

The Dementia Crisis

By Robert Abrams

Dementia, of which there are over 100 types, including, but not limited to, Alzheimer's disease,¹ vascular dementia,² dementia with Lewy bodies³ and frontotemporal dementia,⁴ is a:

*syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) . . . It affects memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgment. . . . The impairment in cognitive function is commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation.*⁵

Approximately 47 million people have dementia worldwide,⁶ over 20 percent of whom reside in the United States.⁷ By 2050, 135 million people worldwide are projected to have dementia⁸ and similar growth of this disease is expected to increase proportionately in the United States.⁹

None of us are immune from this debilitating and deadly disease, which, according to the U.S. Centers for Disease Control (CDC), is now the sixth leading cause of death in the United States. The World Health Organization (WHO) has called dementia a “global epidemic.”¹⁰ Victims of dementia include famous people such as President Ronald Reagan, Senator Barry Goldwater, the husband of Supreme Court Justice Sandra Day O'Connor, Civil Rights leader Rosa Parks, sports legend Sugar Ray Robinson, as well as many entertainment icons including Rita Hayworth and Robin Williams, who was believed to have had Lewy Body Dementia.¹¹ Most of dementia's victims, however, are everyday people, no different from those of you reading this article.

The financial and business devastation caused by dementia not only affects the victims but also the victims' loved ones, co-workers, neighbors, communities, and business partners. Cognitive decline is not only emotionally painful but often simultaneously requires one or more family members to participate in providing care.¹² As the dementia progresses, basic care, such as bathing, dressing, toileting and eating, may need to be provided. Providing such care is physically and mentally challenging, and may require other family members to forgo responsibilities such as work and familial obligations.¹³

In addition to the personal toll on the individual with dementia and his or her loved ones, there is also a substantial financial cost. The average per-person cost of care for an individual with dementia is estimated to be tens of thousands of dollars each year.¹⁴ New Yorkers requiring nursing home or other specialized care may incur annual costs in excess of \$200,000.¹⁵ The financial challenges to provide care and a safe environment for an individual with dementia can result in serious financial hardship and possible impoverishment for the individual and his or her family.

Further, the societal costs of dementia are staggering and growing. According to a 2013 study conducted by the RAND Corporation Center for the Study of Aging, “[t]he monetary cost of Dementia in the United States ranges from \$159 billion to \$215 billion dollars annually, making the disease more costly to the nation than either heart disease or cancer.”¹⁶ The Alzheimer's Association believes the cost of dementia care is even higher than that reported by RAND and projects that by the year 2050, Alzheimer's disease will cost the United States over \$1 trillion.¹⁷

Not surprisingly, the personal, financial and business costs of dementia have serious and, in some cases, potentially catastrophic legal consequences. While we in the legal profession cannot prevent the occurrence of this destructive and deadly disease, we can empower our clients to prepare for and/or minimize the legal challenges they may face if they, a loved one or business partner have dementia.

In this light, the Honorable A. Gail Prudenti¹⁸ urges the legal professional to address the dementia crisis in a swift, professional and sensitive manner:

The dementia epidemic has forced the legal profession to re-think and re-focus on how it will address the cares and concerns of our rapidly aging population and families in crisis. As they have with every other broad societal issue, lawyers must be prepared to meet their rightful burden by counseling their clients in a professional, caring manner with information and advice to both protect and to guide affected families through a myriad of difficult situations.

What exacerbates this problem even further is the large number of people who will be afflicted with or affected by dementia. The numbers of those with dementia is simply staggering and is forecast to explode exponentially in the years to come. We have an obligation to meet the concerns of clients who look to us for strength, assistance and knowledge at the worst times in their lives. In order to meet its duty, the bar must prepare now – tomorrow is too late!

As evidenced by the contributions made by judges, lawyers and law students in this special issue of the *Journal*, I have no doubt that New York's legal community will respond to Judge Prudenti's call for action.

Examples of the commitment of New York's judges and attorneys can be found in the articles, *Dementia in the Courtroom* and *Perspectives on Dementia, the Legal Profession and the Law*. Our colleagues who authored these articles acknowledge our collective desire to fulfill our respective professional obligations in a manner that is understanding of and sensitive to the special needs of individuals with dementia, their loved ones and those who provide them with care. Such an understanding requires legal professionals to have the skills to distinguish between *Dementia, Mental Illness and Other Causes of Decline*, as well as provide immediate and timely assistance, to the extent possible, to individuals "recently diagnosed with early-stage dementia."

As noted in the articles *Dementia and the Law* and *Proving Your Client's Diminished Mental Capacity Post-Death*, there are many laws that address the consequences of diminished mental capacity both prior and subsequent to death. These laws vary in their scope and effectiveness. They also fail to establish a coordinated legal framework that adequately addresses the legal implications of dementia in an efficient and comprehensive manner.

