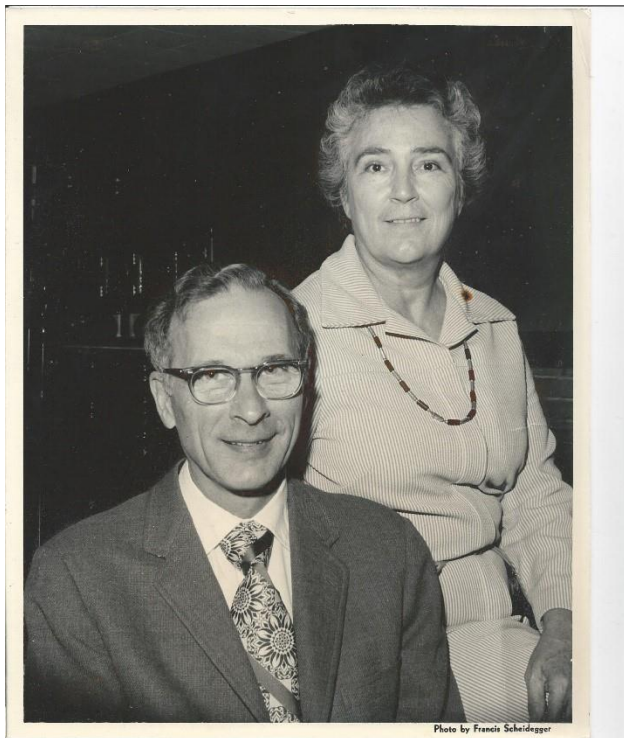


My Father's Journey: A Reading and Interview with Susan S. Deusinger, PT, PhD, FAPTA

By Susan S. Deusinger, PT, PhD, FAPTA

This is the story of my father's 83-year journey—from life, beginning November 27, 1917, to death, on February 12, 2001.



Susan Deusinger's parents celebrating their 50th wedding anniversary

My Father's Journey: A Narrative

"Is this my fault?" No, Daddy, it's not your fault—or anyone else's. It just is.

This conversation started the journey toward my father's death, a journey touched by loss, but lightened by choice. Choice, I believe, is the highest privilege patients have in health care—a privilege the system struggles to honor. This is the story of my father's beliefs and choices and how they supported his final time in life.

An architect by trade, German by heritage, and a Christian Scientist by upbringing, my father had a legendary work ethic, a deliberate and detailed approach to life and an inviolable belief in personal responsibility for health. Daddy, as I called him for his 83 years, approached life with vigor. If something needed to be done, he found a way; few things stymied

him and he expected others to have the same confidence of action. You just had to try hard enough to create intended outcomes. Having good health was no exception. Daddy was physically active, intellectually engaged and nutritionally sound. A laconic person, he modeled those approaches rather than lectured about them. His impatience with poor health may have arisen from his family belief systems, or may have just been a result of his general impatience to see visible outcomes from planned actions. In life, he produced creative architectural plans, built two swimming pools for his daughters, made toys for 200 children at Christmas, planned special outings for his grandchildren specifically to learn new things, and renovated rental and historic houses. He was a draftsman, carpenter, woodworker, beekeeper and community organizer. His was a busy life!

The symptoms must have been there for several months. A strange allergy to mulch arising in a man who had a life-long passion for landscaping and gardening, pain and abdominal swelling emerging in a slender man who never recognized pain, and fatigue that sapped his energy and interfered with the rhythm of his life. Although I am guessing, I suspect the fatigue must have been the most maddening for a man who defined his life around productive work and had always had more than enough energy to support that work. I am guessing because these changes and their meaning to life were never discussed. At the least, he must have seen them as inconvenient. However, as this journey unfolded, I believe Daddy regarded these changes as failures of the soul.

