



HOW AM I DOING?

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Ever since I was diagnosed with amyotrophic lateral sclerosis (ALS) three years ago today, Wylodine and I have been overwhelmed with cards and letters, calls and visits, food and flowers. In this outpouring of love, friends from far and near have offered us their prayers, encouragement, and willingness to help as we struggle with a cruel disease that will finally rob my body of everything, even life itself.

For these many gestures of affection, our gratitude is so boundless that to convey it, even in small measure, would be impossible. But there is one request to which I can respond, and this third anniversary of my journey with ALS may be as good a time as any to do it. Lurking in many conversations, particularly with those who seldom if ever see me now that my traveling days are over, is the unspoken desire to know how I am really doing. Most people know nothing about ALS, a rare disease afflicting only 22,500 in the U.S., thus are unsure about such things as what I can eat, where I can go, or who I can see. Even the folks greeting me every week or two at church want to know more about my needs but do not ask

what they are, primarily out of courtesy.

While I honor the wishes of those who go to great lengths to keep their ailments a secret, my policy is one of full disclosure regarding both the physical and spiritual dimensions of my plight. After all, I am still Theologian in Residence at our church, which makes it incumbent on me to dialogue with members regarding the spiritual consequences of bodily disease and death. We all know those who delight to recite in wearying detail the horror stories of their latest illness, each telling more dramatic than the last! So I shall be as brief as possible, candid without wishing to solicit your pity, majoring on what I think you might want to know.

Past

In my final sermon at Mountain Brook Baptist on October 19, 2008, I sought to describe the shock of suddenly receiving a death sentence. Since copies of that message are still available, I shall begin here with what happened next. A more practical agenda demanded my immediate attention as I adjusted to a new way of life. Our downstairs guest bedroom was converted into my hospital-room-at-home, including the construction of a handicap accessible bathroom. After we made one end of our family room into my office/study, I have lived ever since in three rooms of our eleven room house. A lift built in the garage provided an exit without steps. The displaced cars were transferred to family members, since neither of us could ever drive again, and a van purchased that is wheelchair accessible. Occupational therapists identified the equipment I would need and how to use it, while physical therapists showed me how to maintain enough strength to cope with this strange new environment.

With these living arrangements in place, I next sought to understand the sinister intruder that I knew nothing about. I was fortunate to secure a superb medical team comprised of my primary care physician, an ALS specialist, and a pulmonologist, plus my urologist to monitor complications indirectly caused by ALS. All share my values regarding the rights and responsibilities of the body; two are active members of our church. As you might suspect, I also read several books and articles that recounted the experiences of others with ALS. I even watched the old movie on Lou Gehrig, the Yankee first baseman who became the most famous victim of ALS. But I learned the most from my own experiences, especially on the afternoon of December 28, 2009, when, without warning, my legs suddenly collapsed and I went crashing to the floor, breaking my ankle in two places.

As I wore a surgical boot for six weeks, family and friends joined me in the hope that, when I could again put weight on both feet, a program of exercise would restore me to my previous condition. But it was not to be. Despite the best efforts of therapists at Lakeshore Rehab, plus excruciating attempts on my part to follow their guidance, no progress was made. Gradually the truth dawned: The trouble was not with my ankle that had healed nicely. Rather, the trouble was that

the muscles making my legs work had atrophied because the motor neurons in my brain that tell them what to do had mysteriously died! In one fell swoop I lost my mobility, never again to stand, walk, pivot, or climb.

And yet it had happened silently, painlessly, without warning. I learned from this ordeal that ALS works by stealth. It sneaks up and blindsides its victim when least expected. Furthermore, it is content to choose one target at a time. When my legs were knocked out from under me, the rest of my body remained largely unchanged. Call it death on the installment plan.

Once a motorized wheelchair became my only means of mobility, I had to learn - quickly! - how to maneuver my mechanical legs so as to shave at the sink, eat at the table, and work at the desk. The hardest part of all this were the transfers, from bed to shower to chair and back again. I soon discovered, again by surprise, that I could no longer comb my hair, button my shirt, or tie my shoes, thus would need someone to dress me. Since my wife was battling serious health problems of her own and could not meet my rapidly growing needs, our only recourse was to recruit caregivers outside the home. Fortunately, grandson Andrew volunteered for this assignment, at first working part time when not occupied with his church job, but eventually fulltime, coordinating a team of three caregivers providing support to both grandparents on a 24/7 basis.

