Of course not! Marriage is much more than sharing a bed, a bedroom, a house. At Sky View I met Diane and Joe, a devoted couple both of whom are much younger than I. Joe had a stroke long ago and has lived here more than ten years. Diane spends the major portion of every day with her husband, sitting by him in our common rooms; lovingly caring for his needs; including him in conversations, even though he does not speak. It is beautiful to see! Diane told me she read the article in the paper about our anniversary and offered congratulations. When I told her I still considered Leo and me to be married, she wholeheartedly agreed. After all, she and Joe are still married! Who says every marriage must be the same?

Two incidents from the past helped prepare me for this kind of thinking. How well I remember a story Agnes told our Bible study group at least 30 years ago. She and her husband had four daughters, two of whom were living on their own at the time of the story. When her husband was transferred to a new location, the family bought a four bedroom house for their new abode. “Just think!” one daughter exulted. “We each get our own bedroom!” Agnes said a different arrangement never occurred to any of them. I tucked that information into my mind for further rumination.

Approximately ten years later the results of my musing brought comfort to my mother. She and Dad were different in many ways, but with creativity and give-and-take on both sides, their marriage lasted more than 69 years until Dad’s death in 2000. Mom usually felt cold, while Dad was very warm-blooded. So they would both feel comfortable during the night, Mom would put a sheet and perhaps one blanket over the whole bed and in addition, pile several blankets folded lengthwise onto her side. Then Dad began to desire air conditioning. Mom knew he needed it, but being in air conditioned rooms made Mom feel sick. Their solution was to put an air conditioning unit in the adjacent bedroom, which soon became the room where Dad slept. Once when I was visiting my parents, Mom revealed to me that she was uneasy about the sleeping arrangements. I knew immediately what she meant: Might GOD disapprove of their actions? “Mom, there’s nothing in the Bible that says a husband and wife must sleep in the same bed or in the same room,” I said. “There’s not?” she asked hopefully. “No,” I reassured her, smiling as the worry drained visibly from her face. What, then, is the meaning of marriage? If I had to put it into one word, I would choose the word

COMMITMENT: commitment to each other and, in our case, commitment also to God. The vows that we commonly use in wedding ceremonies certainly warn that things may not always be the way they are at that moment. Oh, how much can change – and so quickly! I appreciate the examples that I have witnessed or heard about of marital commitment, and even joy, in spite of difficult circumstances. Thank you! If you find encouragement from our story, I'm glad. And now: What would YOU say is the meaning of marriage?

Thursday, August 9, 2007. This was a special day for me! Within the past two weeks my friend Carolyn Burke gladly agreed to become my traveling companion, making arrangements with Sky View and Paratransit, going with me on the bus, and assisting me at our destination. Today was our first trip as a team, and it went so well! We went to a medical complex in Yorktown where I had an appointment to have the wax taken out of my ears. The ride was a half hour each way and the drivers took two different routes; many memories were stirred up as we rode along.

Carolyn handled all the paperwork at the doctor's office. The fact that she is a nurse who has experience working in nursing homes certainly showed in the way she handled the medical questions. Dr. Siglock was chosen by Sky View because his office was accessible to the handicapped and because he was willing to treat me from my chair. A bonus was that he was a very pleasant man who cleaned out my ears efficiently with minimal discomfort! Dr. Siglock said I should get my ears cleaned annually and that his office would send me a reminder. The funny thing was that the plan sounded reasonable to me. A year or two ago I would have laughed inwardly at the thought of living that long!

This day also was special because it contained a fine example of God's perfect timing and foreknowledge. During our adventure Carolyn asked me if I had seen our mutual friend, Vallie Turner. "Not lately," I replied. "She's been away." We had both missed her at our Sky View service on August 2. Carolyn and I had been delayed on our return trip and got back around 3:00. We entered an elevator that already had in it a resident in a wheelchair and several aides. When we got off at the fourth floor, Carolyn said, "Well, look who's here!" And there was Vallie, standing at the nurses' desk, trying to find out where I was. Her first question after we entered my room was curious: "Did you forget all about the service today?" What a story unfolded after that!

Vallie returned from vacation yesterday. Today, thinking it was the day for our service, she showed up before 2:00 only to find that no member of our team was present! People were gathering for a service, however. Still more puzzling, she heard staff members talking about going to get Verna. When no one showed up to conduct a service, Gloria, the Activities Director, went to Vallie and asked if there was anything she could do with the assembled group. Vallie said she would at least sing some hymns with them. Before she knew it, she had conducted a whole service, nearly an hour in length! Vallie said she talked between songs, prayed with them, and, because she had no Bible with her, spoke with them about Psalm 23. She really enjoyed her time with the group!

