



Dementia: Tearing Down the Wall of Fear

by Leslie Hayes Russo

"Getting old," my Aunt Fran used to say, "is not for the faint-hearted." Nor, she might have added, is caretaking for the faint-hearted, particularly when the elderly parent or relative has Alzheimer's disease or some other form of dementia. The challenge can be daunting: arranging or attending doctor's visits, weathering troubling ups and downs and recurrent hospitalizations, and maneuvering around a complicated system of insurance reimbursement. Residence in a nursing home or assisted living setting is often inevitable.

This article concerns the additional, often unspoken hurdles advocates face when speaking to a jury about the loss of a member of the family with Alzheimer's or dementia. In a medical malpractice case involving the wrongful death of a nursing home or assisted living resident, particularly one with dementia, the argument is made, explicitly or implicitly, that the family has been spared the unimaginable horrors of watching their loved one's further mental and physical deterioration. The argument is made, explicitly or implicitly, that the decedent is better off. There is the suggestion that the individual who has succumbed was already at the zenith of his or her life expectancy, that the death, though regrettable, is therefore something of a *so-what*.

And yet.

My Great Aunt Alice, at 102, spoke to me of the "welcome burden," or the "better half" of love's equation. She had welcomed the "burden" of tending to her mother and father as they became ill and suffered from atherosclerosis. She was grateful for the opportunity to pay her parents back for their many years of self-sacrifice and devotion. If one of her parents had been wrongfully taken due to malpractice, Aunt Alice would, despite their dementia, have felt robbed. If she had been asked to describe that loss, she would not have focused on *her* loss of their love and succor; she would have emphasized the loss she sustained because *she was deprived of further bestowing her own love upon them*. She would have described the loss of the joy of reading to her father, who, despite imperfect comprehension, was inevitably soothed by her voice. She would have described the pleasure of brushing her mother's hair, or rubbing her mother's back, even when her mother confused her with her sister. She would recall the simple joy of making sure that her parents still listened to music, even if they could no longer recall the name of a favorite composer or that the tenor was Caruso. She would have spoken of the indisputable moments of recognition and the deepening, not lessening, of

the parent-child bond, despite all. Their death, she would have explained, would have deprived her of the *gift of giving*.

So often the loss we ask our clients to describe to the jury is the loss of the *receiving* side of love. What do they miss most about their mother? What did their father do for them? The loss of the *giving side* of love and the joy derived from that giving should not be ignored when we speak to the jury of the effects of the loss of one who suffered from some form of dementia. To speak only of the loss to our clients of their parents' affection *for them* is but half the cup.

And what of the implication that the decedent is better off? Given the attitude of much of the medical community and reporting media about Alzheimer's, defense counsel hardly need raise the suggestion that death is preferable to the disease. It will be foremost in the jury's thoughts. As one woman who was diagnosed with AD wrote, "Can it be that the term 'Alzheimer's' has a connotation similar to the 'Scarlet Letter' or black plague?"

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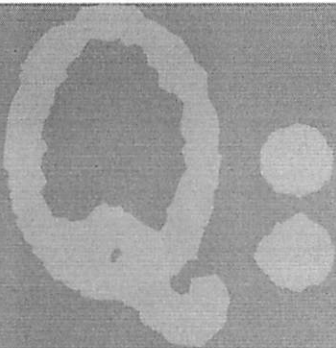
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Dementia

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Is it even more embarrassing than a sexual disease?"

A client whose mother died within a week of her residency in an Alzheimer's Unit in an assisted living facility due to a medication error had this to say about the suggestion that her mother was better off:

One of Mom's friends said she was better off anyway to have died. That outraged me. Would someone say that if the medical profession had failed someone who had lymphoma, had heart failure, was going blind or deaf, had multiple sclerosis?

We are a society that is very intolerant of anyone with any mental disabilities, progressive or not. The thought is "that person makes me uncomfortable and I don't know how to act. They aren't contributing to society and, thus, would be better off dead." Look at John Nash, played by Russell Crowe in *A BEAUTIFUL MIND*.¹ Nash was a paranoid schizophrenic, yet won the Nobel Prize in Economics. He was very "deranged", but made an astounding contribution to society.

