

Testimony of

Laura N. Gitlin, Ph.D.

Director,

Jefferson Center for Applied Research on Aging and Health

Thomas Jefferson University¹

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Until There's A Cure: How to Help Alzheimer's Patients and Families NOW"

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¹ *Dr. Gitlin, will become a faculty member in the Johns Hopkins University School of Nursing (JHUSON) Department of Health Systems and Outcomes with joint appointments in Psychiatry and Geriatrics, Johns Hopkins University School of Medicine on January 15, 2011*

Mr. Chairman and members of the Committee, thank you for inviting me to present testimony before the Senate Special Committee on Aging regarding How to Help Alzheimer's Patients and Families Now.

I would like to tell you about Millie. Shortly after her husband passed away, Millie became increasingly forgetful and delusional. Her daughter, Diane, initially attributed her mother's memory loss to the stress of losing her husband. With time however, Millie's condition worsened and she was diagnosed with Alzheimer's disease. Millie moved in with her daughter Diane, and her family. Diane had to stop working to be her mother's primary caregiver and to manage the complications of the disease beyond the memory loss. Millie followed Diane around the house, she repeatedly asked Diane what day and time it was and where she was going, she resisted taking a bath and appeared fearful of the tub, and she roamed the house in the middle of the night sometimes trying to leave, and disturbing the rest of the family. Diane thought her mom's irregular sleep patterns might be due to pain from arthritis and possibly a kidney infection. However, Diane was unsure if she should take her to the doctor as she could not gauge her mother's level of pain as Millie had difficulties communicating—a common factor in dementia. Diane felt a lot of guilt that she was not doing enough for her mother. She was becoming increasingly distressed due to her lack of sleep and having to juggle caring for her mother and that of her family. Her health in turn began to suffer as she missed her own doctor appointments.

Millie's story is not unusual. She is one of the over 5 million people in the United States who suffer from Alzheimer's disease or a related disorder.¹ The majority of people with dementia live at home with a family member or in the community. This is also the story of the over 11 million family members who like Diane, are caring for their family members with dementia.¹ Although each situation is unique, family caregivers share similar challenges and experiences. They are often exhausted,

frustrated, saddened, and unsure how to manage functional dependence and troublesome behaviors such as wandering, agitation, or waking at night which often occur throughout the disease. They also must make difficult daily care decisions with little to no help or formal support.

Although a cure for dementia is not in sight now or for the near future, something can be done to change these stories. There are treatments available right now that most families coping with dementia never hear about, but which can significantly improve the quality of life of persons with dementia and their caregivers. We can help families stay together longer at home, and have happier and healthier lives.

Called non-pharmacologic therapies, these treatments do not come in a pill. Instead, treatments may involve personal counseling, education, hands-on skills-training of family members, home modifications to enhance safety; or simplifying activities to engage people with dementia. There are a growing number of such interventions that—based on over two decades of evidence from randomized controlled trials-- demonstrate the benefits of non-pharmacologic therapies that are tailored to the strengths and needs of people with dementia and their family members. These approaches have been shown to support families and provide them the skills they need to protect their own health and cope with the intense demands of caregiving, while helping people with dementia stay independent and safe at home for as long as possible.²⁻⁶

One example of an effective intervention, Project COPE, was developed and tested by myself and my research team at Thomas Jefferson University. In a randomized trial with 237 families, we reported in the *Journal of the American Medical Association* (Sept. 1, 2010) that a home-based intervention provided by occupational therapists and nurses, minimized functional dependence in individuals with dementia and enhanced their quality of life; it also reduced caregiver burden, and helped caregivers keep their family member at home. We also found an alarming number--close to 40%--of people with dementia in the intervention group who had an undiagnosed but treatable medical condition such as a

urinary tract infection. This finding raises significant concerns about the medical care provided to this clinical population and how frequently individuals should be evaluated.⁷