Even statutes such as Article 81 of New York's Mental Hygiene Law, which was specifically designed and enacted to address the legal and personal needs of individuals with diminished mental capacity, fail to adequately address critical substantive matters. Moreover, statutorily imposed time frames which were enacted to meet the needs of alleged incapacitated persons (AIP) are routinely ignored, causing delays which sometimes deprive the AIP of receiving the care and services they require and which almost always result in additional costs and undue stress to the AIP, family members and other participants in the proceeding.

The legal profession can and must do better to ensure that laws are properly developed and enforced. Moreover, we must continue our dialogue with representatives of other disciplines, most notably geriatricians, neurologists and other physicians; scientists with an expertise on dementia-related research; and health care professionals, particularly those familiar with how and where individuals with dementia and their family members access care and services. As Michael Miller, Esq. and Robert Freedman, Esq. remind us, we cannot cure or treat dementia, but we can minimize the legal and financial obstacles that further exacerbate this debilitating and deadly disease for our clients and our loved ones.

In this light, in cooperation with NYSBA, Touro Law Center's Aging and Longevity Law Institute and many of my colleagues throughout New York State, we will dedicate 2017 to providing the legal profession with information and resources that will help us meet the needs of individuals with dementia and their family members. Beginning in February, we will launch the Guardianship Quality Initiative which will be a 12-month collaboration between New York judges and attorneys. We will also finalize an update to the NYSBA treatise *Guardianship Practice in New York State*. Finally, in June 2017, we will present a special program on "Dementia, Science and the Law," which will review alternatives on how legal capacity should be determined.

Before closing, I'd like to thank the current and past leaders of NYSBA who have provided me with the opportunity to participate in various projects, like this special *Journal* issue, and my partners at Abrams,

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ENDNOTES

1. Alzheimer's disease is the "most common form of dementia" and is a "progressive disease beginning with mild memory loss possibly leading to loss of the ability to carry on a conversation and respond to the environment." *Healthy Aging Home, Health Information for Older Adults, Alzheimer's Disease*, CDC, www.cdc.gov/aging/aginginfo/alzheimers.htm.
2. "Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients. Vascular dementia is widely considered the second most common cause of dementia after Alzheimer's disease, accounting for 10 percent of cases." *Alzheimer's & Dementia, Vascular Dementia*, Alzheimer's Assoc., www.alz.org/dementia/vascular-dementia-symptoms.asp#symptoms.
3. "Dementia with Lewy bodies (DLB) is a type of progressive dementia that leads to a decline in thinking, reasoning and independent function because of abnormal microscopic deposits that damage brain cells over time." *Alzheimer's & Dementia, Dementia with Lewy Bodies*, Alzheimer's Assoc., www.alz.org/dementia/dementia-with-lewy-bodies-symptoms.asp.
4. "Frontotemporal dementia (FTD) describes a clinical syndrome associated with shrinking of the frontal and temporal anterior lobes of the brain. . . . As it is defined today, the symptoms of FTD fall into two clinical patterns that involve either (1) changes in behavior, or (2) problems with language." *Frontotemporal Dementia Information Page*, Nat'l Inst. Neurological Disorders & Stroke, www.ninds.nih.gov/disorders/picks/picks.htm.
5. *Media Center, Dementia, Fact Sheet April 2016*, WHO, www.who.int/mediacentre/factsheets/fs362/en/.
6. *Id.*
7. Approximately 10 million Americans have dementia. "An estimated 5.4 million Americans of all ages have Alzheimer's disease in 2016." Alzheimer's Assoc., 2016 Alzheimer's Disease Facts and Figures 17 (2016).
8. *Media Center, Dementia, Fact Sheet April 2016*, WHO, www.who.int/mediacentre/factsheets/fs362/en/.
9. See Alzheimer's Assoc., *supra* note 7, at 22. Some studies show that the ever-increasing rates of dementia may not be as extreme as publicized. Kara Gavin, *Dementia on the downslide, especially among people with more education, study finds*, Univ. of MI. Health Sys. Blog (Nov. 21, 2016), www.uofmhealth.org/news/archive/201611/dementia-downslide-especially-among-people-more-education.
10. WHO, *The Epidemiology and Impact of Dementia: Current State and Future Trends 1* (2015).
11. Rebecca Robbins, *How Lewy Body Dementia Gripped Robin Williams*, *Sci. American* (Sept. 30, 2016), <https://www.scientificamerican.com/article/how-lewy-body-dementia-gripped-robin-williams1/>.

12. *Media Center, Dementia, Fact Sheet April 2016*, WHO, www.who.int/mediacentre/factsheets/fs362/en/.
13. *Id.*
14. Michael D. Hurd et al., *Monetary Costs of Dementia in the United States*, 368 *New Eng. J. Med.* 1326, 1329 (Apr. 2013).
15. MetLife, *Market Survey of Long-Term Care Costs: The 2012 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs* 19 (Nov. 2012).
16. *Cost of Dementia Tops \$159* Billion Annually in the United States*, Rand Corp. (Apr. 3, 2013), www.rand.org/news/press/2013/04/03.html.
17. See Alzheimer's Assoc., *supra* note 7, at 56.
18. *Hon. A. Gail Prudenti*, Hofstra Law, <http://law.hofstra.edu/directory/administration/prudenti/>.