

## DECISIONS, DECISIONS: FACING A FEEDING TUBE

Today is Wednesday, May 25, 2005. A few hours ago I was in a doctor's office with my daughter Marty and daughter-in-law Janet making arrangements to have a feeding tube inserted. Something seems unreal about the situation. Several years ago I wrote down my wishes for the end of life issues, including the fact that I don't want heroic efforts made to keep me alive if my body is in the process of dying. I still feel that way. I have a health care proxy who knows my wishes, yet wants me to get the feeding tube. The date has been set: I must be at the hospital Tuesday, May 31, 2005 at 7:00 AM. If all goes well, I will be discharged the next afternoon, returning home with an alternate method of getting food into my stomach.

To my knowledge, I've never been around anyone who has a feeding tube. My nurse friends show no signs of the revulsion that I sometimes feel at the thought. Certainly my borders are being enlarged by this experience, by being forced to think about a subject that was purely academic before, and that's a good thing.

As usual, I have wondered about the will of God in connection with my getting a tube. All this is complicated by the fact that a few years ago I helped make the decision that my mother, who was refusing to eat most foods, should not have one. Am I being hypocritical here? Or am I making a more informed decision than I could have made before? No doctor had recommended a feeding tube for Mom; my doctors are strongly suggesting that I get the tube now, before my body is further weakened with another bout of pneumonia.

Back to the issue of God's will. On February 27, 2000 I preached a sermon entitled "The Will of God." It was one of the few that I wrote out in full. Recently I reread the sermon, thinking I might be able to use a condensed version in this essay. Not finding parts I would want to omit, I'm going to reproduce the entire sermon here, using it as a foundation for exploring my thoughts about feeding tubes. For that is what I want to do, what I need to do, in order to be true to myself.

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### THE WILL OF GOD

All sorts of questions come wrapped around the phrase "the will of God," none of them simple, all worthy of consideration. What do people mean when they say they want to know the will of God? Are they looking for guidance in specific situations that involve choice? Does God have everything planned for our lives? Is it our job to discover that plan and follow it? Does God's will for us negate our free will? Are we puppets after all? Is everything that happens in our lives God's will? Should we consider everything that happens to be God's will?

#### **THERE IS SOMETHING CALLED THE WILL OF GOD. WE ARE MEANT TO KNOW IT AND LET IT SHAPE OUR LIVES.**

An abundance of Scripture passages affirm this, such as the portion Jesus included in his teaching on prayer: *"Your will be done on earth as it is in heaven"* (Matthew 6:10). Jesus also said, *"Whoever does the will of my Father in heaven is my brother and sister and mother"* (Matthew 12:50). And then he gave us a sublime example of living according to God's will when he prayed in Gethsemane, *"Yet not what I will, but as you will"* (Matthew 26:39).

The apostle Paul, who knew he was an apostle *"by the will of God"* (see Colossians 1:1, for example) often referred to God's will, as though he were aware of and attuned to God's guidance in his activities. As he was about to leave Ephesus, he told the elders that he would come back *"if it is God's will"* (Acts 18:21). He told the Roman believers that he constantly remembered them in his

prayers and added: *"I pray that now at last by God's will the way may be opened for me to come to you" (Romans 1:10)*. Paul asked the Roman church to join him in prayer: *"Pray that I may be rescued from the unbelievers in Judea and that my service in Jerusalem may be acceptable to the saints there, so that by God's will I may come to you with joy and together with you be refreshed" (Romans 15:31,32)*.

Paul, who certainly practiced what he preached, gave us a beautiful picture of God's will in Romans 12:2: *"Do not conform any longer to the pattern of this world, but be transformed by the renewing of your mind. Then you will be able to test and approve what God's will is – his good, pleasing and perfect will."* If we consider God's will to be a burden, it may be that our minds are in need of transformation and renewal! Jesus Christ is wonderfully able to do that work in us, if we will place ourselves in his hands. We'll know we are changed when we see God's will as beautiful: truly good, pleasing and perfect!

