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Memory loss and end of life: a personal journey

*An elder-law attorney relates the series of goodbyes leading up to **The Long Goodbye***

BY SANFORD I. HOROWITZ

When asked to write another article for *Plaintiff Magazine* (I previously wrote “Musings of an elder-abuse attorney,” July 2012), I immediately realized I wanted to write about end of life issues coupled with memory loss. My inspiration came naturally as a result of having spent the vast majority of my career as a plaintiffs’ attorney in the field of elder abuse. Furthermore, my own beloved father, Harold Horowitz, who passed away on April 11, 2014, was diagnosed with Alzheimer’s in 2004.

After reviewing hundreds of medical charts in which memory loss, from mild dementia to full-blown late-stage Alzheimer’s, was a major concern, to then so profoundly experience the ravages of this horrible disease in my own life, deepened my empathy for and insight into my clients’ concerns and their loved ones’ suffering. To be fair, my empathy for and insight into the many challenges faced by even the best long-term care facilities when trying to protect people with severe memory loss from being injured, or from injuring others, also deepened. Having spent so many years in the trenches of long-term care litigation, I thought I had a thorough grasp of practically every issue that could arise, but as the saying goes, “Until you walk in another’s shoes, you cannot possibly know their path.”

Caring for those with memory loss

For clarification and perspective, it is important to note that almost all of the many lawsuits with memory loss issues that I have prosecuted involve a situation in which an elderly, injured person residing in some sort of long-term care facility (most frequently a nursing home, sometimes an assisted living facility, a residential care facility for the elderly, and occasionally a hospital) is not properly cared for.

Typically, I am contacted by the injured elder’s child or children, who tend to be in their fifties or sixties. Memory loss issues have usually contributed to the injury for which my clients are seeking counsel. Most often, the facility has not adequately staffed and trained employees to properly care for residents with memory loss. This situation is further complicated by the fact that memory-loss custodial and medical issues are often accompanied by other variables, such as mobility and balance difficulties, medication management, dietary restrictions, etc. that affect the elder’s wellbeing and safety, while the facility continuously fails to staff, train, and care-plan accordingly. These problems are naturally



exacerbated when the elder does not even remember that such variables exist.

Understaffing and undertraining are at the root of the problem, as most of the lower paid caregivers, nurses’ aides and nurses working in these sorts of facilities sincerely want to do a good job. However, they are put in an impossible position by corporate owners and/or business owners who place profits over care.

Larger long-term care chains are publicly traded and seem to “always” be in a posture of trying to sell their ownership for a large profit. As a result, they try to keep costs down and profits up in order to offer a promising investment for an even larger chain. In my opinion, much of this corporate behavior borders on the “criminal,” or at minimum, it is devoid of heart and ethics, but in light of what has transpired on Wall Street in recent years without any significant prosecution, I am not holding my breath with regard to future implementation of adequate governmental oversight of the long-term care industry. This industry is wealthy and politically active, and it enjoys a beneficial relationship with powerful medical lobby organizations and other business groups.

Before I step down from my soap box, I wish to impart my belief that it is essential that concerned citizens continue to inform their elected representatives of the need for better oversight of the long-term care industry. We must support non-profits working in this area, insist that doctors raise their voices much higher than they typically do, and urge the media to shine a spotlight on this ever-evolving and important societal issue.

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Family issues and navigating a murky future

The gauntlet of obstacles people face when their loved one's memory loss accelerates is daunting, time consuming, and emotionally draining. Individuals watch the roles of their grandparents, parents, spouse or siblings change from protector, provider, friend, lover, confidante, joyous playmate in life's journey, etc. to that of an individual who, like a young child, needs constant help and attention. Now imagine a young child with a strong will forged by seventy to ninety years of living on the planet, as well as a level of physicality that might still exude quite a bit of strength.

Caregivers and family members hoping to avoid damage and agitation, which could include elopement, falls, physical attacks, yelling, inappropriate sexual advances, and refusal to accept help or care, need to develop unique ways to influence the elder's behavior while continuing to respect his or her dignity and desire to function independently.