Then it was time to clarify the confusion. I told her that the Episcopal service takes place on the second Thursday at 2:00. Obviously, the priest didn't come today, nor was Sky View notified. That has happened before, not only on the second Thursday, but also with the third Thursday service. Usually when that happens, we wait a respectable amount of time and then return to our rooms. Once before there was a woman present who gave us an impromptu message on spiritual things. We appreciated her, too. The reason the staff talked about getting me is that I attend these meetings, if I can. They probably came to remind me, and found I was out.

While all this was being sorted out, two visitors came into my room. The first was an aide who had been on the elevator with us. "I recognize you from somewhere," she said to Carolyn. They talked a few moments and did indeed make a connection! Then the aide said, "I come to this room when I want to pray" and into my mind came a precious picture of this aide, on her break, kneeling by my bed, reading my Bible and praying. What a privilege! The second person was Gloria, who was

looking for Vallie. She gave Vallie a tremendous thank you hug along with appreciative words.

When Vallie and I were alone, we thought of the amazing work God was doing all around us and in our lives. Vallie was wide-eyed with the thrill of having been placed by God in the right place at the right time to serve him. It is awesome to be able to see God at work! I thought of Carolyn and the circumstances that brought us together in 2000 and that made her available to help me now ; I thought of how Vallie and I met in 2004 and how subsequently she and Carolyn connected; and my thoughts made me smile. My God is so good at weaving people together!

The Bible says the fear of the Lord is such a desirable quality; it is the beginning of wisdom and knowledge. But what is the fear of the Lord? I have a new definition as of today. What do you think?

THE FEAR OF THE LORD IS AN AWESOME AWE OF GOD COUPLED
WITH A DELIGHTFUL DELIGHT IN HIM.

Wednesday, August 15, 2007. Hearing some loud noises, my nurse came into my room about an hour ago to check on me. She was relieved to find that I was heartily laughing. "I thought you were crying," she explained. I understood! (Those who have read my earlier journals know that PLS has affected my ability to laugh. Sometimes the sounds I make when laughing are quite startling!) The source of my amusement is too funny for me to keep to myself, so I'm going to try to share it with you. Of course, this will make me laugh all over again! Hopefully I can keep the noise level down so the staff does not become alarmed.

Yesterday Leo read to me two long emails that he had received from Russ Reinert, a missionary friend of ours who now lives in northern California with his wife Donna. Here's how the first one began: "Hi everyone, What's up? Well, here are a few tidbits from our neck of the woods: Donna's garden produced some 18-inch-long cucumbers. Five were baptized the other night in the cold water of Blue Lake at our church's family camp." I tend to take the things I hear or read literally, but I knew something figurative had happened to 5 of Donna's extra long cucumbers. What could have happened that Russ would describe as baptizing them? Were they perhaps stored in a container in cold lake water until they were made into a salad sufficient to feed everyone at family camp? In this way, did they serve as a sort of firstfruits offering that might be likened to baptism? This was something I might never know, and it really didn't matter, so I went back to concentrating on the email.

When Leo read the second letter, written the next day, I found out others had also questioned those sentences. Russ said, "When several inquired about our baptizing cucumbers in the lake, we burst into noisy smiles. I hasten to assure you that we are not promoting some sort of vegetarian religious cult bent on immersing cucumbers to improve our status with God. It was just a matter of being poor editors of our own writings. But being thankful for all things, we're grateful that our oversight gave you chuckle to start your day." This afternoon I decided to read the letters myself. It was not until then that I realized 5 people had been baptized in the lake! That's when I burst into the laughter that brought the nurse to my room.

Can you imagine what a great loss it would be if you could no longer laugh heartily? Across the hall from me lives a man who does understand. John, in his mid-80's, is a wonderful storyteller. He also has emphysema. He likes to share his stories with me because I appreciate them and catch onto the jokes. For both of us, though, our laughing soon turns to coughing, and we retreat to our rooms. That doesn't stop us from getting together again whenever either of us has a story! I'm glad John is my neighbor. I think, if I had a choice, I'd rather lose the ability to laugh aloud than to lose my sense of humor. I can still smile, and I can laugh heartily on the inside, even at myself, as I have done by writing this entry.

Saturday, August 25, 2007. Here is another story about laughing. This morning Viris, my aide, was bathing me in my bed prior to getting me into my chair. I noticed that she was using the lotion that Carolyn and I had bought on our trip to the mall two days ago. While lying on my side facing away from Viris, I thought of a funny story about the lotion and began to laugh. First she had to find out what the noises were. When she saw I was laughing, Viris (like most of the staff) assumed I was laughing at her or at something she had done. When I shook my head “no,” she joined in my laughter, glad that I could still find things funny. But she also wanted to know what was the source of my laughing, which refused to stop. I told her I would write it for her, which I am now doing.