The teaching in Paul's letters include more references to God's will. Ephesians 5:15-17, for example: *"Be very careful, then, how you live – not as unwise but as wise, making the most of every opportunity, because the days are evil. Therefore do not be foolish, but understand what the Lord's will is."* And Colossians 1:9: *"For this reason, since we heard about you, we have not stopped praying for you and asking God to fill you with his knowledge of his will through all spiritual wisdom and understanding."* In the same letter, chapter 4, verse 12, he says, *"Epaphras, who is one of you and a servant of Christ Jesus, sends greetings. He is always wrestling in prayer for you, that you may stand firm in all the will of God, mature and fully assured."* Wisdom, maturity, assurance and effective service for God all seem to be tied up with knowing and doing the will of God.

James includes practical advice in his letter about making plans for the future: *"Now listen, you who say, 'Today or tomorrow we will go to this or that city, spend a year there, carry on business and make money.' Why, you do not even know what will happen tomorrow. What is your life? You are a mist that appears for a little while and then vanishes. Instead, you ought to say, 'If it is the Lord's will, we will live and do this or that'" (James 4:13-15).*

How important it is for us to keep our place in relation to God! As Paul says in 1 Corinthians 13:12, we see but a poor reflection, certainly not well enough to know what tomorrow will bring, but God is GOD, the one in love with us and in charge of the mist that is our life on earth. What peace there is in factoring the Lord's will into all future plans!

## **WHERE DETAILS OF GOD'S WILL ARE GIVEN, THEY HAVE TO DO WITH OUR RELATIONSHIP TO GOD AND HIS PEOPLE, AND WITH OUR CHARACTER DEVELOPMENT.**

I have found five New Testament passages where something is specifically said to be God's will. Surely anyone sincerely wanting to know God's will should be careful to carry out these clear directives:

1. John 6:40: *"For my Father's will is that all those who look to the Son and believe in him shall have eternal life, and I will raise them up at the last day."* God's first desire for us is that we believe in Jesus, receive eternal life and realize that this is a permanent transaction.

2. 1 Thessalonians 4:3-8: *"It is God's will that you should be sanctified: that you should avoid sexual immorality; that each of you should learn to control your own body in a way that is holy and honorable, not in passionate lust like the heathen, who do not know God; and that in this matter no one should wrong or take advantage of a brother or sister. The Lord will punish those who commit all such sins, as we have already told you and warned you. For God did not call us to be impure, but to live a holy life. Therefore anyone who rejects this instruction does not reject mere human beings but God, who gives you his Holy Spirit."*

After we become believers in Jesus, thus establishing a relationship with God, we are to set ourselves apart for him and lead lives of practical holiness. Foremost in this injunction is the imperative of avoiding sexual immorality. This letter was written in a time when sexual immorality was the normal course of action in the culture – just as it is in our country today. The standards (or lack of standards) in our culture can easily carry over into the church, into the lives of believers. We need so much to be countercultural in this area! Sexual activity belongs in marriage. Anything else is outside the will of God. This includes both premarital and extramarital sexual relationships, as well as homosexual activity. All sorts of excuses are proffered to legitimize sexual immorality, but let no one call it the will of God!

If it were not for the fact that God offers forgiveness to those who have broken his laws (and who hasn't?), the above paragraph would crush the hope of most of us. But there is hope! Listen: *"If we confess our sins, he is faithful and just and will forgive us our sins and purify us from all unrighteousness"* (1 John 1:9). After that we can again walk the paths of righteous, holy living. What a Savior we have in Jesus!

3. 1 Thessalonians 5:18: *"Give thanks in all circumstances, for this is God's will for you in Christ Jesus."* How simply stated is this command: be thankful in all circumstances! Following the command takes practice, more for some people than for others, but what a worthy goal for us! What character development this brings, for true gratitude brings contentment – and peace! Above all, it is God's will for us, and that should be enough.

4. 1 Peter 2:15: *"It is God's will that by doing good you should silence the ignorant talk of foolish people."* Here are some related verses: 1 Peter 4:19 *"Those who suffer according to God's will should commit themselves to their faithful Creator and continue to do good."* And Ephesians 2:10: *"For we are God's handiwork, created in Christ Jesus to do good works, which God prepared in advance for us to do."* Surely it could be said of Jesus that he went about doing good, and so should we. Even if we are suffering – and according to Peter, some suffering is God's will – we need to keep on doing good deeds. By doing so, foolish people may be quieted, and some may even begin to glorify our Father in heaven! (See Matthew 5:16.)

