

**PROPOSAL FOR A NEW STATE (NATION)-WIDE MODEL FOR LONG-TERM
ALZHEIMER'S CARE DELIVERY**

The problem: We know that Alzheimer's Disease is putting an ever increasing burden on persons with the disease, their care-givers, the health care system, and society at large. It presents an urgent problem for our Nation, our State and our local communities.

One key issue is finding affordable care for persons with Alzheimer's. This presents significant challenges for spouses, children and friends of those with Alzheimer's. Adult children often have to leave the workplace to provide care for aging parents, resulting in economic hardships and increased emotional stress as well as physical illnesses for themselves and their family members. Spouses may also end up with financial struggles as well as social isolation and additional psychological and physical ailments at the end of their lives, taking care of their spouse with dementia. The toll on children, spouses, friends, businesses, the healthcare system, and governmental programs such as Medicare and Medicaid, mark this challenge as a future crisis for all of us.

Currently, there is a lack of affordable care options for persons with Alzheimer's. The cost of care ranges from \$4,000-\$5,000/month for assisted living/memory unit care to \$5,000-\$7,000/month for nursing home care. Daycare is around \$10/hour. Long term health insurance often pays for a limited number of years of care, requiring families to assume costs after this period ends. For many persons with Alzheimer's, Medicaid may eventually pay for their care.

Most would agree that whenever possible, care should be given at home. The benefits of optimal home care are many, and include:

- 1) the familiarity and security of a home-like setting
- 2) 24/7 supervised care from familiar individuals
- 3) constant interaction/stimulation/socialization
- 4) adequate diet and nutrition
- 5) the possibility of regular outings outside the home, such as trips to the gym, salon or dinners out with familiar companions

In a word, such care ideally enables the person with Alzheimer's to age with dignity, respect, optimal health, and have excellent, continuous care for the rest of their lives.

But what does this require? It often means the care-giver leads two lives, theirs and that of the person with Alzheimer's. Those who have done it know this is unsustainable and will take a significant and dramatic emotional, physical, and financial toll on them and their families.

The solution: What is needed for persons with Alzheimer's is optimal, AFFORDABLE care in a home-like setting without requiring 24/7 care from

their family members or friends. Imagine a world in which NO ONE WITH ALZHEIMER'S WOULD HAVE TO WORRY ABOUT LONG-TERM CARE! You and your family members/friends could rest assured that you would have an optimal, affordable long-term care option if you had or were to develop Alzheimer's. Although this sounds like a dream, **it can become reality if several parties who are impacted by this problem (basically, all of us!) work together. THIS REQUIRES A DIFFERENT CARE DELIVERY PARADIGM, one that is NON-FOR PROFIT, IN WHICH LOCAL, STATE, AND FEDERAL GOVERNMENTS AS WELL AS FAMILIES AND LOCAL BUSINESSES WORK TOGETHER TO MAKE IT HAPPEN.**

What would this look like? How could this be achieved? The following is a suggested model.

- 1) **First, there would be a registry of individuals needing such care.** This could be developed by the State for each county. Registries would include personal and financial information for each applicant. In addition, APPLICANTS WOULD NEED TO BE LOCATED IN THE SAME AREA (COUNTY) AS THEIR FAMILY MEMBERS/FRIENDS WHO WOULD BE ASSISTING IN THEIR CARE. So, for each county in Florida, a registry (waiting list) would be established showing individuals with Alzheimer's needing care as well as locations of nearby family members/friends who would need to commit to helping in their care.
- 2) **Local homes for sale/in foreclosure would be purchased to create home settings in which the applicants would live.** This would be the responsibility of the State, working with local governments, possibly with Federal/agency grant support. Initial costs for setting up the home might also be covered by Federal grants, possibly coupled with local government tax breaks as well as local business and charity support.

Each home would have 3-4+ residents living there (depending on the size of the home) The residents for each home would be selected on the basis of their monthly incomes, with each home including a mix of upper, middle and lower income residents to insure a sufficient income stream to take care of home costs (mortgage, utilities, food). Each person in the home would be required to pay only their monthly income (be it Social Security or other pension or income source), allowing for spousal support, if that were an issue.
- 3) **Staffing for each home would include a small number of full-time professional staff (again, supported by State**