Note: a little black humor can be a big help when reversing child/parent roles becomes necessary. This might sound obvious, but I have been surprised by how few people are able to employ this method.

When navigating the process of long-term care, doctors who might have been treating the elder for many years are typically not very helpful, as they do not continue providing care once an elder moves into a long-term care facility. This situation is highly problematic.

Staying in their home

When possible, it is almost always best for an elder nearing the end of life, even for those suffering from severe memory loss, to stay in their own home with the necessary level of care being provided. Unfortunately, the necessary level of care, often one-on-one and around-the-clock, is very expensive, and few people can afford this option or have an available family member who can fulfill the caretaker role. Also, many elders with health and memory issues simply cannot be properly managed in their

own homes or in the homes of well-meaning family members. As memory loss advances, it is common for individuals to be up and active at night, walking around, hallucinating, wanting to leave the premises, and drifting in and out of a dream-like, confused, and possibly quite agitated state.

This scenario frequently becomes the tipping point that forces many elders into some sort of care facility where well-meaning, guilt-ridden family members and friends will visit when they are able. However, in our "go-go" mobile American society, visiting our elders on a consistent basis can prove challenging as multiple family members might not live in the same area, meaning that the majority of the responsibility will fall greatly on one individual.

One person bears too much responsibility

There is often a lot of pressure on this one individual to manage all insurance and government reimbursement issues and to navigate doctor and hospital visits, while at the same time, and of great importance to their own emotional health, trying to maintain a loving relationship with their fading elder who, sadly, might not even recognize their own spouse, children, siblings, or friends. Many people charged with the responsibility of managing an elder's care are also working full time, and thus suffer from fatigue.

Particularly heartbreaking is when your loved one suffers from paranoid delusions and you observe first-hand their very real fear and angst. Sadly, much more than necessary, the medical industrial complex prescribes powerful psychotropic and other drugs to deal with memory loss, despite the fact that these drugs come with a host of problematic side effects, such as increased agitation and dizziness leading to falls.

Furthermore, because elders with memory loss frequently take multiple drugs due to a wide range of medical maladies, the unpredictable ways in which medications interact with one another create a vicious cycle. Fortunately, there is

a trend away from using psychotropic drugs in favor of less invasive and more holistic and creative calming techniques.

Music calms agitated patients

For example, music therapy has been proven to help calm agitated patients, instill joy, and bring memories to the forefront in a manner that no drugs have even come close to achieving. I highly recommend that anyone with a loved one suffering from memory loss see Michael Rossato-Bennett's documentary *Alive Inside* (winner of the 2014 Sundance Audience Award), which movingly shows how, when provided, iPods programmed with "the patients' own" music (music with which they are highly familiar and that speaks to their hearts), even those in the most advanced stages of Alzheimer's become more alert, more aware, and even conversant. Listening to their own music miraculously triggers parts of the brain where memories associated with favorite songs reside.

Another issue I have repeatedly seen and personally experienced, one that conjures great emotion and a necessity for adaptability, is that of the level of interaction between siblings once a parent's memory loss becomes problematic.

It is quite rare that siblings and other family members are all on the same page, as their life experiences and individual relationships with the afflicted loved one vary greatly, and there is often underlying resentment regarding who takes on more of the caregiving responsibilities. Further, numerous other concerns arise including, but not limited to, religious beliefs regarding death and dying, hospice versus hospital, lawsuits, and unresolved emotional issues with your loved one.

The "sandwich" generation

When a son or daughter is part of the "sandwich" generation, tensions can run particularly high, as he or she becomes literally sandwiched between raising a family, pursuing a professional career, and caring for an elderly parent.

As referenced earlier, to properly care for a loved one nearing the end of

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life, even if memory loss is not a major concern, usually involves numerous people and entities, such as hired caregivers (either private or through an agency), caregiving agencies, and a vast array of medical facilities (from primary care doctors and specialists' offices, to hospitals, to nursing homes and assisted living). And on top of this, there is the additional layer of insurance companies, navigating government benefits, and a host of money issues, from managing a family trust to closing bank accounts, etc. Financial planning may require help from an attorney in order to protect the crucial finances needed for care as well as for other family members.