5. 2 Corinthians 8:1-5: *"And now, brothers and sisters, we want you to know about the grace that God has given the Macedonian churches. Out of the most severe trial, their overflowing joy and their extreme poverty welled up in rich generosity. For I testify that they gave as much as they were able, and even beyond their ability. Entirely on their own, they urgently pleaded with us for the privilege of sharing in this service to the saints. And they did not do as we expected, but they gave themselves first to the Lord and then to us in keeping with God's will."*

It is God's will that his children give themselves first to him and then to one another. In this passage Paul was commending the actions of one church to another church, for their instruction. God wants his people to interact, to meet together in groups (congregations, churches), to take care of each other. *"Let us not give up meeting together, as some are in the habit of doing, but let us encourage one another – and all the more as you see the Day approaching"* (Hebrews 10:25).

## **THE HEART MATTERS!**

David, who was chosen by God to be king because of the quality of his heart, said in Psalm 40:8: *"I desire to do your will, O my God; your law is within my heart."* Where did this desire come from? Psalm 37:4 says: *"Delight yourself in the Lord and he will give you the desires of your heart."* David certainly did delight in the Lord, and I believe, in turn, God put into David's heart the desire to do God's will. And how did God's law get into David's heart? David's mind was constantly centered on God; that was his part. God notices hearts that beat for him (see 2 Chronicles 16:9). Hebrews 8:10, where the writer quotes Jeremiah 31:33, says, *"I will put my laws in their minds and write them on their hearts."* That, along with uncovering the meaning of those laws, is God's part.

Like David, God's people today need to choose to do God's will, to delight in doing so, because of overwhelming gratitude and love for God. That's our part. Surely this is involved in our fulfilling the first commandment: *"Love the Lord your God with all your heart and with all your mind and with all your soul and with all your strength"* (Mark 12:30).

## SPECIFIC GUIDANCE

It seems to me that those who are following all the known will of God as outlined above – that is, they are true believers, fully assured and appreciative of their salvation and their Savior; they are set apart for God, especially living sexually pure lives; they are thankful, full of good deeds, and are interacting with the body of Christ (the church) on a regular basis, and their hearts are overflowing with desire to do the will of God – will not have much problem staying within the will of God in circumstantial matters. The responsibility for such people falls partly on the Lord, according to Proverbs 3:5,6: *"Trust in the Lord with all your heart and lean not on your own understanding. In all your ways acknowledge him, and he will make your paths straight."* People who are walking in the ways of the Lord will have a sense of his presence and guidance. They will learn God's warning signals; they will know if the lights are flashing red, green or yellow, and will plan accordingly.

I do believe that there are many things where God does not have a specific will for us, such as where we should go to college; where we should live and work; what we should wear, eat, etc. I believe God lets us make decisions in the details of our lives and that there are circumstances where any choice we make would be acceptable. Should you move to Ohio or Kentucky? Surely God could use anywhere a person whose character exudes the will of God! Of course, if you strongly feel that God wants you to move to Kentucky, then go there, for God sometimes does give specific directions to his servants.

If the choices we are facing are all decent and honorable, instead of begging God to show us his will for the situation, maybe we need to use good judgment, consider the advice of worthy acquaintances, evaluate the circumstances, think about our strengths and weaknesses as well as our preferences, and then decide! What if, after all, we make a mistake and go the wrong way? *"If you wander off the road to the right or the left, you will hear his voice behind you saying, 'Here is the road. Follow it' "* (Isaiah 30:12). God will nudge us back to the right way! There really is nothing to worry about, is there?

Ah, but knowing God's specific will is not always as simple as I may have made it sound. Consider the story told in Acts 21:7-15. Paul felt that he had to go to Jerusalem at this particular time. A prophet came to Caesarea, where Paul and his coworkers were staying with the local believers, and delivered a striking message that foretold danger for Paul if he went to Jerusalem. *"When we heard this we (including Luke!) and the people there pleaded with Paul not to go up to Jerusalem. Then Paul answered, 'Why are you weeping and breaking my heart? I am ready not only to be bound, but also to die in Jerusalem for the name of the Lord Jesus.' When he could not be dissuaded, we gave up and said, 'The Lord's will be done.' "* And so Paul and his companions did go to Jerusalem, where indeed he was arrested. Who was right? I believe everyone had good motives. Maybe there was no right or wrong! And maybe it is the same with us. We make our choices the best we can, accept the changes and the consequences involved in our choices, and move on – all for God's glory!