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We had just finished with the oncologist, who delivered a diagnosis of inoperable duodenal cancer. The physician’s manner was compassionate, yet straightforward and ideally tailored to his patient’s personal style. Chemotherapy was the medical option—the only medical option. Daddy made a choice: take chemotherapy and then get back to life. Two treatments later, he announced that he would not continue. The care was excellent, but the setting was not a good “fit.” As he stated, “there were sick people there.” I believe that my father regarded chemotherapy simply as an adjunct to his time-honored remedy for preventing or treating illness: sleep. Sleep refreshes, renews and even cures. Sleep—paired with not acknowledging illness—had always been Daddy’s solution to discomfort or malaise. And, not surprisingly, the outcomes of that approach were usually excellent—reinforcing his belief (also reinforced by science) that rest and sleep are important for health. So, consistent with his usual deliberate action, Daddy carefully crafted an alternative choice that eliminated the chemotherapy and retained the core importance of rest.

The plan to reinvigorate his Christian Scientist roots was made privately, perhaps with my mother’s knowledge, but not involving her participation. Daddy re-joined the church (after a 50+ year absence), engaged a practitioner for prayer and healing, and attended services regularly for a few months. To better understand the Christian Science tenets, I visited the local Reading Room, checked out resources and discussed my questions with the librarian. Daddy seemed to value interacting with the practitioner and with others who shared the view that illness is an illusion, akin to sin, which is addressed through prayer. Although we did not discuss his decision to return to the church, it seemed to yield energy and focus for the prospect of returning to the projects so important to

his life.

That is, until he called me to report extreme difficulty breathing, request that I come over, and instructed me to bring some oxygen. I explained that even a non-physician clinician like me cannot just “buy” oxygen commercially. However, his typical impatience with petty excuses (probably exacerbated by the anxiety that must have accompanied his shortness of breath) left me with a dilemma of how to help. Fortunately, the kindness of a physician friend willing to visit him at home helped catalyze Daddy’s next consideration of options: go to the hospital (a conflict with his church’s tenet) or stay at home (a risk for drowning from pulmonary effusion). He chose the hospital. After aspiration of several liters of fluid from his chest cavity was completed in the emergency department, Daddy was admitted to the hospital.

My father was a practical man, and I believe that his choice to seek medical care was influenced by a practical situation: breathe or not breathe. Daddy had made this medical choice twice before—once for appendicitis and a second time for cataract surgery to be done concurrently on both eyes—also for practical reasons. Because my father was generally a trusting man, I imagine he did not even consider that the choice to enter the hospital might have a negative impact on his relationship with the Christian Scientist practitioner. In fact, when he reported the following day that his practitioner was not returning his phone calls, he mused “I thought he was my friend.” No, Daddy, he was your practitioner. Being hospitalized is not consistent with the tenets of your church; you have crossed a line.

It seemed the loss of this “friendship” left a void in my father’s heart, as he had invested sincerely in the church and personally in the practitioner as a vehicle

for healing. He also believed that he was truly part of a supportive community that would be there for him as he regained his health. However, the practitioner never returned and Daddy was left to deal independently with an increasingly debilitating condition in a culture he regarded as a poor “fit” for him (i.e., “there were sick people there”).

“Is this my fault?” No, Daddy, it’s not your fault—or anyone else’s. It just is.

My responsibilities during the ambulance ride, the hospital admission and treatment, and the eventual transfer to a skilled nursing home were to shepherd the process and support my mother who silently grieved at every step. An additional necessity was to remain controlled, neutral and logical—consistent with my father’s view of good decision-making. The nursing home welcomed my father, who had been active in designing its recent renovations, and my mother, who had beautified its gardens. He selected a room with a view of the majestic, century-old oak trees that graced the property. Admission went smoothly. Daddy must have made his next choice almost immediately upon admission, but he waited a few days to share it with me. In the meantime, he invoked his belief in rest as a healing strategy by allowing nursing care only if it did not waste precious energy. Thus, he chose not to participate in rolling, walking, sitting or being helped to bathe. This was not a non-compliant behavior; it was a deliberate strategy to direct the body’s energy sources to healing. Nothing else.

Daddy’s next choice was equally deliberate and well-considered. He chose to die. He said clearly, “Unless I can work, I choose to die.” This, in my view, was not

suicidal ideation, but a clear recognition that the various interventions had been supportive but not effective, and that the outcome was clear. In conversation with me, he tested the various options for accomplishing this outcome, the best of which was to stop eating and drinking—behaviors of which he was in control. In fact, in the face of a different kind of cancer, his own father had made the same choice.

