

A PENNY FOR YOUR THOUGHTS – 36

(JULY – SEPTEMBER, 2014)

Saturday, July 19, 2014. Hello, everyone! Welcome to Penny 36, my quarterly journal, in which I record my thoughts and happenings as primary lateral sclerosis (PLS) limits my movements more and more. If, Lord willing, I am able to complete this issue, we will have a record of 9 years of my life, including my moving into a nursing home at the end of December in 2005. Praise God!

In the previous Penny, I ended by discussing the enjoyment of God, and that's where I want to begin this issue. If you haven't met her before, let me introduce you to a young girl named Anna, whom I met through a book God put into my hands in the 1980s, a book titled Mister God, This is Anna. It was written by a man named Fynn, who, as a teenager in England in the 1930s, found 4-year-old Anna wandering the streets alone one night. After giving her some food, Fynn took her home, where he lived with his mother and other family members. There she lived for the rest of her short life, dying before she turned 8. (No, I haven't spoiled the story for you; Fynn opens his book by telling us this very fact.)

At the age of 4 and for her remaining years on earth, Anna had a relationship with God that I find so desirable: she really enjoyed God! Not only did she love the Lord her God with all her heart, soul, mind, and strength, Anna DELIGHTED in God, her constant companion who was always in her thoughts. She was also comfortable talking about God, often exclaiming with happy laughter, "Isn't Mister God wonderful?" And that's another thing: Anna had the utmost respect for God, symbolized by her always calling him MISTER God. Her question made others at least think about God, which may very well have been her purpose. Her contagious faith caused several people to become believers, including Fynn!

I hope many of you will read the story of Anna's life. I read the book for the first time as a middle-aged woman, and found myself identifying with her in major ways, age being one of them. Anna was born just 2 or 3 years before I was, but more than that, we both enjoy God similarly. For example, Anna would have loved seeing the birds on the swinging tree and the man in the tree, stories that ended Penny 35. She would have laughed and clapped and said, "Isn't Mister God wonderful?" And I would have replied, "Yes, Anna, He is!"

CAUTION: Do NOT read this book if you would be offended when Anna's theology is not completely correct. Remember her age, and marvel! Isn't God amazing?

July 31, 2014. In Times of Distress. This afternoon I got the idea of using some of the notes I've written in the past 2 weeks as the basis for an entry about the stresses I encounter while going about my daily life here at Sky View. I was searching my mind for a good title when a tune began playing in my head. Not only did I recognize it as one of the Scripture songs I had written long ago, I also knew then that God was involved in this writing project; God had given me the idea, and now, from the song which he had inspired when I wrote it, God was giving me the title. I smiled in anticipation – AND appreciation!

When my son George arrived for his next scheduled visit, I had an assignment for him: Get my songbook and, from these clues, find the song and its reference. Though some of the words I had given as clues were wrong, George soon located the one I wanted. It was titled Morning Prayer. The reference was Isaiah 33:2, which says:

O Lord, be gracious to us; we long for you. Be our strength every morning, our salvation in time of distress.

The last 4 words, changed only to make the subject plural, were perfectly suited for our topic, as you will see. It is ironic that the elusive title should be in this verse, because twice each morning, as I prepare to do the difficult task of turning my electric toothbrush on and off, I mentally sing *"Be my strength every morning,"* a singular form of another phrase from the same verse! And every time the toothbrush responds, a sincere "Thank you, Lord" travels from my heart to God's.

Now, before I get into the subject of my own stresses, I want to comment on stress in general. I recall doing that in a recent Penny, in which I asked you to list the ways that Jesus handled HIS stress on earth. From the fact that Jesus was stressed we get the welcome truth that stress itself is not sinful. God knows our various personalities and how we react to troublesome situations. God also knows it is not good for us to remain in a state of high tension inside, as evidenced by his giving us so many remedies for reducing stress. If our minds are filled with images such as these –

- casting all our cares upon the Lord, because he cares for us;
- seeing ourselves as yoked with Jesus, who is always there;
- being still and knowing that God is God; nothing is impossible with him –

then disturbing incidents can be seen as opportunities to practice God's presence, giving our faith a chance to grow and to be seen by others! This makes our distresses a part of our adventure with God, doesn't it? Amazing!

Now here is the first of the notes I want to share with you. My daughter Marty and I were seated in the Conference Room along with 4 or 5 people who are heads of their departments. At the start of the meeting Marty handed to each person a copy of this paper:

Notes for Annual Care Meeting (Thurs., July 17, 1 PM)
from Verna Kwiatkowski 413

5 months on the Hoyer lift. Am I the only one using the pads that allow me to use the toilet? I was told not to let the pads out of the room, but sometimes they are taken, and there is nothing I can do to stop this. If they are mine alone, the aides should be told. If not, tell me. Please clarify.