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## FACING A FEEDING TUBE

Last summer my neurologist ordered a swallowing evaluation, after making it clear that at some point I would need a feeding tube. The evaluation showed some aspiration, and thus began the first of the drastic changes in my eating habits. Things became more and more restricted, until now I can say that eating is no longer fun. In the dining room I generally order a selection from the always available

applesauce, cottage cheese, vanilla yogurt and ice cream, and the sometimes available mashed potatoes, soft chicken and creamed soups. I try to keep up good nutrition by adding healthy vitamin and mineral drinks.

As I understand it, having a feeding tube does not mean I would no longer be able to eat by mouth, though I don't see why I'd want to. I have adjusted pretty well to my food restrictions, I think. Completing the job of giving up oral consumption should not be too difficult. Several other issues, though, loomed large during these past few months.

Today is Monday, May 30, 2005. If all goes as planned, tomorrow at this time I will be in the hospital being prepared for surgery. Our daughter MaryBeth, her husband Charles and sons John and Graham have been visiting with us this holiday weekend. When they arrived from Massachusetts on Saturday, Charles asked me how I felt about the upcoming surgery and I admitted to being somewhat apprehensive. Over the past few months I have had many conversations with my children and others about feeding tubes, each one contributing something I needed to know to make an informed decision. As Charles, MaryBeth and I talked at length, the final piece of the puzzle must have fallen into place, for when I awoke yesterday, I was totally changed inside! All apprehension was gone, replaced by perfect peace, the peace that I have recognized through the years as coming from God. My mind was filled with a new thought for this essay which I wrote down with delight and awe. The words of one of the songs I wrote years ago comes to mind as I recall this: "Oh, my Lord, faithful and true, always faithful and true, I love you!"

And then God gave me an extra gift, like icing on a cake. After church MaryBeth took me to see my dear friend Diane, who has long suffered from the pains of arthritis. How I have admired the way she, by the grace of God, has handled her illness! On this visit Diane, who has been reading my essays, told me of the ministry she has in her home using my writings. That was so encouraging and gave me the desire to keep on writing. Then she told me that her mother (whom I knew) had a feeding tube for the last three years of her life (unknown to me; her mother didn't want it known, Diane said). Diane was the one who fed her, a job, she assured me, that was "easy, no problem at all." Then she added, "You might find yourself with more energy when you get proper nutrition through the tube." What a glorious Sunday morning that was! I was so uplifted that I felt like I was soaring in the clouds under the smile of God!

It is now late in the evening. I must soon go to bed as I'll be getting up at 5:00 to prepare for my trip. I had hoped to finish this essay before the feeding tube was installed, but it was not to be. My times are in God's hands; I have no regrets. I must write this final thought, though, before the surgery. I have been on the operating table many times and never do I go without recognizing that things could go wrong: complications or even death. I am to have a local anesthetic plus sedation tomorrow. After the surgery I will wake up – either in the recovery room or in Heaven. Either place is fine with me. If it is Heaven, I would like to say this: I have really enjoyed my life. I am grateful for my wonderful family and the many, many fine friends that I have made along my journey. I highly recommend the life of faith. I remain in awe of my Lord and my God. I have no complaints.

Today is Saturday, June 4, 2005. Obviously, I woke up in the recovery room on Tuesday, but not to the news I had expected. After I was sedated, a lighted tube was put down my esophagus to locate the spot where my feeding tube could be placed. My surgeon then put a needle into the area to administer the local anesthetic. To his surprise, he hit a branch of an artery and I began to bleed internally. The three doctors involved decided to staple the blood vessel and give me time to heal and be observed rather than try another spot right away. The surgeon explained that blood vessels are not shown by the lighted tube and mine was in a place different from usual. So I spent the major portion of two days in the hospital and now, once again, I'm waiting for Tuesday, when we'll start the process all over.

I said above that things can go wrong on the operating table and this time they did. I am happy to

say that God's grace was sufficient for me through this incident. I was surrounded by love – coming from my wonderful family (the ones present, including son David and grandson Paul visiting from North Carolina, and the ones absent), coming from friends, coming from the medical staff, coming from God. All is well with my soul.

