

ADDRESS THE MENTAL HEALTH NEEDS OF PEOPLE WITH DEMENTIA AND THEIR CAREGIVERS¹

By
Michael B. Friedman, LMSW
Winter 2012

Ms. S. began to experience confusion when she was 84. She was a friendly woman and active in local politics. One day when she was on her way to a meeting at her political club, she forgot where she was going and got lost. It happened again and then again. She began to make excuses for not going out at all. Increasingly she kept to herself. It took a while but eventually her friends and family realized that something was wrong. The family doctor diagnosed her as in the early stages of Alzheimer's. In fact, Mrs. S. was also depressed, and the depression added to the cognitive impairment due to Alzheimer's.

Mr. V. moved into an assisted living facility after his wife died. At first he did well. He made friends and participated in activities both inside and outside the facility. Over time he suffered major memory loss and became extremely repetitive in conversations. His friends and family became increasingly uncomfortable with him and began to avoid him. He had to rely on facility staff for company and to engage him in activities. Despite their patience and kindness, he became edgy with them, sometimes angry, and occasionally verbally abusive. He was miserable—lonely, bored, and embarrassed by his dependency.

Mrs. A. was determined to keep her husband of nearly 50 years at home despite the fact that he had advanced dementia. He needed help eating, bathing, and going to the bathroom. He often paced around their apartment in the middle of the night, so that she got little sleep. Seeing him this way and not being able to talk with him as her life's partner made her very sad. The demands of caregiving and lack of sleep also took a toll on her. She began to look and feel haggard. Their family doctor, their children, and her friends all told her that she had done enough and that she should send her husband to a nursing home. Eventually, she could not bear the stress and agreed. He moved to a lovely facility, but she remained profoundly guilty that she had "abandoned" him.

These are just three examples² of the kinds of mental health issues that arise for people with Alzheimer's or other dementias and their caregivers. Mental health problems are common—perhaps even universal—for them. Addressing such problems is key to helping them have the best possible quality of life; but, sadly, mental health issues have been largely ignored in the development of America's current long-term care system and even in efforts to bring about long-term care reform.

Passage of [The National Alzheimer's Project Act \(NAPA\)](#) in 2011 has created an opportunity to address the mental health needs of people with dementia. This act calls for the U.S. Department of Health and Human Services (HHS) to develop a long-term

plan regarding dementia. Hopefully that plan will recognize the importance of mental health issues.

But it will be an uphill battle, I suspect, because of competition regarding what the nation's priorities should be. Many press for singular focus on the search for a biomedical breakthrough that will produce a cure for dementia or at least result in the development of medications that will arrest its progressive decline long enough for people with dementia to die from other causes. (It's interesting, to say the least, that almost everyone seems to believe that it is preferable to die from cancer or heart disease than from dementia.)

This point of view was recently expressed in an editorial in *Alzheimer's and Dementia* by Zaven Khachaturian of the Campaign to Prevent Alzheimer's Disease by 2020. Khachaturian—a researcher himself—argues, "Ultimately, the only deliverable that counts is a credible plan of action that calls for significant and systematic increases in the allocation of resources and funds for Alzheimer's research... particularly in the discovery and development of interventions to prevent disability."³

Many of us, however, are more than a little skeptical that biomedical research can bring relief in time for the 5.4 million Americans who already have dementia or for the additional five to six million people who will develop dementia over the next two decades.⁴ We believe that humane care to help them have the best possible quality of life is the critical goal. We see this not as competitive with, but as complementary to, biomedical research.

Even among those of us who are focused on the need for more humane and more effective services and supports, there is some dispute about the importance of mental health services.

In part, this is the result of an outmoded view about the separation of mind and body. Dementia has physical roots with mental manifestations. Many advocates for better Alzheimer's care and treatment focus on the physical roots and do not regard dementia as a mental health condition. Others of us believe that mind and body are inextricably intertwined and that both physical and mental health perspectives and interventions are needed to help people with dementia and their families to have the best possible quality of life.

As the examples at the beginning of this article illustrate, many mental health issues arise in the lives of people with dementia and their caregivers. One way of thinking about them is very well articulated in a recent article by Constantine Lyketsos and others, who argue that "neuropsychiatric symptoms (NPS) are core features of Alzheimer's disease and related dementias." They cite "depression and apathy ... verbal and physical agitation ... [and in later phases] delusions, hallucinations and aggression" as particularly common and important to address with mental health interventions, preferably non-pharmacological interventions.⁵

Lyketsos and his colleagues recognize that many, if not most, people with dementia have co-occurring mental disorders, that they can be treated for these disorders albeit

with great caution regarding the use of anti-psychotic and anti-depressant medications, and that treatment often results in a significant improvement in cognitive functioning and quality of life. It's not that treatment for psychiatric disorders reduces cognitive impairment due to dementia, but, when effective, it does reduce cognitive impairment due to depression, anxiety, or psychosis.

