

9/24/07

## Iowa Governor's Task Force on Alzheimer's Disease

To the Members of the Task Force:

Congratulations to you on your appointment to this critically important task force. This is the perfect time to revisit some of the old issues of dementia and study the new ones in order to make recommendations for care of Iowans afflicted by all of the illnesses causing dementia.

Over the years Iowa has made steady prudent progress in meeting the service needs of people with Alzheimer's Disease and related disorders. The former Task Forces on Alzheimer's disease worked with numerous agencies and the Alzheimer's Association to develop public awareness, dementia-friendly and dementia-capable services in all settings, and to find families in need of help when caring for a loved one.

Working with the University of Iowa, Iowa State University, and other providers families have gained access to dementia care specialists working with people in their homes to solve problems, excellent diagnostic and medical care, waiver programs to help demented elders with modest means locate services, and develop specialized environments to enhance functional capacity. Yet there is one particular rapidly growing group who may seem small at first glance, but are excluded by almost all of the service programs: people with dementias who are under age 60. Many of these people have Alzheimer's disease, yet a significant number have frontotemporal dementia or other related dementing disorders making their care complicated and difficult.

Known in the "Alzheimer's Community" as "young onset," these people have similar needs for activities and care as their older counterparts yet are often excluded because they are under 60. Additionally they have highly individualized special needs related to their young age including:

1. Many of these people still have children – even young children at home. These children, who may be as young as 6, often become caregivers to their parent. Or the person with dementia, who has a limited understanding of safety and risk, may serve as a babysitter for their young children. This affects the child's schooling, ability to socialize, and develop normally. In teens and preteens it is not uncommon to see the children "opt out" of the family either by "adopting" a new family or turning to drugs.
2. Because the family is too young for retirement and Medicare, a partner or spouse must remain employed. Often the young onset person remains in the home alone long past when it is safe because the family is unable to afford a companion.
3. The young onset person is often fired from work, losing salary and health insurance. Caregivers must often add the patient to their health insurance, thereby increasing the health premium. Applying for disability, SSDI, and Medicare takes years and many people with young onset dementia are routinely denied for one or two years, needing to resubmit and go through rounds of appeals.
4. The few Adult Day Programs who accept people under age 60, lack funding to help these people. In addition the activities are designed for older adults are not appropriate for younger individuals who were not socialized to play bingo, cards, and enjoy "gentle" music programming. There is a critical need for sheltered-workshop type programming for these patients, similar to services offered for people with developmental disabilities. One could probably not however mix the two groups. Approximately 40% of my practice in Iowa is people with young onset disease. My biggest problem is finding activities that can fill their days while their caregiver works.

5. When young caregivers need to disengage from work to care for a young onset person the family becomes newly poor. Moreover it is my experience that employers are less-than-enthusiastic about providing prolonged family leave for caregivers of young onset people. I have experienced where several of the caregivers of young onset patients have been fired when applying for family leave in order to save the employer increased health coverage costs.

6. If all else fails and the young onset person requires institutionalization, again the younger family is thwarted. Many lack the savings to afford nursing home or assisted living care, yet the caregiver's income is usually too high to qualify for Title 19. Moreover, once the young onset person is admitted to long term care the money that is used was probably what had been saved for educating the children and the caregiver's retirement. Few if any caregivers of young onset patients recover from this extreme financial hardship. And, because of the higher-than-average likelihood of other family members having the same disease, there may be no family to turn to for help.

7. The younger the age of onset, the higher the likelihood of a severe presentation of dementia, regardless of etiology, including seizures, myoclonus, sleep disorders, swallowing difficulties, psychosis, and behavioral issues. This further reduces the person's ability to find adequate services and placement.

8. And, when behavioral problems present they are less well tolerated by providers as these patients may be quite robust and cause fear among older participants and staff.

9. Families of people with young onset disease and the patients themselves have little meaningful support as there are relatively few in each community. Given support, the regional Alzheimer's Association offices might be amenable to the development of online support groups for these patients and families.

The plight of the young onset person with dementia is just now being addressed by the Alzheimer's Association on a national basis. It is a significant problem at this point and seems to be growing at an alarming rate. I would like to ask the Task Force members to give specific consideration to the issues of younger patients and their families including the following recommendations:

- Considering how access to services and availability of Medicaid waivers might be granted for families with a person with dementia under age 60. This would necessarily involve allowing for higher incomes of people with working spouses and children.
- Working with providers of sheltered workshops to accommodate younger onset people with dementia.

I am willing to assist the committee on this issue in any way you feel appropriate. Thank you in advance for your consideration.

Respectfully

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