By now, as I began to understand the ALS story being told by my body, I realized how similar it was to the biblical story that I had long ago chosen to make the story of my life. The scriptural telling begins with how tragically flawed we are by our self-centeredness - Adam blaming Eve, Cain bashing Abel - and how slow we are to realize it - Samson with Delilah, David with Bathsheba. Just so, ALS is a greedy disease, devouring the circuits and sinews that energize the body, doing it so slowly and silently that I did not discover the wreckage until too late. But one day a man named Jesus appeared out of nowhere who was God-centered rather than self-centered. He overflowed with love even for his enemies who unjustly killed him on a cross. That love, and the life that embodied it, could not be destroyed by hatred. When he triumphed over death, his followers began to live out of his spirit in ways they could not live in their own strength. Similarly, when a part of my body dies, Andrew and his team of caregivers take over that function, literally becoming my arms and legs, fingers and feet. I am able to live physically because of them just as I am able to live spiritually because of Christ.

Present

ALS follows no predictable path in its conquest of the body. For me, it began at the bottom and is traveling upward, while for others it begins at the top and travels downward. After three years, the scourge has done about all the damage it can to my legs and feet, so let us see what it is now doing to my abdomen and arms.

Again the story is one of silent surprises. For example I never knew that muscles in the torso help to hold the stomach in place. As ALS weakens those

restraints, the internal organs that they support may tend to protrude more than usual. During my adult life, my weight varied between 175-180 pounds, my waistline between 36-38 inches. With the onset of ALS, my weight fell to 158 pounds before I regained much of it back by taking nutritional supplements. And yet, when at that lowest weight, my waist expanded, by careful tape measure while sitting in the wheelchair, to a whopping 48 inches. Why do I weary you with these statistical details? Because they explain how my entire wardrobe, carefully collected over many years, was suddenly rendered obsolete. I can no longer button a single coat or fasten a single pair of pants in my closet and no tailor can do anything about it. Call it collateral damage if you wish. I told you that ALS was sneaky!

Speaking of collateral damage, this may be a good place to comment on the presence of pain that figures so prominently in most life-threatening diseases. Except for an occasional tremor, ALS does not announce its presence by torturing the body. But the condition that it leaves behind may contribute indirectly to an assortment of ills. I now suffer regularly from bladder spasms (think: abdomen-in-agony) and peripheral neuropathy (think: feet-on-fire). As if this were not enough, there is the insatiable itching caused primarily by sitting in one chair in one position for sixteen hours every day of my life. So: stabbing pain alternates with frantic scratching - does God have a sense of humor, or what?

Not to give away the plot prematurely, it is when ALS reaches the throat that the final battle is joined. To prepare for that showdown, I learned to utilize two new procedures:

(1) To assist in eating, a feeding tube was inserted directly into my stomach through which I receive all of my medications in liquid form. Formerly I swallowed some twenty-five pills a day, but this posed too many hazards of choking and ending up with a pill in my lungs. I also ingest through the tube a medical food supplementing the table food that I continue to eat and enjoy. When I can no longer swallow, increased tube feeding will be able to provide my body with balanced nutrition for an indefinite period.

(2) To assist in breathing, I am now tethered to an oxygen tube for most of my waking hours. In addition, my pulmonologist is guiding some deep breathing exercises calculated to strengthen and utilize the full capacity of my lungs, especially the lower section that can get crowded out by nearby organs. Whenever I sleep, whether at night or during a daytime nap, I wear a face mask connected by a hose to a Bipap machine that supplies the needed amount of air on a consistent basis. Anyone being treated for sleep apnea will be familiar with this arrangement.

The most common thing that friends say to me these days is, "you look good." While I deeply appreciate this word of encouragement, I must take it with a grain of salt. Appearances can be deceiving with ALS. For example, you always see me in shirts with long sleeves, even during this long hot summer, because my arms have withered away to the size of a broomstick. Then there is the slowing pace of life. It now takes me three times as long to do one-third as

much as I once did. For example, whereas I used to get ready for church in an hour (7:00-8:00), it now takes more than three hours (5:15-8:30), even with the help of the fastest caregiver in town! The most heartbreaking challenge that I am facing now is the loss of my ability to communicate. I can barely talk, write, or type, and soon these capacities will be gone. Look for me to be experimenting with AAC (augmentative alternative communication) devices such as DynaVox and iPad2 with apps.

Brooding over these physical frustrations is the major plot of ALS, namely, to condemn me to a relentless, remorseless decline from skillfulness to clumsiness to helplessness to uselessness that cannot be reversed or stopped. Right now this is already happening to bits and pieces of my body, but eventually this hit-and-run damage will coalesce and my entire fleshly framework will become dysfunctional. What will I do then?