On Thursday Carolyn and I took another Paratransit trip, this time to the mall where I used to shop. One thing I wanted to buy was unscented body lotion, as strong fragrances give me problems. We couldn't find any, so I chose one that I thought would be the least fragrant. Back in my room, I was anxious to know if the lotion would be all right for me to use, so I began to type a message asking Carolyn to open the bottle, smell it, and give me her opinion. I didn't get far when I noticed a shocked expression on Carolyn's face. Then she said, “Oh! You want me to smell the LOTION!” I nodded, still puzzled about her reaction. A glance at my Lightwriter solved the mystery. The screen clearly said, all in capital letters: “U SMELL”. We both laughed so heartily! When she was leaving, Carolyn teasingly said, “Now that I've been thoroughly insulted, I'll go.” More laughter! Now I will show Viris this story so she can chuckle with us.

Wednesday, September 5, 2007. Here's a P.S. to the previous entry. In the following days my story circulated among the staff on the 4th floor, bringing many laughs. Several people told me they enjoyed my story and I was glad to smile with them. Last week a nurse came into my room while I was still in bed. As she was leaving she cheerily said, “Remember, you smell!” And with a wave of the hand, she was gone. I was stunned! What did she mean? Was she referring to my diaper? I didn't think so! I was so relieved when I understood that she was still laughing over my “U SMELL” message to Carolyn! Now I know how Carolyn felt when she looked at my Lightwriter; it was terrible!

Thursday, September 6, 2007. What a flurry of activity took place in my room last evening! It all started at 5:50 when my nurse arrived to give me my medicine. I was so pleased, because Andrea, my reflexologist, was due to arrive around 6:00 to begin an hour long session with me. This time it looked like Andrea would be able to do her work without interruption, as the nurse would be finished by then.

But my feeding tube did not cooperate. It was clogged, and would not respond to the manipulations that the nurse tried. I even tried coughing, which does clear the tube at times, to no avail. When he left to consult with the nurse supervisor, Andrea began my treatment. Twice she had to stop, once when he brought in a can of 7-Up to try and once when he came with cranberry juice. By then the nurse was really worried! I had been through this many times before and knew it was not serious. I also knew that plunging water through the tube might work, but remember – I CAN'T TALK! It never occurs to some people to consult with me and others don't have the time or patience to let me type what I have to say.

At 7:15 the nurse was out of the room and Andrea was trying to finish her work, when into the room came – MY HUSBAND! That was so unusual! Leo rarely visits that late in the day. We just had time to apprise Leo of the situation when the nurse came in, rushed over to him and asked, “Are you Mr. Kwiatkowski?” He then reported that my doctor had been called and he wanted me to go to the hospital right away to get a new tube. Vigorously, I shook my head “no” and pointed to Leo. “You don't want to go?” the nurse asked incredulously. “Then how are you going to eat?” He went on to explain that the procedure was so simple that it would only take 15 minutes to complete and then I would return home. I knew better than that, and so did Leo. When I continued to shake my head and look at Leo, the nurse left to tell the doctor I refused to go to the hospital. Andrea also left; now Leo and I were alone.

For the first six months that I had my feeding tube, I was still living with Leo in our apartment in Drum Hill. Many times he had unclogged my tube, and I was sure he had not lost his touch. First he squeezed the tube with his fingers down the entire length, beginning at the end and working toward my stomach. Then, inserting the plunger into the chamber used for getting medicine and water into me tube, he drew in water until the chamber was filled. Inserting the tip of the chamber into my tube, he began to plunge – so gently – and found no resistance at all! The tube was open! The whole procedure took about a minute.

The nurse returned and had no problem giving me my medications. To his credit, he wanted to know all about what Leo had done and gave my husband high, well deserved complements. I sent Andrea the news by email. Here is part of her reply:

“Thank you for updating me. I prayed! Thank God for Leo and his timely arrival! God is so good. And I must say, I was so touched by Leo’s support of your decision not to take off to the hospital just like that. I applaud both of you.”

Monday, September 24, 2007. Nearly three weeks have passed since my last entry, and I still have the same feeding tube. Though it continues to work well, after 11 months it does show signs of wear. My family and I have decided to become proactive this time and schedule a tube change before an emergency arises. My Sky View doctor and the nursing staff here agree with our decision. Now I must await the setting of the date.

