

## Art Appreciation: Answering the Call of Caregiving

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*Art: skill acquired by experience, study, or observation; the conscious use of skill and creative imagination, implying a personal creative power which cannot be analyzed: the creation of beautiful or significant things*

It is a distinct honor and privilege to speak to you today about my experience as a Neurologist, the son of an Alzheimer's victim, and a caregiver. Having just completed my journey down this path, perhaps fresh observations and recently developed insights may be beneficial to you who perform such vital services to those affected by this and other mental illnesses.

To begin, let me tell you the story of a man. A strong man. An upright man. A man of unsurpassed integrity. A dependable man of his word. A capable man of many talents. A loving mentor. A humble, gentle man of God. A broken jar. Let me tell you about my father, Lester Potts.

He was born to sturdy Pickens County, Alabama folk and learned the Great Depression work ethic through toiling in the family sawmill and farm. In many ways, he never really left this place where wood and sweat and food and family and work and love together formed the earliest rings in his white oak core. This sturdy oak provided the stability and shade under which I grew to manhood, and was the very ideal of a father to me.

He never swayed or bent, not one inch, from what he felt to be the righteous way.

Lester was the friend the townsfolk sought when someone needed help. They knew they could depend on him to do the right thing in every situation, to provide the assistance needed without hesitation or groaning. He was the perfect neighbor. And his neighborhood extended across all boundaries of race, religion, and socioeconomic status. Some of the dearest souls in the world to him were those who walked on different roads, perhaps without the benefit of streetlights to guide them. For folks with eyes to see, Lester Potts was the nearest thing to a beacon they will ever know.

They thought so much of him they wouldn't let him rest. From sixteen years as chairman of the administrative board at First United Methodist Church, to city council member, to Lion's club member with perfect attendance, to set-man for the Aliceville Little Theater, to lay speaker and Sunday school teacher, Lester gave and gave. But even so, he was ever-present in the life of his family. He learned, like so few, how to fulfill his civic and occupational duties without infringing upon family time. Would that I had sat at his feet and asked for advice.

Though he didn't know it, Lester was a master artist even then.

A few years back this oak chose to tug his tap root out of red clay Pickens County soil and plant closer to his boy and little granddaughters. This may have been the hardest storm his timbers ever had to stand, but he knew he had to do it. Looking back with clarity of hindsight, one can see the earliest signs his white oak bark had been breeched, dementia's blight beginning its relentless boring to the core.

Denial, common to all who lose a loved one to dementia's scourge, plugged my ears at first. After all, I am a Neurologist who hears concerned families complain daily about a patient's perceived loss of cognition, which often turns out to be due to normal aging. But then it came: the visit from Dad's employer notifying me he had been terminated due to mental errors on the job. I thought myself a failure, a poor excuse for a dementia doctor... and inadequate as a son. And I felt such pain for him, the perfect worker, who for the first time had been told his labor didn't measure up. His call to me that day was pitiful; I'm sure he felt he'd let me down. Perhaps he sensed the earliest splintering of his white oak grains which, until that point, had held in every gale. A man who had prided himself in his industriousness and capabilities was now failing in his tasks.

In many ways, the last few years were a blur. His disease course was uncharacteristically rapid, precluding adequate planning and adjustment regarding care. Those familiar with dementia know the primary caregivers bear the brunt of this cyclonic illness. My mother, the most diligent caregiver I have ever seen, was the unheralded loving constant every day of my father's life. With unsurpassed attentiveness, she sought to ensure that every possible need was met, and poured out her life in self-deprecating love. She is a master artist, as well.

I had been asked by my minister, Dr. Charles Durham, to serve on the board of Caring Days shortly after moving to Tuscaloosa in 1997. Caring Days is a facility which provides a safe, stimulating and comforting daycare environment for dementia patients. Its parent organization, Caring Congregations, is composed of nineteen churches and synagogues which provide support for this and other worthy causes in the Tuscaloosa area. Through my participation there I came to know what a vital ministry the organization provides, and have referred many clients over the years. Little did I suspect, however, that my family would be in desperate need of its services.

The day arrived, predictably, when my father could no longer safely stay at home. Providentially, an opening became available at Caring Days along with scholarship money. This was truly a turning point in the life of my family, and saved us in so many ways. Immediately Dad fell in love with the place, with its director Vicki Kerr, and with the caring, capable staff who embraced him so openly. Amazingly, his cognition improved, and once again a smile returned to a masked countenance. It was then a miracle occurred, the fruits of which you are about to see.

The only paintbrush he had held to that point was one which white-washed fences, painted barns, or trimmed siding on a house. Time was too precious to waste on

something not considered work. As more of nature's wall of inhibition fell, however, he became open to the fine instruction given by a kindly volunteer art teacher at Caring Days, George Parker. What subsequently happened could be compared to wildflowers blossoming from a fallen log in the Alabama woods. Beautiful florals, inviting still lifes, breathtaking landscapes, and heartwarming Christmas scenes came home with him to the amazement of the family. And, more poignantly, a broken man was given once again something for which to be proud.

The innate power of art lies in its ability to meld the heart and mind of the artist with that of the observer, to call to consciousness in one human being the depth of emotion, experience, spirituality and intellect behind the creation of the artistic work. I believe art, in all its forms, to be the purest medium of human connection, the one which most truly promotes holistic communion between individuals. And at times, this power may kindle a creative fire in those of us who attentively listen, who earnestly observe. Such a phenomenon happened to me.