Our first conversation about this choice occurred on a Sunday, with Daddy making a commitment to consciously and consistently withhold food and water. Our next conversation was two days later, on Tuesday, during which he stated, “This isn’t working.” What’s not working, Daddy? “I’m not dead yet.” This exchange likely resulted from his non-emotional analysis of the outcomes of the decision on Sunday, a life-long impatience for “projects” to be completed, and a poor understanding of the time-frame in which the intended results could be achieved. Ten days later, my father completed his journey—supported by his own beliefs and enabled by his own choices.

Clearly, my father left a void in our hearts. To me, however, he gave the privilege of honoring his beliefs and supporting his choices—something we don’t always have the opportunity to do as clinicians, and may not have as daughters. I will always treasure that opportunity to share the journey from life to death with my Daddy.

No Daddy, it’s not your fault. It just is.

Behind the Narrative: Interview with Susan S. Deusinger

A STORY OF PATIENT CHOICE

Well, I only wrote it...I think I wrote it, in [2017], which was 15 years after his death. But I had never forgotten the details, and I didn't record them in a journal or anything at the time. I had thought it was laced with family messages of health, with religion, and with the key concept of choice, which I really think is important in patient care. So, I thought it was an interesting story for many perspectives. ...I for many months didn't share it with anyone except my husband... He's also a clinician, and so I think...it prompted me to write it. Partly because I was in a new phase of life, having retired from academic work, ...and having a little bit more time to be still and reflect on things and get those things recorded. I've written a similar but very different story about my mother; ...I'm ...interested in people's stories. ...So, I wanted to know my dad; ...I just thought this was a very interesting story and it meant a lot to me personally, but it [also] meant a lot to me as a clinician. ...I would have loved to have had this story to share with my students because I think the stories that people tell are important lessons.

ON LOGIC AND EMOTION

From a personal standpoint, I'm fairly emotive anyway and [Daddy] was not. And so, it was an exercise in being logical under illogical conditions, and non-

emotional under highly emotional conditions. And I found myself watching from my own shoulder..., just watching myself be non-emotional under those conditions. As a practitioner, I think we have the same challenge often. We are highly connected with our patients in a professional way, but sometimes their stories are very sad, and I've learned that crying with a patient is not inappropriate.

But it's not an everyday experience ... to be logical and unemotional in illogical and emotional contexts. I ... really clearly remember that I was watching myself and saying, "Isn't this odd? I'm the one in the family that is always emotional." So, this role was very challenging, and it was very different. I have one sister and she's less emotional and she's older... I also assumed that the older sibling would be the one that would take care of these things. But ...even though she's very supportive and a wonderful person, she was not in town. And even if she had been, I would have been the one taking care of that because I'm a clinician...And I think I learned more what we struggle with as practitioners, although I had been a practitioner for a long time by the time this happened, and...I think we need to forgive ourselves as practitioners for feeling about our patients. That was always a theme in my teaching, because I think in my PT school in the '60s we were schooled to believe that emotions were not part of our professional life. And I always thought that odd, because they are part of your world and they are part of your professional life, not to the detriment of the patient. But by this time, I had balanced the idea, I thought, in my teaching, that emotions are going to be part of your practice. But this was a time to test that.

MORE THAN "NONCOMPLIANCE"

I think one of the questions I still have about the "refusal to roll, transfer, sit and so on" as a clinician is whether I would have the strength to support a person who made that choice in life, who is definitely going to have negative consequences and further pain by lying inert in a bed for too long. And so, you know too much about tissue friability, and yet it's a choice. I have also reflected back to see whether I have had a patient—I've been a PT for 50 years now—who refused to roll and ... I didn't understand why. You know, perhaps I have, but I had maybe judged and not met that person ... at their level, to understand why they might have been refusing that as my father did refuse. I think the first thing the therapist has to do is to reorder their thinking; that a patient's refusal is not necessarily noncompliance. It might be the right thing. So, we make a judgment about people who refuse to do what we think is right, and we fail ... maybe to ask a few more questions that would reveal why this... I'm using the word refusal because we use that in clinical practice, why this choice is being made. And sometimes it might be two more questions or even one more question. Tell me more. Maybe it hurts too much and maybe they need medication. Maybe it's a choice like my dad needs. It could be anything, but we come from a perspective of refusal rather than choice. We've had people who choose not to learn to walk again, who choose not to put on a brace, and we label that refusal and then that is recorded for everyone to see in the documentation. Everyone who will also make the same judgement. The way we write our documentation matters a lot because everyone else shares that, and everyone else therefore has the opportunity to make the same judgments.