The Hoyer is safer, but the rough, heavy canvas straps are harder on my skin. So far there have been no abrasions, just temporary discomfort.

We were told we were getting new Hoyer lifts. Is that true? The aides complain about the current lifts. I don't know the difference. They seem to think the new lift will be better.

Declining physical abilities and energy. The time is coming! More & more I am content to remain in my room, resting in my chair, because to do anything else would take too much effort. I can't help wondering what will happen when I can no longer:

- drive my chair?
- brush my teeth?
- type?

To whom can I talk about these things?

Bottom line. After more than 8-and-a-half years at Sky View, I'm still glad that I live here! I appreciate all you do to keep me as healthy as I can be, and I appreciate the beauty of Sky View, both inside and out. I like living among so many wonderful people! Next year I may not be able to type, so while I can, let me say **THANK YOU** from a well satisfied resident!

Comments: A big part of my stress comes from not being able to talk. Writing my thoughts has some advantages, but there is one key factor that writing cannot supply, and that is tone of voice behind it. Neither of my questions about the Hoyer lift was answered. I had thought I WAS the only one using the new pads, so I couldn't imagine why anyone would want to take them. All I wanted was a yes or no, yet when I looked at the first question later, I was surprised to realize that it could seem harsh and critical! The next day I had some explaining to do.

July 18, 2014

To Michelle, Nurse Manager, 4th floor
From Verna 413

I made a mistake at the meeting yesterday. I never had 5 pads, but I had 4, & they were in 3 different styles. I had:

- 1 basic blue pad, the one you used for demonstration;
- 2 blue mesh pads used for showers;
- 1 gray pad with no support for the head. This disappeared first.

Elizabeth went downstairs today to get a mesh pad of the style I use for showers. So now I have 2, both different.

*****NOTE***** I am writing this entry entitled "In Times of Distress" in the month of August. Yesterday, which was Saturday, August 9, my aide went downstairs and found a different style basic blue Hoyer pad that fit me perfectly! With this pad I truly feel safe! (By now I certainly know the answer to one of my questions about the Hoyer lift; yes, there are others at Sky View using the same kind of Hoyer pads that I use!)

Another point of stress for the 4th floor was that Michelle, our nurse manager, had given us notice on July 16 that she was leaving Sky View for a new job on July 24! Her replacement, Lisa, did not arrive until about a month later! Meanwhile, our regular aides and nurses kept going on vacation, 1 or 2 weeks in duration, sometimes leaving us with a whole shift of workers who do not know our routines. But they ARE trained, and time goes on day by day until things are back to "normal."

During times of upheaval there are many opportunities for spreading good will among the substitute workers. For example, my night shift routine was disrupted one night this summer. Usually an aide comes about 2:00 and 6:00 to change my position, for I cannot move alone. The nurse comes around 5:30 with my inhaler. This time when the nurse arrived, I was still on my back, so I knew I had been skipped at 2:00. I relayed the news to the nurse, who said she'd talk with my aide. Before long a young woman I had never seen before was standing apologetically by my bed saying, "I know you are very upset with me!" I shook my head no. "Aren't you angry with me?" she asked, and again I shook my head. Visibly relieved, she proceeded to attend to my needs, while I was glad to have had the chance to splash someone with God's grace!

In July I went out for doctor's appointments twice! That is noteworthy because I rarely leave Sky View. The first was a routine ENT examination. The second was a feeding tube replacement at the hospital on Wednesday, July 23. In the weeks prior to the exchange, the tube deteriorated badly. I was certainly anxious for the procedure to be done, in all the ways you can interpret this sentence. Finally the day arrived, and with it 2 appointments: a specific time for the ambulette to come (late morning), and 1 hour later, when the doctor would meet me in the hospital. I prepared everything on Tuesday, even laying out my clothes for the trip. In plenty of time on Wednesday the staff had me ready. Dressed, and lying on my bed awaiting transfer to the ambulette stretcher, I was totally UNprepared for what happened next!

After I was put on the bed, everybody left my room, leaving me alone to watch the clock. I am one who likes to be on time, and the ambulette drivers had always been punctual – until that day! The designated time came and went, and nobody even brought me news! I was trying hard to calm my stress when in the door, most unexpectedly, came my husband Leo! He had never come that early before, and why today? He said he forgot about my tube change, or he would not have come. I think God was behind all this, giving me the relief I needed, and my heart was grateful! I asked Leo to find out what was happening. He reported that everything was under control; the ambulette, Sky View, and the hospital had all been in touch, adjustments had been made, and all was well. When the crew finally came with the stretcher, they apologized for being late and explained that an emergency had held them up. Within myself I smiled and said, "Oh, so you're not the center of the universe after all!" Then I relaxed, said goodbye to Leo, who was just as glad as I was that he had come, and the trip was underway!