All of this, of course, takes substantial time and energy and understandably becomes overwhelming for most people.

For instance, if your loved one never executed a detailed dying declaration or indicated their DNR (Do Not Resuscitate) wishes, as the decision maker you will have to determine how to proceed with no clear direction. You might even have to go to Court to be designated your loved one's Conservator if he or she has not previously completed a Power of Attorney (Financial and Health) and Trust and Estate Planning.

Surprisingly, many people do not complete these crucial tasks in a timely fashion, and I highly encourage everyone reading this article to take the initiative to handle such matters, not only for your elders, but also for yourselves. Many people are reluctant to talk about family money, and even more so when it comes to death and dying, but with tact and

patience these sorts of conversations need not be contentious or frightening. In fact, getting these conversations out of the way can be hugely liberating and empowering for everyone involved.

With everything I have discussed thus far, I have not yet touched on the importance of remaining engaged with and supportive of your failing elder, who often cannot adequately convey the extent to which your help is needed or just how much your involvement is appreciated. Being called upon to manage another person's life can feel like a tremendous burden, but experience has taught me that the more support you can offer and the more love you can share while your loved one is still alive, the better you will forever feel after their

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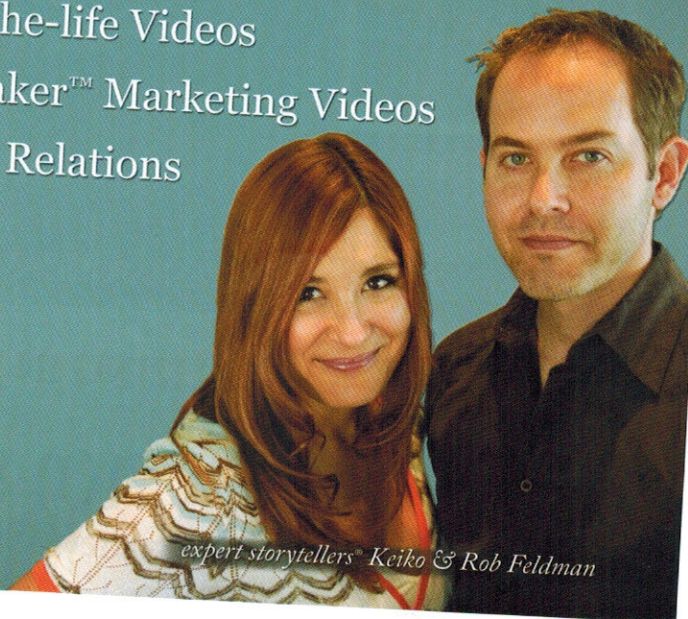
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passing. Experience has also taught me that there is nothing as sad as sitting alone at dinner with someone suffering from advanced memory loss and feeling lonelier than if you were actually all by yourself.

Nevertheless, this is a harsh reality of dealing with end-stage memory loss and all that this unfortunate condition implies. Also heartbreaking is realizing that family and friends will at times react in unexpected and even disappointing ways when it comes to maintaining a relationship with your loved one. Older contemporaries, fearful to even be associated with memory loss, will sometimes avoid or shun their previous friend, knowing it is they who could be next. Fortunately, others will readily embrace being helpful.

However, it is important to remember that other people cannot possibly read your mind. If you are not vocal about your need for help, friends and family might simply be unaware of the extent to which you are stressed out. Speak up and ask for what it is that you need, and if friends and family are unable to fulfill your requests, Alzheimer's support groups, elder advocacy groups – churches and synagogues offer much needed support and resources. Last, I have met many caring and devoted people working as home-health aides or as caregivers in long-term care facilities. For little monetary compensation, they feed, dress, diaper, and engage with your loved one on a daily basis.

Not surprisingly, they too can become deeply attached to the people in their charge. Nurturing your own relationship with your elder's caregivers is crucial to the quality of care he or she will receive. When your loved one eventually passes, be sensitive to the fact that his or her caregivers might also experience feelings of deep grief and loss.