In *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*, Peter J. Whitehouse, M.D., Ph.D., and Daniel George challenge the historic and "all-too-tragic and reductionistic narrative" that medical professionals and the media have told to a terrified public for decades about Alzheimer's.² They suggest "that both our perspective on brain aging and how we treat patients might be less distressing if we could give persons and their families the choice to see AD (Alzheimer's disease) not as a loss of self wrought by a disease, but as a *change in self* that is not so unlike many others a person undergoes in various other life stages; not as a *war*, but as a natural stage of life that introduces challenges and offers opportunities for families to grow closer as they recognize the interdependency with others and embrace the opportunity for closeness in the face of cognitive loss." They urge, compellingly, that:

¹ *A BEAUTIFUL MIND*, by Sylvia Nasar, is the unauthorized biography of Nobel Prize-winning economist and mathematician John Forbes Nash. It inspired the 2001 film by the same name. It covers Nash's youth, years at Princeton and MIT, and his struggle, and that of his family, due to his schizophrenia.

In *TOUCHED WITH FIRE: MANIC-DEPRESSIVE ILLNESS AND THE ARTISTIC TEMPERAMENT* (1993), Kay Redfield Jamison, Professor of Psychiatry at Johns Hopkins University, and bipolar disorder sufferer herself, describes many famous persons who have suffered from mental illness, including Lord Byron. Some of the world's greatest achievers have been troubled by mental illness. Ludwig Von Beethoven wrote many of his greatest works during times of psychotic delusion. Abraham Lincoln suffered from suicidal depression. Sir Isaac Newtown suffered many breakdowns, but was knighted for his scientific contributions.

The effects of dementia *do* damage the awareness of one's identity and can be serious, troubling, and tragic. People may eventually lose some of their essential qualities, like communication. But these alterations in personhood give us little grounds for saying that an identity has been destroyed or lost, and certainly don't provide justification for ceasing to understand, engage, and include them in our own minds or in our society. Dementia changes selfhood but it does not erase it all together or create non-persons who are shells of themselves. As Tom Kitwood, a pioneer in dementia care, once wrote, the perceived loss of self is not linked exclusively to the progress of the disease, but results from us *projecting hopelessness and confusion onto people with dementia* and failing to take time to engage them, understand their needs, perceive aging as part of the human condition, and reintegrate aging persons into our lives.³

In his book, *What Your Doctor May Not Tell You About Alzheimer's Disease: The Complete Guide to Preventing, Treating, and Coping with Memory Loss*, (G. Devi, M.D. Warner Books

² *Id.* at 24.

³ *Id.* at 25 (emphasis added).

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2004), the author reminds those who have family members with Alzheimer's that,

Individuals who are affected by Alzheimer's are *not* their disease; they are not Alzheimer's patients – they are people affected by Alzheimer's disease. They are still mother, father, sister, brother, aunt, uncle, grandmother, best friend; they are still individuals capable of loving and sharing; they still need a hug and a smile...And you'll be better able to give and receive those feelings once you become more familiar with your challenges – the human brain and the changes it can go through during this disease process.⁴

The advocate's job is an extremely difficult one – to educate the jury, convincingly, and with expert testimony, that Alzheimer's is no better or worse than any number of ailments which will inevitably strike substantial numbers of us when we are elderly; that Alzheimer's is better understood when we cast aside the fear and myths associated with the disease.

Aside from the minimal *voir dire* permitted by most judges, you must use elicited from your witnesses, expert and non-expert, testimony which will assist the jury in discarding preconceived notions about the lost family member. What acts or interchanges demonstrated that she could still be loved, that she could still love? That his presence offered comfort to his family? Did he or she behave differently when in the presence of a family member; was he calmer, did he seem more cogent? What exchanges did the LPN witness? How did the family "communicate" even if in untraditional ways? How were staff trained to make life as dignified and meaningful as possible for the individual with Alzheimer's or

other form of dementia?

Laura Kessler, reporter and author of *Dancing with Rose: Finding Life in the Land of Alzheimer's*, acknowledged that she faced her own mother's illness and death of Alzheimer's "with a combination of fear and detachment, a stunned observer, emotions shut down. I knew that big, awful events like this were *supposed* to be at least instructive if not life-altering. I knew I *should* have learned something from the experience." After her mother's death, she determined to gain greater insight. She worked as a resident caregiver in a "memory care"

nothing remains, about communicating after words fail, about meaningful life lived in the moment, about patience and kindness will always remain with me.⁵

We could endlessly debate whether loss is more easily sustained when our loved one departs suddenly or after a long struggle; but there can be little doubt that the loss is the more horrific when unnecessary, unjust. In a death case involving an elderly woman whom the defense contended would likely have soon died from illnesses unrelated to

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facility for four months. During that period she learned:

The people I cared for were ill, but they were not their illness. The world they inhabited — dreamy, fragmented, often wordless, sometimes confusing — was far more vivid, more alive, more deeply human than I could ever have imagined. I became part of their lives: Jane, energetic, gregarious, the social center of the unit; Eloise, elegant, alternately dreamy and contentious; Marianne, who created an alternate reality for herself and lived in it happily and comfortably; Frances, the almost-centenarian whose senses were more alive than anyone I'd ever met; Hayes, who ping-ponged between clueless oblivion and witty repartee; Jack and Caroline, the lovebirds... The lessons I learned about what is left when you think

the negligent perforation of her liver, our colleague, David J. Wildberger, did not dispute this eventuality. But he reminded jurors that she should have died in her own time -- "not then, not that way, not at the hands of man." Ending a life prematurely, wrongfully, is *not* the more forgivable because the decedent had dementia rather than heart disease, stroke, end stage renal disease, diabetes or any combination of the above.

Finally, we cannot ignore even the unspoken implication that life becomes less important to one who has had the good fortune of living a long one. To the contrary, as the days "dwindle down to a precious few,"⁶ they are exponentially more important. The lyrics to a song, sung by a daughter to a struggling, elderly mother, remind her that with all the frailty and uncertainty that old age may bring, there is much to live for: Winter's sun is not as warm, but still it gives off light.

⁴ *Id.*

⁵ Essay, "Seeing Instead of Watching," Lauren Kessler.

⁶ Kurt Weill's "September Song"

Autumn leaves come tumbling down,
but then unite in reds and gold,
Life to behold, though it is waning.
And for you, there is still love.
And for you, there is still joy.
Flowers we will bring,
Music we will sing to you.

Our medical experts are not limited to testifying in sterile language about breaches in the standards of care and proximate causation. They can describe the non-linear nature of dementia. They can describe the essential role of the family in providing context and orientation to the patient or resident with dementia. They can describe how a patient with moderate to severe Alzheimer's who is, in the vernacular, "disoriented x 3," may not know the year or the state in which he lives, but may experience orientation "x 1" when a son or daughter visits. Our experts can dispel the notion that a diagnosis of Alzheimer's is worse than death itself, by describing any advances being made with treatment for dementia. The treating physician, nurses and social workers can describe how the family treated their parents' lives as meaningful and derived meaning themselves from the experience. They can speak of patience, love, understanding, and the value of each to the family member's well-being.

In his remarkable book, *Awakenings*, the renowned neurologist and author, Dr. Oliver Sacks, renders an unforgettable account of a group of patients who contracted sleeping-sickness during the great epidemic just after World War I. Frozen in a decades-long sleep, these men and women were given up as hopeless until 1969, when Dr. Sacks gave them the then-new drug L-DOPA, which had an astonishing, "awakening" effect. Dr. Sacks recounts the moving case histories of these individuals, the stories of their lives, and the extraordinary transformations they underwent with treatment. In the film of the same name, Robert DeNiro, one of the "awakened," speaks with such difficulty, and shakes with such violence, that he asks his beloved to stop visiting him. He stretches his hand out in a gesture to say goodbye. She takes his hand and brings him close to her, holding him tight as they dance slowly in place. The jarring movements slow, then stop. All of time seems to be compressed in those few seconds.

For every family we have the honor to represent, we can surely take the time to discover that special moment, however brief, which tells the jury how much can be lost even if life is cut short for a single day. And we should tell *that* story. ■

About the Author

Ms. Russo is a trial attorney and appellate advocate. She is a partner at Otway Russo, LLP in Salisbury, Maryland. She focuses her plaintiffs' practice on serious personal injury, medical malpractice, and product liability actions. Ms. Russo has handled numerous appeals to Maryland's Courts of Appeal. Her appellate victories include a decision affirming a substantial verdict in a defective product case alleging failure to warn of the dangers to passengers of using a reclined seat when the vehicle is in motion (*Toyota Motor Corporation v. Kumar*). Recently, she won an appeal on behalf of members of a volunteer fire company, the Court of Special Appeals holding that genuine issues of material fact had been demonstrated on the question of the application of exceptions to the Fireman's Rule (*IWIF v. Eastern Shore Gas Company*). She is President of the Women's Bar Association for the Lower Eastern Shore.

Ms. Russo is the author of numerous articles and treatises. She co-authored *The Products Liability Law Manual* (MICPEL 2d Ed.) (2003), the leading legal treatise in Maryland on the law related to defective products. She is also a contributing author to the leading book on Maryland appeals, *Appellate Practice for the Maryland Lawyer: State and Federal* (1st and 2nd eds. MICPEL). Her works are also cited in other leading treatises, including *Pleading Causes of Action in Maryland* (Paul Mark Sandler, 3d ed. 2004).

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