Today is Tuesday, June 28, 2005. I returned to Drum Hill yesterday, after a twenty day absence and yes, I do have a feeding tube! It was inserted easily on Tuesday, June 7. Getting my digestive system to resume operation after having been put to sleep, however, was another story. Instead of two days, I was in the hospital for three. Noticing my weakness, in addition to my lack of digestion, the hospital staff released me to a nursing home / rehabilitation center, where I spent the next seventeen days. It's a good thing I learned to say "Lord willing" when making plans!

It is now Thursday, June 30, 2005. Because I had this Friday's service to plan and because of all the activity involved in my home care, I am only now able to resume my narrative.

I did not chafe under the change in plans; instead, I tried to be a good ambassador for Christ both in the hospital and in the rehab center. I found that God has many people of faith in the medical profession and the supporting staff! What a blessing it was when a staff member and I found our spirits connecting or when someone came to me to talk about spiritual things. I left behind some of my writings, placed in the right hands, to speak what I could not speak orally, and hopefully I also left behind a witness to the power of God's grace. To God be the glory.

Before I got my feeding tube, I did very little research on the subject. Actually, none; I just asked my neurologist a few questions and was shown a brochure that had no pictures. This is typical of me. If something must be done, I let the experts do it and then learn what I must to maintain it, instead of trying to become an expert myself. In this case, my ignorance of basic anatomy really shocked me. I had expected the tube to be placed somewhere around my waist. You probably know where it is: just under my rib cage! The esophagus into the stomach is shorter than I had thought!

As for the mechanical parts, there too I was surprised. I had expected a plastic tube about twelve to fifteen inches in length. (I wondered what color it would be; perhaps clear, so you could watch the food go down?) I also heard mention of a possible button: something about keeping the tube in place. (I couldn't figure that one out at all, having put the button on the wrong end in my mind – something to keep the tube from flopping around!) To give you an idea what it's like to have a feeding tube, think of this: how would you like to go around every day with a foot or more of heavy plastic tubing, a large button, a large pair of plastic children's scissors and a small roll of Scotch tape tucked under your clothing? The "scissors" is a clamp; the "tape" is a two part intake apparatus, one marked "Feed" and the other "Flush." The button is separated from my stomach opening by a gauze pad held on by tape. I've been told there is a balloon inside my stomach also holding the tube in place. That gave me peace of mind. (In case you're wondering: my tubing is white, with the manufacturer's name and other information written on it in blue letters.)

I'm not complaining, believe me! I am amazed at how much stronger I'm feeling already just with getting proper nutrition regularly. (Two changes I noticed in rehab seem huge to me: I regained the ability to have a good noiseless yawn and to clap my hands in such a way that noise is produced!) I had no idea I was malnourished because I was maintaining a rather constant weight. Now I know part of my weakness was from PLS and part from poor diet. The PLS is still with me; seeing how much function I can regain with proper food will be another adventure.

Food is another area where I had wrong ideas. I really thought some of my food would be ordinary food pureed to fit through the tube. Not so! The only things that have gone through the tube are the specially formulated liquids guaranteed to give me enough calories and nutrients; crushed or liquid medicines; and water. That's much easier than I had expected. Oh, and I am scheduled to have 8 ounces of Coke once a week to flush out the feeder tube! I wonder if I will consider that a weekly

treat, since it bypasses my taste buds?

Instead of four to six feedings a day, I've chosen to be fed overnight. For nine to eleven hours food is slowly pumped into my stomach, almost all the nutrients I need for the day. I may supplement this by mouth with thickened juice, ice cream or pudding if I wish, but meals are no longer a concern during the day. Strange! Other things fill up the time, though: physical therapy, personal care, socializing, writing, reading ... Right now we are going through much transition, harder on others than on me. An illness like I have becomes a family (and an extended family) project. I thank God for the family and friends I have. Their devotion is amazing!

If you have read all this, you will be much better prepared if a feeding tube becomes part of your life than I was. But now I want to get back to the reason I brought up the subject in the first place: How did I make the decision to have a feeding tube inserted? What role did the will of God play in my decision? I'll try the best I can to reconstruct my thinking in the conclusion to this essay.