SPIRITUALITY AND PATIENT CARE

I think one of the surprising things about my father's re-entry into the church was that for my entire life I had not heard him speak of going back to the Christian Science Church. He had attended church when I sang there ... a Presbyterian or Methodist church. He had attended church a few times during my lifetime. So to renew his public expression of faith was a surprise and made me wonder whether there was always a stronger private expression of faith that he was just not sharing. Similarly, in patient care, there may be people who are very public about their spiritual connections and some of those people ... are anxious, in a sense, to move on to what they would call the next life. And they may make choices that in our regard are not helpful, because their view of the next life is very positive, and they've learned that. ...[T]o me, that would be very important to know. Now, we have an obligation in health care to provide as much as we can provide, but we don't have an obligation to *force* what we can provide. So, then, learning ... about the person's spiritual belief would be very important.

And we know now with some additional literature that spiritual connections are very, very important in patient care, both for the practitioner and the patient. So, I think the surprise ... was a lesson in somehow trying to understand both our family members and our patients, and whether their core beliefs and family messages are just not [apparent]. But they're still there, and they need to be honored and fed, and used in the sense of putting together the right kind of care for patients. And ... they mean that we need to "let go" earlier than we know that science would drive us to persist. That's always been a dilemma for me as a clinician. I know some stuff that could help, and my goal is to help, but not to *inflict* help—and that's what we do sometimes. There was some discussion about my father going home and not spending time in a nursing home. And had I pushed that idea, which he was not in favor of, that would have been inflicting something very bad on my mother *and* my father. And yet people often have the belief that dying at home or recovering at home is the best option. But for my family, that would not have been the best option.

About the Author



Susan S. Deusinger spent 36 years at Washington University building a progressive academic culture in physical therapy to ensure excellence in clinical practice, education, and research. Upon her retirement in 2014, Dr. Deusinger had served for 24 years as director of the Program in Physical Therapy and achieved the rank of professor of Physical Therapy and of Neurology. She now serves as professor emerita. As director, Dr. Deusinger inspired students and colleagues to apply their knowledge to optimize and advance human health through movement. Her work helped lead Washington University's Program in Physical Therapy to obtain a consistent No. 1 national ranking by *U.S. News & World Report*. The program has been recognized in the top 1 percent for two decades.

Dr. Deusinger earned her bachelor's degree in physical therapy in 1969 and spent the next decade in full-time clinical practice in venues across the country. During that time, she developed rehabilitation programs for patients with brain injuries, aquatic programs for people with physical disorders, educational programs for patients with arthritis, and a therapeutic riding program for children with developmental disabilities.

She joined the faculty at Washington University in 1978 to coordinate clinical education for baccalaureate-level students. To hone her ability to develop new models of practice and education, she completed two graduate degrees at Washington University—a master's degree in education in 1980 and a PhD in social work in 1987. In 1990, she was named director of Physical Therapy at the School of Medicine. At the university, Dr. Deusinger facilitated advancing professional education to the doctoral level, and also gained approval in 1989 of the PhD in Movement Science. In 1980, she developed the program's first faculty clinical practice—a community-based service. Subsequently, in collaboration with her colleague and husband, Robert H. Deusinger, PhD, she worked to establish an on-site evidence-based faculty practice. This practice has grown into a major outpatient service that is fully integrated into the School of Medicine's Faculty Practice Plan.

Dr. Deusinger has served as editor of the *Journal of Physical Therapy Education*, president of two components of the American Physical Therapy Association (APTA), a lead reviewer for the Commission on Accreditation of Physical Therapy Education, and a member of groups planning the future of professional and post-professional education. She is a Catherine Worthingham Fellow of the APTA. In retirement, she consults with institutions wishing to change education and practice in ways that inspire new visions for healthcare.