When Millie became a recipient of Project COPE, an occupational therapist conducted a systematic assessment of her abilities and deficit areas, and observed Diane's communication style and the physical home environment for its safety and support for Millie. The therapist helped Diane understand the disease and what Millie was still capable of doing. She introduced practical methods to help Diane cope including stress reduction techniques to ease Diane's stress level, assistive devices such as a grab bar and tub bench to help Millie bath safely and without fear, and simple activities to decrease Millie's anxiety. As Millie had been a housewife, teaching Diane how to involve her in washing dishes and folding laundry enabled Millie to participate in a meaningful way in daily life and feel a sense of accomplishment. The occupational therapist also helped to establish a nighttime routine for Millie that included eliminating caffeinated drinks by early afternoon and before bedtime, taking a bath, playing soothing music and using a nightlight. The routine prepared her for bed in a relaxed manner and reduced her erratic behavior. This in turn benefited Diane, who was able to sleep through the night and have more time for herself. A nurse also helped Diane understand how to detect pain in her mother by paying attention to her facial gestures and physical movements, and also how to monitor her fluid intake and daily elimination patterns. The nurse also took blood and urine samples from Millie and discovered that she had a urinary tract infection and hyperthyroidism, conditions which may have contributed to her agitated and sleepless states, and were subsequently treated by her doctor.^{24,25}

A recent study by researchers at Johns Hopkins University of 264 families surveyed at home found that for individuals with dementia, 90% had home safety issues, 64% had medical care issues, 48% had legal concerns, and 37% were not engaged in any meaningful activities. With respect to their caregivers, 88% needed a referral for a resource, 84% needed education about the disease, 45% had

unaddressed mental health issues, and 24% had unmanaged health problems.¹⁰ Yet, the research by myself and my team and that of numerous other scientists suggest that non-pharmacologic approaches can address all of these unmet critical needs.

Collectively, research on nonpharmacologic interventions shows that for caregivers:

1. Providing specific skills training in stress reduction, communication and problem-solving techniques can reduce depression, and improve self-rated health, sleep quality, and overall well-being of caregivers;^{11, 15-17}.
2. Addressing the specific concerns family caregivers themselves find problematic can enhance their sense of well-being and confidence, and improve their quality of life;^{12, 14, 16, 17}
3. Ongoing counseling and supportive services can reduce caregiver depression and delay nursing home placement.¹⁵⁻¹⁷

Collectively, research on nonpharmacologic interventions shows that for people with dementia:

1. Use of pleasant events and activities matched to the preserved capabilities of persons with dementia, minimizes or eliminates troublesome behaviors such as depression, agitation, and anxiety;¹¹⁻¹⁴
2. Simplifying everyday tasks can help people with dementia remain independent for as long as possible at home;^{7, 12, 13}
3. Simple, low-cost, common assistive devices and training in their use by an occupational therapist can enhance home safety and help family caregivers manage troublesome behaviors and functional decline;¹⁸
4. More frequent brief medical assessments by a nurse or other healthcare provider may be necessary to screen for underlying but treatable illnesses or pain that may contribute to troublesome behaviors;^{7, 12}

In the Philadelphia region, we are now able to offer COPE as an outpatient, home care service for people with dementia who have Medicare and qualify for skilled care. However, most families do not have access to proven nonpharmacologic dementia care services.

The NIH supported multi-site randomized caregiver trial (Resources for Enhancing Alzheimer's Caregiver Health (REACH II))¹⁴ has shown important benefits to Hispanic, White, and spousal African American caregivers including reductions in burden, depression, and upset with behaviors in addition to improved quality of life and health. In response to the outcomes of this trial, Dr. Kenneth E. Covinsky, stated in an editorial in the *Annals of Internal Medicine* (2006):

“If these interventions were drugs, it is hard to believe that they would not be on the fast track to approval. The magnitude of benefit and quality of evidence supporting these interventions considerably exceed those of currently approved pharmacologic therapies [for dementia].”