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Above all else, I had to be convinced that I was living, not dying. Some of my earlier essays clearly show that I thought I would soon be with the Lord. And that was not only a figment of my imagination! When I visited my neurologist in the summer of 2004, he was alarmed at how drastically my speech had deteriorated since the last visit. What's more, he thought some muscle in my hands may have deteriorated. When I told him that I had flutterings at various places on my body, he said, "That's not a part of PLS." Then he stated that he wanted to repeat the very painful electrical shock test that he had given me a year earlier. As he was leaving the room to make an appointment for the test, the doctor looked so distressed that I said to him, "If you have to tell me that it's ALS after all, don't worry; it will be all right." He brightened considerably at that and went about setting the date.

My son George was present at the rerun of the test. The doctor said very little as he prodded and shocked for an hour. At the end he said, "To my surprise, I do not find ALS." But he wanted me to return to the specialist at Mt. Sinai Hospital, New York City with the results of the latest test. I did, and the specialist, after a careful evaluation, said the same as he had the year before: "It's PLS." Then I began to joke with family that since so little is known about PLS, I will no doubt end up having PLS-VV (Verna's Variety, a fast moving kind). In my mind, time would tell, as ALS moves much faster and is life threatening, whereas PLS is said in the literature to be lifestyle threatening, though not fatal.

But I certainly thought time was running out for me. I set to work assembling and sending a legacy to my grandchildren and was so relieved when that was done. At the end of July I discontinued a Bible study I was teaching in our apartment, wanting time to work on a writing project I had in mind: essays called "Thoughts on Ageing and Dying." The only story I had written from our January move through July was one called "Flashback," which I later added to the essays, since it does address an issue of ageing: moving into a senior living community. I located in my computer a few pieces I had started, completed them, and started a file for my new series. And then I began to compulsively write. Each time an essay was completed I was so delighted that another part of my thinking, my philosophy of life, would be left behind, would not die with me.

All my children and grandchildren came from around the country to see me last summer and fall. The urgency was partly because my speech was fast failing, but also because of the unknown: how long until my death? In November, surrounded by grandchildren, I told them that I did not know if I had three months or three years to live. Shortly thereafter I came down with aspiration pneumonia again. During that time, while my friend Genevieve was visiting, I mentioned something about dying and she asked, "How are you dying more than, say, I am dying?" I was dumb-founded! What a question! "Why, I already have the disease from which I will die!" was my reply.

In my January 2005 visit to my neurologist, he mentioned a different medication he wanted me to start taking. For possible side effects, I would have to have my liver function checked through blood tests every three months. He said he would order the test several times and then, if there were no problems, would discontinue them. Again I was shocked! I said to my son, "He's talking as if I could be around a year from now!" I had not expected to survive the winter. I think it was then that I began to wonder if I might have to adjust to living with limited physical capacity for a long time. If so, some big decisions would have to be made, none larger or more imminent than what to do about a feeding tube.

Again I had to face the question of whether my body was in a living mode or dying (more than from everyday wear and tear, that is). I have friends who have other debilitating, painful, permanent diseases whom I never think of as dying; rather, they are living, adjusting as needed to their changing conditions. Several people with arthritis come immediately to mind, as well as a relative who has had multiple sclerosis for years. Perhaps PLS is like that. If so, I needed to change my thinking and prepare to take care of a living body.

Time to make an assessment. When I look into the mirror I notice first of all colorful, healthy-looking skin. For the past year the nurse friends who have given me personal care – as well as the staff in the hospital – have remarked that my skin is good. One of them mentioned what a vital organ skin is and that I must be diligent to keep my skin good. I never thought of skin as an organ before! Anyway, it's nice to know that my body's largest organ is in fine shape. My blood is also good, and my heart; even my lungs, despite seventy years of living with chronic bronchitis and sinusitis. People can live with spastic, weak legs and arms. Speech is not vital either, but eating is! Does it matter how the food gets into my still-functioning stomach?

Behind all my thinking is the desire to honor God in my life. The sermon about the will of God expresses the way I live and how I seek guidance in specific things. Certainly there is nothing about a feeding tube in the Bible! I talked over the issue with family and friends, especially friends in the medical field, including physical therapists. Not one person tried to discourage me. Many who had experience with people who had used them (like Diane) were very positive in their assessment of the tube. There was no nudging from God suggesting that I was going astray in my thinking. And then two very important things happened to conclude my decision process. But first, a complication.