The Apostle Paul often found himself battling so many foes that he felt impotent to respond. After cataloging the calamities that had engulfed him, he described his condition as one of "weakness" (2 Cor. 12:7-10) or even "death" (2 Cor. 4:8-12). Reflecting on why he had been able to transcend these severe limitations, Paul concluded that "by the grace of God I am what I am, and his grace toward me was not in vain" (1 Cor. 15:10). Even though ALS often leaves me so weak that I feel dead, it cannot destroy "what I am" - my being, my selfhood, my spirit. And by God's amazing grace I enjoy a wonderful life. God has given me a wonderful wife, wonderful family, wonderful friends, wonderful church, wonderful physicians and caregivers. I have done nothing to deserve such blessings. Rather, they are all the result of God's unmerited favor. When I compare what others have done for me with what I have done for them, my contributions are as nothing. I say this, not to blame ALS, but to thank ALS for making God's grace so clear and dear to me.

Future

We might as well deal first with the elephant in the room. ALS is a 100% fatal disease and, if I remember correctly my first course in math, that percentage does not leave any wiggle room. Thus, I am certain that ALS will kill me, and I suspect that it will do so sooner rather than later. Doctors and nurses refuse to make personal predictions but, if pressed, will cite statistical averages surrounded by disclaimers, a caution that is fully justified. For example, one "average" might include two white males of similar age, one an academic colleague of mine who died from ALS after six weeks; the other a famous physicist, Stephen Hawking, who is still going strong after forty-eight years with ALS, despite being profoundly handicapped. As for me, those who are diagnosed with ALS at my age live, on the "average" for three years, which anniversary falls today! This means that, from this point forward, every day I live I am beating the so-called "law of averages."

Why do I suspect that my exit may be sooner rather than later? For one

thing, I entered hospice on March 8, 2011. One Medicare requirement of admittance is that my doctor and the hospice medical director "certify that I am terminally ill and have six months or less to live if my illness runs its normal course." Regardless of whether or not I beat this prediction, I am content to live with death staring me in the face, for it wonderfully concentrates the mind. Many of our most painful regrets are caused by procrastination, the daily deferral of doing what matters most because, in the refusal to face death, we suppose that there will always be more and better times to complete the highest priorities of life. But one does not dally when death is knocking at the door, for it draws a bottom line that makes all of life accountable, giving it an intensity, even urgency, that is bracing indeed.

When the end does come, the patient, family, and attending physicians walk together through a thicket of knotty moral problems being fiercely debated by both scientists and theologians. So complex are the issues that I could not begin to comment without making this report unduly long. Therefore, I have attached an appendix that was prepared as a supplement to my Advance Directive for Health Care (Living Will) in order to be more explicit about how to handle special circumstances presented by ALS. If you have done your homework on the end-of-life agenda, you will easily spot the choices I have made. I offer this case study, not because my decisions are better than someone else's, but as a reminder that you do have to choose or risk fracturing your family and frustrating your doctors in your dying days. My plea: start early, give it your best thought, decide how you want to die, and work to achieve a consensus with all members of your immediate family.

What am I doing to prepare myself spiritually when, as Andrew Marvell put it, I hear "time's wingèd chariot hurrying near"? I have never been a fan of foxhole religion (turn to God now because any minute you may die). While it is better than nothing, I much prefer a growing faith sturdy enough to see me through the vicissitudes of both life and death. So I do what I have always done: read and ponder the scriptures, meditate and pray, worship and fellowship with the people of God. Because I have never journeyed this way before, I concentrate on the deeper dimensions of death by immersing myself in the great literature, poetry, and music that abound in this area.

As a result, I am at peace with my impending demise. After all, why should I be exempt from that death that is the destiny of everything that lives? As for the Great Beyond, I am not particularly interested in the rewards it may offer, having already received far more blessings in this life than I deserve. Nor am I eager to be dazzled by pearly gates and streets of gold, being more concerned about whether I have lived "on earth as it is in heaven," as Jesus taught us to pray. His guidance for doing that has become my imperatives for living:

- *Repent* as a radical reorientation of life around the foci of justice and mercy, rather than the issuing of a public relations "apology" for possible "mistakes," which changes nothing.

- *Love* as unconditional acceptance of friend and foe alike, rather than clinging to those so like ourselves that their affirmation is merely a form of self-congratulation.
- *Forgive* as the basis for a fresh start in a ruptured relationship, rather than blame the adversary as a way of evading our responsibility to work on reconciliation.

If you think me a moral simpleton for advocating such idealistic guidelines, I invite you to consider what one young man with only a handful of followers was able to accomplish by following these precepts during two or three years of public life.

As my brief chapter in this unfinished story that began so long ago soon draws to a close, I sing to myself (since I am no longer able to sing aloud):

When I tread the verge of Jordan,
Bid my anxious fears subside;
Bear me thro' the swelling current,
Land me safe on Canaan's side.

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