

# Thinking Out Loud... More Than a Human Experience Wedged in the Core of Science

*“Listen to the sages,  
For what they say is true;  
Break the wheel that’s broken ages,  
Lest it do the same to you.  
Then like the puppet truly blessed,  
You’ll live your life in humanness.”*

—“Strings,” by Gregg Anthony Valenzuela, MD

**R**are are the times when we witness sheer astonishment race across a loved one’s face. The source of astonishment may be a prank that startles, an unexpected gathering of friends and family, a gift that delights, or a revelation that is contrary to that person’s understanding or expectation. Such is the case in this vignette, describing how a kindly physician revealed information to my mother... information that spit confusion into her mind as she tried to reconcile a physical condition of which she believed herself free. As her personal caretaker, I observed denial, incredulity, and resignation all within the span of 30 seconds—a lifetime of experiences in a moment; a human experience wedged in the core of science.

## Background

Over the course of two and one-half years, Mom and I visited her physician many times. The result of each quarterly visit was virtually the same... an exam and tests, followed by the scheduling of the next appointment. Each visit was uneventful—nothing remarkable noted—except for one. This was the time when Mom received news that her glucose test results were somewhat higher than they should have been, though she was told at the same time that there was nothing about which to be overly concerned. The recommendation she received was to pare back her daily intake of bread.

Somewhat disturbed by this new turn of events, Mom was determined to receive good marks at her next quarterly visit, stating emphatically that she would conscientiously follow her physician’s directive despite her deep, abiding love of bread.

The next three months passed as do all months, and we again traveled to her next visit. At the conclusion of this visit, she emerged into the waiting room and announced with some pride that her glucose level was just fine. Cutting back on bread had done the trick. Pleased with the outcome, she stated that she would continue her regimen of reduced bread intake as a general rule... just to be safe. Everything was in control, or so we thought.

## Here’s What Happened

In the wee hours of August 16th, I unexpectedly received a phone call from Mom. She had fallen. I called 911 and then rushed to her home with a list of her medications in hand—the only medical information I had about Mom. I knew inwardly that I should have more at my fingertips... (*mental note to self*).

The pre-dawn hour lent a surrealistic feel to an uncharacteristically high-speed trip to her home. I could still see the stars and moon outlined in the blue-grey sky. The traffic lights mirrored a mental iridescence that was ultimately reflected in the ambulance’s and rescue squad’s circling yellow lights in front of Mom’s home.

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Their strobe lights outlined the quietly moving shapes of rescue squad personnel who went to work with a disciplined compassion.

This was the beginning of a long journey into the corridors of our healthcare system... beginning with the Emergency Room (ER) and continuing with a return visit to her physician, a man who had overseen her care since she arrived in Richmond in 1999.

Notwithstanding the events surrounding the ER visit, a dialogue occurred during one of the subsequent physician office visits that was instrumental in unraveling a diagnosis that had been hidden from our view. This was only the third time since her fall that I stayed with Mom for her entire visit. While I was there, her physician stated that he was dismayed at his inability to treat her effectively and appeared angered by her refusal to quit the only remaining less-than-desirable habit she had—namely, cigarette smoking. At the conclusion of the visit, he stated, “I don’t know what to do with you,” quickly adding that he was referring her to her cardiologist in hopes of *his* knowing what to do.

I told him that I appreciated his professional quandary about the cigarette smoking, and mentally questioned whether he was dismissing us or referring us. When I heard him state this revelation-in-the-making, I was pleased that I had requested a copy of Mom’s medical record at the beginning of the visit. The purpose for the request was to stock our information bank in preparation for another ER visit, an event Mom and I believed would probably happen again. Before leaving the office, I had her records in hand. The month and year of her last visit to this physician was August of 2001.

### **Human Experience Wedged in the Core of Science**

Mom agreed that I should read her medical record to become familiar

with her history. I approached the reading of her medical record with great respect. A medical record is one of life’s most private documents. I felt daunted by reading it... not because of its difficulty, but because of the life-fullness of its facts.

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As I read its contents, I began to see a pattern emerge. To assay them, I carefully entered her medical history and test results into the AMI TIME® System and generated the disease profiles across her data. What emerged was a profile that included a diagnosis that had been in the background silently chipping away at her physical foundation... a diagnosis that had not been isolated as one of her confirmed morbidities. The diagnosis was diabetes. In fact, we learned through the AMI TIME System that diabetes had gone undiagnosed for more than five years.

In response to this new information, we sought the services of a multidisciplinary practice that would oversee the management of Mom’s care. We were fortunate to locate a

care team through the help of two caring family physicians. One was retired and residing in Florida; he was a friend and professional confidant who had practiced in Virginia for many years and who had also taught at the University of Virginia. The other was a friend of the former and a practicing physician still teaching at the Medical College of Virginia. We promptly made an appointment with this new care team.

### **A New Road**

Mom and I went to her first visit armed with the medical record compiled by the AMI TIME System. It was a medical history detailed over five years consisting of in-process, working, and de-activated diagnoses; test results; progress notes; and the disease profiles alluded to above. We also included the EKG strips we had received from her providers.

When I handed the records to the physician, he silently flipped through the pages for no more than 30 seconds. No one in the room said a word. The only sound was that of the turning pages. After scrutinizing them, he said he would be back in a few minutes. With little to do in the meantime, I scanned the room for intelligence about this new physician. My eyes focused on a picture of a child under which was displayed a poem written by the physician we had just met.

Approximately seven minutes later, he returned to the examination room. He was not smiling. With feet spread about 12 inches apart and set squarely, no more than five feet from Mom in her wheelchair, he looked into Mom’s eyes and said, “You have diabetes,” to which Mom replied with chin slightly elevated, “No, I don’t. My sugar was up only slightly, and I’ve been told it’s not a cause for concern.” He said slowly, “You have diabetes. You need to be treated.”

Mom’s eyes widened as she replied, “Why do you think I have diabetes?”

Holding up the medical record I had just given him—the one that the AMI TIME System had produced—the physician replied, “The facts in your medical record support this diagnosis.”

Mom’s chin dropped slightly in response to his statement. Looking at her resolute face, I recalled her memories of her brother and sister, who had been likewise afflicted and whose fate I now believe she supposed she would escape. In a matter of 30 seconds, she became a resigned believer in what for her was a brand-new diagnosis.

During the rest of the exam, her new physician found that her feet had been left untreated and that their circulation was poor. Her eyes also required attention, her diet needed overhauling, and her medications needed updating. These were diagnoses that would start to direct her care in the future.

### **The Practice of Information**

I thought at the time that her medical history had been seen in a new way, and hoped that for her a better future would be in the making. I saw that the practice of information *is* a guide to medical care and felt deeply that she would be more than a human experience wedged in the core of science... more than an interesting statistic for future research. Information technology had been *our* research assistant.

I was astonished at how quickly a medical record—profiled with facts that existed for the past five years—had been transformed into actionable items using information technology as its tool and had, as it were, broken “the wheel that’s broken ages.”

For different reasons, Mom and I were astonished that day—Mom because she had not known that she was a true diabetic, and I because, up and until now, I had merely intellectualized the relationship between the science of information and patient care, and had neither really experienced its power nor fully internalized how the practice of medicine would indeed become the practice of information. **D&T**