funding/Federal grant support) as well as MANDATORY VOLUNTEERS comprised of family members/friends. A REQUIREMENT OF RESIDENCY IN THE HOME IS THAT FAMILY MEMBERS/FRIENDS MUST WORK A SPECIFIC NUMBER OF HOURS/WEEK IN THE HOME. The less income a person living in the home has to provide to the home for his /her care, the more hours would be required of their family/friends as "sweat equity" to support the home. Volunteers would undergo criminal background checks and mandatory drug testing at their own expense. They would also undergo possible inservice/orientation training. THEIR ATTENDANCE FOR WORK SHIFTS AT THE HOME WOULD BE MANDATORY. Not showing up for their scheduled weekly times could result in their family member/friend being expelled from the home. (Family members could substitute time shifts for each other, provided they were in-serviced/screened to work at the home.) These volunteers would take care of all home needs such as meal preparation, home maintenance (cleaning, lawn work, home repair, etc.), driving residents to appointments, socializing with residents, etc. They would also complete select activities with their own family members, such as bathing and when working their shift, dressing their family member, as possible. Their general supervision and schedules would be established by the permanent staff. Given the presence of the volunteers, at any given time, there would be a minimum of a one-to-one or greater staff-to-resident ratio. That is, there would always be optimal supervision, socialization, and attention given to each resident and their individual needs. Also, given that family members would always be working at the home, everyone would have a vested interest in the success of the home. This arrangement would also insure that family members/friends would have exposure to Alzheimers/senior needs and care and the aging process, resulting in a more educated, informed population with respect to these issues. Finally, family members and staff would have an available, in-house network of support, to assist with any issues or emotions they might be experiencing as family members/caregivers of persons with Alzheimer's.

Salaries of the permanent staff, although possibly a government expense, would be small in comparison to the increased burden to the State and Federal

governments of escalating healthcare costs. For example, how much would Medicare and Medicaid save in not having persons with Alzheimer's over-medicated, incorrectly medicated and/or in and out of emergency rooms/hospitals/doctor's offices for preventable problems, not to mention the costs of taking care of the health issues of their family/friend care-givers? How much would Medicaid save in not having to provide indigent care to these individuals once they've exhausted all their resources?? These cost savings could be enormous.

A further benefit to the healthcare system might be in the training of professionals dealing with Alzheimer's care and care of the elderly given that resident physicians and other professionals in geriatric medicine might staff the homes or be on-call for the homes, increasing their direct exposure to aging individuals and those with Alzheimer's. Such an arrangement might significantly decrease the need for emergency room visits, doctor's visits, and hospital stays for persons with Alzheimer's. This would also increase professional education/experience and, as a result, might dramatically decrease healthcare costs for this population. An alternate model might include established physicians volunteering some of their time to examining residents of the homes or consulting with the permanent staff in the homes re: health issues of the residents, again eliminating unnecessary use of the medical system.

Residents would stay in the home, with hospice care as needed, until the end of their lives. Transfers to nursing homes might be needed in some cases. When a resident left the home permanently, another resident on the registry (waiting list) would take that individual's place, preferably matched on the basis of financial criteria to insure the continued viability of the home.

If less homes are needed at some time in the future (possibly due to effective Alzheimer's treatments or a cure), homes could either be sold with the purchasing agent (State or Federal government) recouping the costs + profit OR the registry model and homes could be used for those with different, chronic health issues, such as housing for adults with Autism. THIS MODEL OF CARE WOULD NOT AFFECT CURRENT DELIVERY MODELS in that there will always be a need for existing assisted living facilities for persons who do not want to relocate close to

family members/friends, have sufficient funds to be cared for as part of different care models or in their own homes, who prefer current facilities, and/or have significant medical needs to require nursing home care. WHAT IMPLIMENTATION OF THIS MODEL PREVENTS IS THE PROFLIFERATION OF NEW FACILITIES AND THE ESCALATING COSTS TO CONSUMERS, WHO, ALONG WITH LOCAL, STATE, AND FEDERAL GOVERNMENTS, WILL BE CRUSHED BY THEM.

In conclusion, we all know that something MUST be done to care for persons with Alzheimer's. The current model of care delivery, whether done at home or in a facility, is UNSUSTAINABLE for the majority of citizens. It is crushing to care-givers, the government, the business community, and society at large. The care given to the person with Alzheimer's is often inadequate. The current model will destroy our healthcare system and economy if something isn't done soon to change it. And the human toll is most significant, for persons with Alzheimer's as well as their family members, friends, and community at large.

What is needed is a dramatically different model of care deliver AT THE STATE LEVEL with Federal support. It must be not for profit to contain costs. It must be a model in which all levels of government (local, state, federal) work with patients, families and local businesses to provide compassionate, dignified, and quality care to persons with Alzheimer's until the end of their lives. Our country is well positioned to show the world how this can be done, and Florida, with its large elderly population, should be at the forefront of this effort. If we can put a man on the moon 40 years ago, we can solve this health care crisis and show the rest of the country and world how it can be done!

Background: Dr. Smith is a speech pathologist, currently in part-time practice. She cares for her 93 year old mother, who has moderate Alzheimer's, at home. She is well acquainted with assisted living facilities of various types, where her mother has stayed for respite care. She is also familiar with local activity groups for Alzheimer's, which her mother attends, as well as a local senior gym, where she takes her mother 3x/week for exercise. Dr. Smith's husband, James Ingram, assists in her mother's care.