This winter a controversy raged around Terri Schiavo's feeding tube. She was a severely disabled person in Florida who had been fed through a tube for years. Her husband wanted it disconnected; her parents did not. The courts got involved and it was big media story. Finally the tube was disconnected and soon thereafter Terri was dead. My concern was this: if I have a feeding tube inserted, would I cause trouble for my family later on when it was time for me to die? Obviously, if no tube is inserted, none has to be removed, nor its use discontinued. My health care proxy felt that I had made my end of life wishes abundantly clear in written, signed documents: I did not want to extend my life on earth if I were dying.

As for the two important events, the first involved one of the therapists I had from the Visiting Nurses Association who came for a few weeks during the winter. She read some of my essays from this series, "Thoughts on Ageing and Dying," and it reminded her of something. She knew of a booklet written by someone associated with Hospice that dealt with dying from the physical aspect: what happens to the body when it is the process of dying. When I expressed an interest, she asked, "Are you sure you want to read it?" I knew then that it was intense, but still said yes, having high regard for Hospice. And so she brought me a copy of Crossing the Creek by Michael Holmes, RN. Gratefully I received it, put it on a pile on my table, covered it over with other papers and forgot about it.

There is a time for everything, the Bible says. Toward the end of April I found Crossing the Creek and read all of it. It is so well written, out of much experience with dying people. As I read section after section one thought was outstanding: my body is not yet in the dying mode; my body is living,



functioning quite well, in fact, except for what PLS has taken away.

Then came the second important thing: the May issue of Christianity Today arrived. In it was an article entitled “When to Pull a Feeding Tube” by Jeff M. Sellers. The subtitle says, “Leading bioethicist Gilbert Meilaender discusses the problems of withdrawing Terri Schiavo’s lifeline.” The article is really the report of an interview that Sellers had with Meilaender, and I found it interesting from start to finish. Here is the question and answer that gave me the guidance I needed:

“When did a feeding tube go from being considered basic care to a medical treatment?”

*There’s been an increasing tendency over the last 20 years to bring a feeding tube under the rubric of treatment. The reason for this has obviously been that nobody would say you shouldn’t give a person certain kinds of basic care, whereas treatments are sometimes dispensable. So if you bring feeding tubes under the category of treatment, it’s easier to dispense with them.*

*I’m not persuaded that it’s more accurate to classify a feeding tube as treatment. Nourishment is something we all need to stay alive, and the fact that for certain people it has to be provided in different ways doesn’t alter the fact that nourishment is fundamental to human life in a way that various treatments are not.*

After that I had no further questions. I certainly wanted basic care for my body. I keep my body clean, warm and dry; I get enough sleep; I have physical therapy at least twice a week and try to be active in ways that I can; I take medications and food supplements to try to maintain health. Now I would add to the list making sure I got proper nourishment through a feeding tube. After I reached this decision all that remained was setting a date for surgery. Even then some inner tension remained until peace descended, as I described before.

My daughter Marty was glad for my decision because she felt it was consistent with other adaptations I had made. In my early 40s I became farsighted and for the first time began wearing glasses to correct my sight. When I could no longer walk, I began using a walker and then riding around in my Power Chair. To make up for my loss of speech, I use a Lightwriter. And since my swallowing mechanism has malfunctioned, I eat through a feeding tube. I agree that this does show consistency. And all of it has to do with quality of life, not extension of life. As Meilaender says, “*Rather than asking whether it’s a benefit to have your life, we ought to ask what, if anything, we can do to benefit the life you have.*”

Today is July 7, 2005. As I said at the conclusion of my sermon about the will of God, “We make our choices the best we can, accept the changes and consequences involved in our choices, and move on – all for God’s glory!” There certainly have been changes – for others as well as for me. Somebody has to hook up my feeding every night and disconnect it in the morning! My thanks to all who take part in this labor of love. Your work will be rewarded. As for me, while the PLS still rages, I have not felt so much strength, energy, vitality in my body for a long time as I do now.

I will close with an analogy that first came to my mind when I was in rehab a couple weeks ago and have enjoyed ever since. I thought of my childhood home on South Lancaster Street in Annville, Pennsylvania, with its front and back doors. Whether a person came in through the front door or the back door, I figured, they were in the house, and that is what mattered. My food used to enter my stomach through the front door of my mouth. Now it enters through the back door of my feeding tube. The important thing is that the food gets into my stomach. That’s what matters.