My personal journey

My personal journey with memory loss leading to full-blown Alzheimer's took me from South Florida (ground zero of geriatric issues) to Oregon to my Dad's last six weeks in Sonoma County, CA and

then to his interment in New York, where he was raised in Brooklyn (Brighton Beach/Coney Island) and where I grew up in the suburbs of Long Island.

My dad first exhibited problems with memory loss while still in his early seventies, right about the time my Mom died of pancreatic cancer. He was running a major business in Miami, of which he had been the proud owner for approximately fifty-five years. For the first time in his long career, he lost quite a bit of money, and it was painfully clear that something beyond the stress of my Mom's death was going on. Early on, when my Dad was confronted by family and old friends about his mental lapses, he simply refused to acknowledge or even discuss the problem.

Unfortunately, this was a stubborn stance he adopted for the duration of his life. We practically never talked about his Alzheimer's or the plans we needed to make for his future. He refused to do so, and I like to think the reason for his refusal was because he trusted me and my sister to make the right decisions and to be there for him until the end (which we were).

Thus, as one of two siblings, and the only one equipped to deal with complex business matters, I had to navigate the closing of his beloved business and convince him that doing so was in his best interest. Without going into detail, this involved selling acreage of industrial property to Argentinians, unloading large trucks and equipment (think Caterpillar and cranes), cleaning up outstanding liabilities, and filing complex tax returns. All of a sudden, I had two jobs and the days got shorter.

My story is unique to me, but the days getting shorter and the tasks getting longer are a common theme of just about everyone who comes to my office looking for guidance. Certainly, it helps to have wealth and education, but I have noticed over the years that, regardless of socioeconomic, cultural, or racial differences, almost all families face the same issues and challenges I have outlined here in regard to tasks, bureaucracies, family infighting and/or cooperation, etc.

As Dad's dementia progressed, he went from living alone and receiving much needed help from his new girlfriend to needing daytime care in his apartment to needing around-the-clock care. For the most part, he remained the extremely optimistic and happy person he had always been, but uncharacteristic aggressive behaviors began to manifest. I live in Northern California, and managing Dad's life in Florida while maintaining my law practice became increasingly difficult. However, we wanted to keep him in his home and familiar surroundings as long as possible.

Eventually, and when his memory was quite far gone, we moved him to an assisted living facility in Oregon near my sister, Shekinah, where we provided him with private 24-hour care. This, of course, greatly affected my sister's life as she now had the responsibility, worry, and joy of living close to Dad for the first time in many years.

That chapter lasted for almost two years until we were asked to remove him from his apartment because he required a level of care that could only be provided in that facility's memory unit. Finally, we moved Dad to a small six-bed residential care facility in Santa Rosa, CA, close to our home where my family was able to oversee his care.

Had we known Dad would only live another 40 days, we would have moved him into our home and employed private nurses to look after him around the clock. However, we were under the impression he could possibly live another year or more. Having him in our home indefinitely would have been a lot to ask of my wife and children, but if that scenario had become absolutely necessary, that is the reality we would have embraced.

Luckily, Dad had acquired enough money throughout his life that we were always able to provide high quality care and avoid nursing homes where, from my experience as an elder abuse attorney, I would not have been able to place him with a clear conscience. In retrospect, I believe the move to California gave Dad permission and peace of mind to die, as

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he had reached the point where little communication was possible, and he was frustrated and tired.

This entire process was time consuming, exhausting, and filled with second guessing – and I am an elder-neglect expert with a supportive wife and kids and good nurses and doctors on my speed dial! I truly feel for everyone who has embarked on a similar path, but this is not to say that the journey will be all gloom and doom or that it will not enrich your life in wonderfully surprising and unexpected ways.

Knowing that if Dad lived long enough, he would one day not know who any of us were, in the beginning we focused on enjoying the times we were able to share with him doing the simple things he always enjoyed doing: eating,

schmoozing, fishing, eating, sitting on the beach – and did I say eating?