Thursday, September 27, 2007. I just got word that a man on the 4th floor died this afternoon. We had known that he was dying, so the news was no surprise. If you have read my earlier “Penny” essays, you know something about this man. He’s the one I called “Brad” in the story of the squeaky shoe. Now I can tell you that his name was Fred, and he really was a very kind man. Eventually I got used to his squeaky shoe, now silenced forever. I’m glad he played a part in teaching me to be more tolerant of noise. Thanks, Fred.

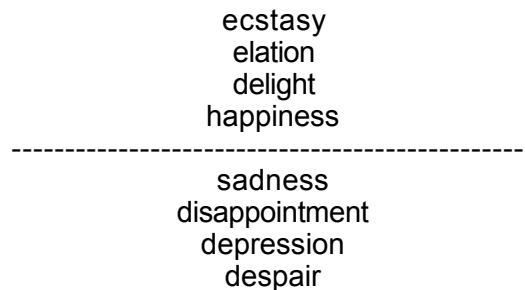
Friday, September 28, 2007. Before I close this issue of my journal, I must write about the launching of my website, which in turn will give me a chance to review the emotional standard I have tried to live by for many years, including now. I have never had an Internet connection on my computer, an instrument I use strictly as a word processor. Hence I have never had to worry about viruses, the unwanted appearance of pornographic materials, or even a junk filled mailbox. For my email, I have a small device called a Mailbug that operates separately from my computer. It has limited capacity and cannot receive pictures or attachments, but it serves me well as a way of keeping in touch with family and friends.

Of course I also knew about some of the good points of the Internet, including the ability to put your own writings on it for the whole world to read. Many people have suggested that my essays should be published. I have felt that way myself, but I cannot pursue that alone and since no one has offered to manage the project for me, I wondered vaguely if I should “publish” my writings on the Internet. When, in January, 2006, my son George asked me how I would like my own website, I was both surprised and delighted. George, with Marty’s assistance, had the ability to make it happen! Quickly I consented, and shortly thereafter a home page appeared that told people they had reached Verna Kwiatkowski’s future website. I was excited about this and told my friends my new address: **www.vernakwiatkowski.com**.

Little did I know that more than a year and a half would pass before my site would be functional! With her deepest apologies, Marty had a number of stressful, time consuming things going on in her life during that time period, and I didn’t want to add to her stress by constantly asking about my

project. So I wrote my autobiography and the other things she asked for, but mostly I waited. Eventually I realized that there was no rush; I didn't even have to be living on the earth for my website to be used to promote the kingdom of God!

The standard I mentioned has to do with a way I've devised to keep myself as emotionally stable as possible. I picture our emotions something like this:



The line represents living on an even keel, with the emotions balanced. The farther away from the line you get, in either direction, the more intense the emotions. Also, the higher you allow your emotions to go, the more you set yourself up for a plunge just as deep when the circumstances change. I don't like the feelings of despair or depression, for example, so I try to avoid elation and ecstasy. I'll give you two examples of how this works for me:

When the website was first established in January '06, I was feeling a mixture of positive emotions such as anticipation and excitement. (There are many more above-the-line and below-the-line words that you can add to the chart besides the ones I've already put there.) When I realized there was going to be a delay, I knew I couldn't sustain the high emotions, nor did I want to wallow in disappointment. So I had a talk with myself, and that's when I concluded that there really was no hurry. I felt as if I were handling the situation well by continuing to write, only occasionally asking about my site. The test began a few weeks ago when I heard that significant progress had been made on the site. I was glad! And then it happened: Marty came on a Sunday evening and told me the website began operating the night before. She even brought her computer along so I could see it. Then she said, "You won't be able to sleep tonight!" But I did sleep as usual and was happy about that, for it showed me I had not gone too far above my "even keel" level. In other words, I passed the test! All glory to God, to whom I dedicate my website. Thanks to Marty, too!

Monday, October 1, 2007. I wanted to finish this essay on the last day of September, but my aide came to put me to bed and I had to stop. Here is my second example, which may surprise you. I enjoy watching baseball games, my favorite team being the New York Mets. I watched most of their games in 2006, when they were excellent, and likewise this year, when they were still entertaining, though not quite as good. Several times this year I evaluated my relationship to the team, adjusting my attitude as necessary. I do not like to become addicted to anything and I certainly didn't want my emotional state to be dependent on whether the Mets won or lost! For most of the year it looked like the Mets would win their division championship and move on into post season play, but in mid-September the team began to fall apart. "It's only a game," I told myself. "In the light of all eternity, it doesn't matter who wins the division." And so, with this mental frame of mind, I watched as the Mets lost their final game of 2007 yesterday. I felt sad for the team, the manager and the fans but was not angry or in despair. My emotions remained stable, and I'm glad!

A happy event also took place yesterday: Vallie Turner had her first scheduled service at Sky View!

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