Though deeply moved and thankful for Dad's newly discovered skills, I was quietly struggling with his plight; in effect, grieving his loss. On a "whim" my perceptive wife gave me a poetry anthology by Henry Van Dyke, a Presbyterian minister, noted educator and member of President Woodrow Wilson's cabinet. From the first line which met my eyes, then wet with tears, my soul was stirred and my life changed. The urge to tap into my heart and try my hand at writing became a consuming fire, and during the first few weeks of 2005 I wrote approximately thirty poems. What gushed forth was an unfiltered flood of memories and gratitude, directed, I believe, by the Holy Spirit, and inspired by an artist's brush and poet's pen. In gratitude to Caring Days, my family and I published "The Broken Jar", a book of Dad's paintings and my poetry, for sale to benefit this vital organization.

The staff of Caring Days attentively listened and earnestly observed. They saw in my father a strong and capable man with a heart full of love who had lost his art. As a physician and a son, I saw only the many abilities he had lost, like I had been trained to do. But they looked beyond inability and saw the creative potential concealed behind aphasic eyes. Seeing Dad struggle with his hammer, they gave him a paintbrush. And in so doing, they gave much, much more. For through his new-found gift came healing power, not only to the heart and spirit, but to the mind and body as well. Yes, his cognition actually improved, and loved ones once again beheld a smile upon a lifeless face. He had found the "art of aging", and they had practiced "art appreciation".

Lester Eugene Potts, Jr. passed away of pneumonia on September 15, 2007 at Hospice of West Alabama with Mother and me at his bedside. The artist died surrounded by his art, which we had placed in his line of sight in the room. He kept his eyes on the art, and, in the end, the "art" remained. Is there a lesson here for us as caregivers? I think there is. Let me explain.

Caregiving is about loss: of companionship, independence, control, etc.. Ironically, those providing care suffer similar losses to those receiving it, but often more keenly

experience the resultant pain due to greater awareness. One of the primary challenges to the caregiver is to look past loss and see “art”: the unique talents, capabilities and personality traits that even the demented or debilitated possess. The focus should be on abilities that remain or can be identified and developed, not those that have departed. Such focus creates an affirming environment in which the patient can be loved “as they are”, and in which the love of the caregiver may be genuinely expressed. In the case of the demented patient, improvement may thus often be noted in cognition, behavior, mood, activities of daily living, etc.. This translates into “respite” for the caregiver in the truest sense of the word.

When admiring a Renoir or Van Gough, very few of us would ponder perceived flaws and imperfections, but rather, would appreciate the vibrant color, line, scene and story depicted in the work. We, as caregivers, should view our patients in the same way.

Over the last 7 years my family and I have experienced fully the plight of the caregiver: denial, stark realization, painful struggles to provide care at home, stolen independence, institutionalization, guilt, financial worries, commitment proceedings, hospice and end of life issues, and finally, the loss of our loved one. We watched as Dad, the most righteous, gentle human ever known to us, threw nursing staff across his bed in the nursing home. We saw this gifted man struggle with the most menial tasks. We sat in a court of law and testified that Lester Potts was indeed a danger to himself and others, and placed him in a state psychiatric hospital. We saw him cry when he looked at his little granddaughters. And, as a Neurologist and only child, I felt a complete failure at times. But amazingly, given all this, we are able to give thanks. How? By listening through the stammering for the song. By watching ‘midst the stumbling for the dance. By focusing past the scribbling on the “art”.

It is true that Alzheimer’s patients often do not recognize there is a problem at the beginning. But in no way does this mean that they, at some level during the disease course, don’t understand something is not right. During bedtime prayers at the moderate stage of illness, Dad would cry and say to my mother, “I am so messed up”. It is important that we remember to treat the patient as if they understand, and that we recognize there may be some insight remaining about their condition.

And now, let me briefly offer a few practical suggestions. Seek medical evaluation for the patient at the earliest possible time so that proper diagnosis and treatment may be instituted. Solicit legal services early; preferably those of an eldercare attorney practicing in the patient’s home state for seniors (often a free service provided by schools of law), or one having expertise in the particular disability with which you are dealing for issues such as power of attorney, transfer of property and financial assets, living will, healthcare proxy and other end of life issues, consideration of long term care options, etc. Early driving assessment is also recommended for dementia patients, preferably objectively performed by a therapist and repeated as the disease progresses. Strong consideration should be given to enrolling the patient in a comprehensive daycare program like Caring Days. Too often excessive guilt keeps caregivers from utilizing this invaluable source of respite for themselves and cognitive stimulation for the patient. Support groups may be

helpful, as well. Developing and following a flexible care plan is also worthwhile. Of course, it is critical for caregivers to take all necessary steps to maintain their own health, physical, emotional and spiritual, the same way a triathlete must train for endurance.

Above all, keep your eyes on the “art”.

As the gasping, gurgling, then silent voice of pneumonia left Mother and me kneeling in Dad’s room, and dark-before-dawn tranquility finally brought peace, we looked up and saw the art...art that spoke for the one in which no language was left, art which enabled a 7 -year-old to know the heart of her “Papa”, art which will stir the souls of those who admire for generations, art that was first discovered at a place of respite for the caregiver. And we remembered...and appreciated.

And now let me lead you into my father’s gallery. He would give gracious invitation himself, if he were still with us. Within, you will see the finest example I know of the art of aging. Believe me...I’ve walked these halls; I’ve loved the treasures hanging there. As you appreciate his art, may each of you come away enriched, inspired, and ready to practice your own.