Towards the end when he tended to confuse his daughter with his sister and not recognize his grandchildren, we concentrated on simple activities such as singing songs and holding hands. We had a lot of laughs over Dad's incessant non sequiturs, and as he became more childlike, he also became more physically demonstrative with his already generous affections. In a very positive way, Dad's Alzheimer's allowed for the closing of old rifts between him and my sister. My wife, Alice, was able to spend a good amount of time with Dad once we moved him nearby, and she cherishes the experience beyond measure. Significantly, my children witnessed the importance of family and self-sacrifice in the name of

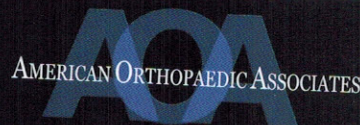
love, and I know that they will one day pass these life lessons on to their own offspring.

The Long Goodbye

Following Dad's blessedly peaceful death, I was constantly reminded of how "lucky" I was to have had the knowledge and resources that so few possess when it comes to elder care. Yet in its own way, my work as an elder-abuse attorney saddled me with a greater level of responsibility that was, at times, challenging to embrace. Spending enormous sums of money for private care, and not knowing how long our money would last, coupled with being so acutely aware of the many problems that can arise once an elder with severe memory loss is institutionalized,

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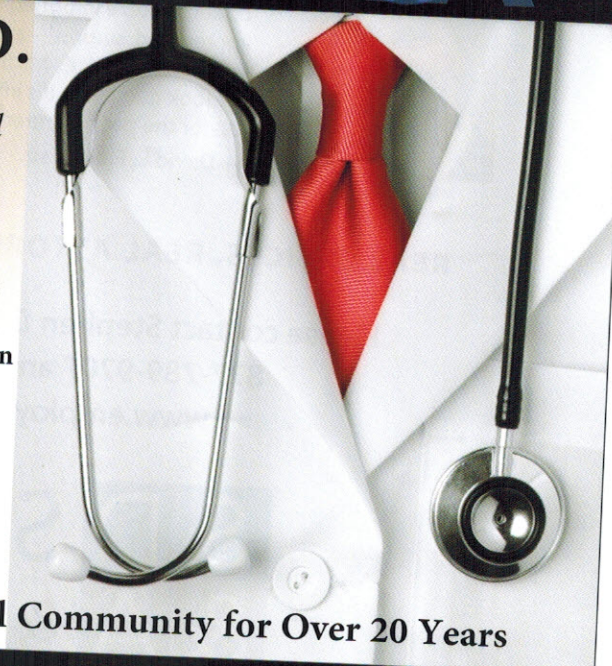
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I found myself anxiously second-guessing my decisions and spinning wheels, to the extent that getting a good night's sleep

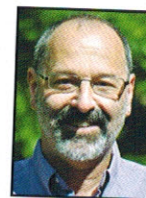
and focusing on my own work was difficult. The last two years of Dad's life were overwhelming and terribly depressing, as

his cognitive and physical abilities took sudden dives.

A sad yet very true fact is that memory loss (especially with an Alzheimer's diagnosis) encompasses a series of good-byes adding up to a very long goodbye. First goes the short-term memory, next goes the long term, and then just about everything goes, including knowing when and how to use the bathroom. Loved ones will only occasionally be recognized (if at all), and even basic items (such as a fork) and what they are used for become enigmas.

Although the person with memory loss cannot verbally articulate what they are experiencing, their frustration, confusion, and horror is often communicated through body language, an increased desire to sleep, keeping one's eyes closed, and violent language or even physical aggression from people who previously never resorted to such behavior. Any individual facing the issues discussed in this article would be wise to emotionally and legally prepare for these many good-byes in order to handle them with as much ease and grace as possible, not only for their own benefit, but more importantly, for the wellbeing of loved ones in need of help and support as they approach life's end.

Sanford I. Horowitz is a plaintiff's attorney in Sonoma, California concentrating his practice on elder abuse and neglect litigation, medical malpractice and personal injury. He was lead trial counsel and co-appellate counsel in the landmark elder abuse case: Delaney v. Baker (1999) 20 Cal.4th 23. Mr. Horowitz is a graduate of Tulane University and University of San Francisco School of Law. He resides with his family in Sonoma Valley. When not working, Mr. Horowitz spends time with his family and friends at beaches near and far, searching for New Orleans' second line parades, and seeking musical and culinary experiences.



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