Happiness abounds. To balance my stories about stress, I want to tell you about 3 very happy incidents (among many) that took place in this quarter.

1. Robert's Letter. In July I got an email letter of appreciation from Robert, a former accordion student of mine, whom I last saw in 1972! What pleasant memories that letter brought back to me! I loved teaching my accordion and piano students at our local music center and directing accordion bands, a part-time job I started in 1963. I considered this to be the perfect job for me, and couldn't imagine leaving it.

In September 1972, however, quite abruptly, and with no second thoughts at all, I gave a one-month notice to my boss and left my students to somebody else. Why? Because God literally told me to! That's right! I was in my house just a couple days earlier when I heard a Voice say, "Quit your job!" I looked upward and to the right, the direction of the Voice, and said, "What?!" And again the Voice said, "Quit your job!" Immediately I knew

God had spoken, and to me, as a believer committed to Jesus Christ, that meant I had to obey.

The fact that I could leave my job with no regrets, but with a sense of adventure, is clear proof this was from God! I didn't know what happened to my students in 1972 until Robert's letter came 42 years later! He thrived under his new teacher, and I'm sure the others were fine, too. From experience I can say: You can't go wrong if you trust and obey God!

2. A Visit with the Nuns. On Thursday, August 14, a much anticipated visit took place in my room among 4 friends: Carolyn Burke (who handled the arrangements), Sr. Noel and Sr. Carolyn from Maryknoll, and I. You may recall that Noel and I both have PLS, and cannot walk or talk. During the course of our visit, I typed on my LightWriter something about not having the strength to write all the things God is revealing to me. Then Sr. Noel wrote on her special tablet, "God and Verna have secrets." I was so happy when I read her message! Immediately my mind went to the verse in Psalms that says, "The Lord confides in those who fear him; he makes his covenant known to them." (I take the word fear to mean reverence; to be in awe of God. For many years I have enjoyed the image of God whispering secrets into the ears of his people!) Then Sr. Carolyn said, "God wants you to keep them secret." Again I was delighted! Not having to share every thought with others was very freeing! God was surely working among us on that visit!

3. The Man in the Tree. In Penny 35 I wrote about seeing a tree from my window that looked like the profile of a man, complete with curly hair, mustache, and beard clearly visible to me were his eyebrow, eye, nose, and mouth, which was open. I wondered if anyone else could see him, and then one day in August I found out! Diane, our social work director, who had read the story, came into my room about another matter. On the spur of the moment, I asked if she would like to see the man in the tree. Eagerly she went to the window, ready to follow my instructions. Suddenly she exclaimed, "I see him! Is his mouth open?" Joy came bursting out of me with laughter and clapping! I was SO happy! Then the Dyers (our daughter MaryBeth, husband Charles, and sons John and Graham) came from Massachusetts to visit us over the Labor Day weekend, and they too saw the man! Again, I was VERY happy about that!

The man disappeared this week (it's October 7). There is a season for everything!

Back now to the notes. Diane is head of the social work department (the one who saw the man in the tree) and Mary is director of nursing. (Clarifications are in parentheses.)

July 31, 2014
To Diane & Mary
From Verna 413
Re: Feeding

The whole subject came up because my nurse told me I had to start going to bed sooner, as the book says the feeding starts at 9:00. Usually I am in bed & ready to start eating between 10:15 & 10:30 pm. I like that time because then my dosage is complete around 9:00 am, a good time for me to get up & start my day. (A basic fact is that I am fed continuously during the night through my feeding)

tube. The entire process takes about 10-and-a-half hours. Then the machine begins to beep.)

I can understand that the nurse may want to avoid potential trouble. I wish the directions in the book could say: "Attach feeding when she is in bed for the night." Or – Maybe the nurse just needs reassurance that everything's OK as is!

PLEASE do not change any settings on my pump. The current settings are good. My digestive system works well with my way of eating, which I've used over 9 years now!

AUG. 2, 2014
TO ALL MY NURSES, ESPECIALLY THOSE WHO HAVE ME ONLY
OCCASIONALLY
FROM Verna 413
ABOUT MY NEW FEEDING TUBE

I got a new feeding tube July 23 and it is working well. To keep it that way, please do NOT use pressure when attaching the feeding or the chamber that gives me meds & water flushes. It should NOT be hard to pull them apart when the process is over. The connecting point of my tube is one of its weakest parts. The tube would be useless if it is stretched or broken there.

Also, FOR MY PEACE OF MIND, please put only 400 units of water in the water bag at night. That's plenty, as the pump only uses 275 units of water all night. I have good reasons for this request, mainly the memory of a substitute nurse who said in the morning, "I'll give you the rest of your water," and before I could object, all the rest of the water had drained into my stomach! If that ever happens again, I want to be sure not much water remains, as was the case the 1st time, thank God!