There is another psychological perspective that can also be brought to bear on the emotional challenges faced by people with dementia. This perspective arises from the fact that, despite widespread belief that dementia is an unmitigated horror, some people with dementia lead lives that they find satisfying. Helping people with dementia to retain a sense of self-worth and be at peace with who they are can result in substantially improved quality of life for people with Alzheimer's or other dementias.⁶

Mental health issues also touch family caregivers, who provide 80 percent of the care for their relatives with disabilities. They are at high risk for depression, anxiety and physical illnesses that contribute to burn-out. Solid research by Mary Mittelman has shown that psychological support helps family caregivers live better with the stress they face, resulting in delay in nursing home placement by upward of 18 months.⁷

Unfortunately, current policy and practice do not reflect the state-of-the-art. For example, long-term care reform is largely focused on reducing the use of nursing homes, which are over-used in significant part because of the need for better home and community-based mental health services for people with dementia and their families. Despite this, long-term care reform has ignored mental health issues for the most part.

Practice also lags behind our knowledge. There is good reason to believe, for example, that antipsychotic, anti-depressant, and anti-anxiety medications should be used with great caution for people with dementia. Yet, it appears to be routine practice in emergency rooms, acute psychiatric inpatient facilities, nursing homes, and primary care practices to rely on medications as the intervention of first resort. There is also good reason to believe that individualized psycho-social interventions can improve the quality of life of people with dementia in their homes and in residential or day programs. But it appears to be common practice to provide activities that are designed for groups of individuals without regard to personal interests and abilities. And, as noted above, there is strong evidence that family support programs that are also individualized and built on realistic understanding of the demands on the time and strengths of family caregivers can result in reduced stress and better health for the caregivers as well as delay of placement in nursing homes. But families are largely left to their own devices.

A sound national plan for Alzheimer's and other dementias would address these facts. Specifically the national plan should include:

- An explicit priority on addressing the mental health needs of people with dementia and their family caregivers
- Increased funding for research regarding non-pharmacological interventions and psycho-social supports that will help to improve quality of life for people with dementia and their family caregivers
- Funding for demonstration projects using state-of-the art practices

- Funding for translation of research findings into common practice
- A study to determine the changes that are needed in Medicaid, Medicare, and other federal funding streams and regulations to make it possible for providers to address the mental health needs of this population appropriately
- A requirement that state mental health, long-term care, aging, and Medicaid plans include provisions addressing the mental health needs of this population.

Can these steps be taken during a period of history when the federal government will be reducing discretionary spending? That depends more on political will than fiscal reality. Demonstration programs, training initiatives, restructuring, and using the federal bully pulpit to lead the nation in a progressive direction would cost a very small portion of the hundreds of billions of dollars currently spent on mental disorders and dementia care. They might even result in cost offsets due to the avoidance of high cost acute and residential care.

Cost savings, of course, are never certain. What is certain is that failure to build the National Alzheimer's Plan on an understanding of the mental health needs of people with dementia and their families will rob them of the opportunity to have a decent quality of life. People who already have dementia and those who will develop it before a biomedical solution is in place don't have to wait for a cure to benefit from care.

(Michael Friedman teaches at Columbia University. He is the co-founder and Honorary Chair of the Geriatric Mental Health Alliance of New York. He can be reached at mf395@columbia.edu.)

¹ This article is an elaboration of an essay called "Meet The Mental Health Needs of People with Dementia" published in *The Huffington Post* on January 10, 2012.

² These examples are composites of characteristics of people with dementia and caregivers with mental health problems.

³ Khachaturian, Z. "Prospects for designating Alzheimer's disease research a national priority" in *Alzheimer's and Dementia*, November 2011. <http://aspe.hhs.gov/daltcp/napa/cmtach21.pdf>

⁴ Alzheimer's Association. "Facts and Figures About Alzheimer's". http://www.alz.org/alzheimers_disease_facts_and_figures.asp

⁵ Lyketsos, C. et al. "Neuropsychiatric symptoms in Alzheimer's disease" in *Alzheimer's and Dementia*, September 2011. <http://www.alzheimersanddementia.com/article/S1552-5260%2811%2902575-1/abstract>

⁶ Zeisel, J. *I'm Still Here*. Avery Press, 2009.

http://us.penguinroup.com/nf/Book/BookDisplay/0,,0_9781583333761,00.html

⁷ Mittelman, M. et al. "Improving Caregiver Well-Being Delays Nursing Home Placement of Patients with Alzheimer's Disease" in *Neurology*, November 14, 2006. <http://www.neurology.org/content/67/9/1592>