Improving quality of life for individuals with dementia and their families is a fundamental treatment goal endorsed by health professionals.⁸⁻⁹ It is also one of the new goals added to the 2020 version of Healthy People 2020, the nations 10 year framework for prioritizing public health activities (<http://www.healthypeople.gov/topicsobjectives2020/overview.aspx?topicid=7>).

However, improving quality of life consistently receives far less attention and funding than drug research. The Rosalynn Carter Institute for Caregiving states that there are proven programs which are actually “more effective” than any known drugs for Alzheimer's disease and adds, “to not make them widely available to caregivers is shortsighted and a violation of the best principles of public health.” (http://www.rosalynncarter.org/how_effective). These programs meet the gold standard for both drug and non-drug treatments: they have been proven effective in randomized controlled trials. And, unlike drug therapy, there are no adverse side effects.

There is also an economic argument to be made for better dementia and caregiver supportive programs. In 2009, the nearly 11 million family and other unpaid caregivers provided an estimated 12.5 billion hours of care to people with dementia. This care is valued at nearly \$144 billion.^{1,19} The country can not afford the consequences of family caregivers becoming burned out or too sick to carry on. Moving a person with dementia to a nursing home, while sometimes unavoidable, is expensive, can increase confusion and agitation, and can sometimes even contribute to an earlier death.

Non-pharmacologic therapies may save more than they cost. Peer-reviewed studies have shown that the NYU Caregiver Intervention of counseling and on-going caregiver support delayed nursing home placement by an average of 557 days. Since nursing home care costs an average of \$65,000 per year, this could mean a savings of \$100,000 per patient.¹⁹

An occupational therapy program at Thomas Jefferson University which tailored meaningful activities to the capabilities of individuals with dementia (Tailored Activity Program) showed that the average cost of the intervention was \$941.63 per family. The intervention proved to be cost effective: caregivers saved one extra hour per day “doing things” at a cost of \$2.37 per day; and caregivers saved up to 5 hours a day in time otherwise spent in hands-on care.²⁰⁻²² The cost of drug treatment is approximately \$5 per day or \$1,825 per year.¹⁹

The NIH REACH II initiative similarly found that 12 contacts including a combination of in-home skills-training and group telephone support was highly cost effective providing caregivers 1 extra hour per day not spent in caregiving, at a cost of \$5 per day. The intervention as with the Tailored Activity Program, provided the most scarce of caregiver commodities - time.²³

Non-pharmacologic therapies can be so cost-effective that, according to a 2009 report in the journal *Alzheimer's & Dementia*. “...failure to fund effective caregiver interventions may be fiscally unsound.”¹⁹

Despite the promise of nonpharmacologic approaches, there are many challenges. Chiefly, we lack a national strategy for developing a new standard of care for individuals with dementia and their families that includes comprehensive and on-going supportive proven nonpharmacologic medical, social, psychological, and home environmental services. A national strategy might include:

- Funding large scale demonstration projects that integrate the most promising nonpharmacologic approaches to date.
- Wide-spread training of health and human service professionals in proven dementia care and caregiver supportive programs.
- Expanding our current reimbursement structures to allow for the provision of existing proven caregiver and dementia care programs at home.
- Expanding funding to support implementation of proven programs into different practice settings including home care, hospital discharge services, care management systems.

I would like to close with a quote by Sandra Day O'Connor and Ken Dychtwald from their recent op-ed in the *New York Times*, on Oct. 28 2010.

“Our government is ignoring what is likely to become the single greatest threat to the health of Americans: Alzheimer’s disease is an illness that is 100 percent incurable and 100 percent fatal. It attacks rich and poor, white-collar and blue, and women and men, without regard to party. A degenerative disease, it steadily robs its victims of memory, judgment and dignity, leaves them unable to care for themselves and destroys their brain and their identity-often depleting their caregivers and families both emotionally and financially.”

I urge the Committee to move forward with a strategic vision for enabling nonpharmacologic strategies to become part of standard care that is available to all individuals with dementia and their

family members in order to address one of the most devastating diseases of our time and which soon will be an epidemic.

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