*****THANK YOU*****

Tuesday, Aug. 26, 2014
To Regi (my nurse on 3–11 pm shift)
From Verna 413

This morning my feeding stopped more than an hour before usual. I don't know why, but suspect the volume setting was wrong. Let's be sure it's set at 990 tonight. Thanks.

Wednesday, Aug. 27, 2014
To my evening nurses
FYI to other nurses
Re: Update on feeding
From Verna K. 413

Above is a copy of a note I gave to Regi Tuesday evening. (I started this memo with a copy of the previous one.)

Regi and I both made sure the volume said 990 last night, yet at 8:15 this morning the machine started beeping and saying "Dose complete." This was the same thing that happened the day before!

Then I recalled that Sunday evening a new nurse had cleared the numbers from the pump and only put 2 of the 4 numbers back. She added the other 2 as soon as she knew about her omissions.

Could this be a clue as to the faulty setting? I would like the "Dose complete" message to come on when I have gotten 990 ml of food, which is between 9 & 9:15 am, not when 8:15 comes. Please help, if you can. Thanks.

Thursday, Aug. 28 Update. The nurses read my notes and tried to be careful. Yet the pump beeped at 7:45! I wonder if the pump is broken?

Friday, Aug. 29 Update. This I know: The pump is set at 990 and it begins beeping when the numbers have run down to 0 (dose complete). Today that was 8:20. Could it be that the pump now has a glitch that (randomly) strips away 100 or so points from the volume number?

One final note.

Friday, Aug. 29, 2014
To Lisa (Our new nurse manager)
From Verna 413

Please handle this for me. I can't do it anymore. Thanks.

The conclusion of the matter. Lisa and I agreed that I should observe the machine over the weekend, and discuss this when she came back to work on Monday. During those days and in the ones that followed I kept track of the various "Dose complete" times. I also noticed that I did NOT feel hungry with eating less food, and wondered if this might be a way of losing a few pounds. (It was!) So I told Lisa on Monday, September 1 that I would be content to let things go on as usual for a while, and that was fine with her. But by the last week of the month I was quite sure my observation in the August 29 update was true, and requested a new pump. Lisa called her supervisor, who placed an order, and on Friday, September 26, my new pump was installed! In the 11 days since then, it has beeped 10-and-a-half hours after being connected!

Bonuses. While working on Penny 36, I completed 2 creative works as well, and with them I will conclude this issue of my journal. The 1st is a poem that always brings a smile! The 2nd is a new meditation on the order of [Words of Encouragement](#), a collection of 42 meditations I wrote in the 1990s. They are on my website, if you want to take a look. And so – I'll say goodbye and God bless you until we meet again.

– Love, Verna

My Wayward Feet

By Verna Kwiatkowski. Wheelchair-bound at Sky View. After my son George read to me a selection of Ogden Nash's whimsical poems.

My feet have their place
On a platform on my chair.
But they often go a-flying,
Dangling loosely in the air

How do my feet go flying? –
Please now don't you scoff! –
They leave their safe position
Because I cough them off!

Don't ask me how that happens;
My body is connected, that's true!
So when I cough or when I sneeze,
Off the platform flies a shoe – or two.

The trick is getting them back.
It seems they PREFER being off!
One thing I know, for I've tried –
I can't get them ON with a cough!

"Aha!" you may be saying.
"I know a simple solution:
Just get rid of the cough!
What an easy conclusion!"

Easier said than done! I've been
Coughing since 1935
When, as a toddler, I became ill.
I am fortunate to still be alive!

My cough reminds me to give thanks:
There were other times I nearly died.
My infirmities all have taken their toll,
But I'll tell you why I am satisfied –

There are no wheelchairs in Heaven!
No platforms for feet to fly off!
Perfect health is normal for everyone,
And NO one will EVER cough!!

In the meantime, this plea I often repeat –
Would you please lift up my wayward feet?

Thank you!

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Verna Kwiatkowski

WORDS OF ENCOURAGEMENT

O Lord, be gracious to us; we long for you. Be our strength every morning, our salvation in time of distress.
– Isaiah 33:2

Rejoice with me! We have a God who can hear, and who invites us to talk with him, wanting to be involved in our lives. On earth we WILL have times of crisis and distress, as Jesus both taught and experienced in his humanity. Our reaction is what matters when the troubles come. We can choose to move away from God in anger or disappointment, or choose to draw closer to God, seeing each stressful situation as an opportunity to grow in our faith and to display godly behavior. That's what Isaiah did in this portion of his prayer in a time of national crisis. He acknowledged God as Lord, on whose grace we rely, the Almighty One who can impart his strength to others, and who saves us not only from our sins (a permanent salvation), but also from our many predicaments. Do we long for the Lord's involvement in our daily lives? We can have it! Isn't that encouraging?

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