Robert M. Southworth

COMMENTS ON THE UNDATED DRAFT NATIONAL PLAN TO ADDRESS ALZHEIMER'S DISEASE

March 31, 2012

INTRODUCTION

The comments presented in this paper are based on my experience as the primary care giver for someone with Alzheimer's dementia and on a book that I read as part of my research on Alzheimer's dementia. The book is titled *The Myth of Alzheimer's Disease* by Dr. Peter Whitehouse, a leading researcher in Alzheimer's disease for over 30 years.

Eight years ago at age 60, my wife was diagnosed with Alzheimer's Dementia (AD). She lived at home for four and a half years, and has lived in an assisted living facility for the past three years and nine months. She has had three different kinds of brain scans (CAT, MRI, and PET), been evaluated for vitamin B-12 deficiency, been evaluated for "water on the brain", been evaluated at the University of Virginia and John Hopkins University, seen four different neurologists, and has taken both of the medications typical given to people with AD all to no avail. I concluded several years ago that the only thing left was to ensure that she is taken care of. Not only to pay for the care but to participate in it, which I do on a daily basis.

Dr. Whitehouse's book summarizes most of the experiences that I have been through in the last eight years and confirms my conclusion about care for my wife. In my view, everyone who has a loved one diagnosed with AD should read this book. I also believe that Dr. Whitehouse should be considered for inclusion on the Advisory Council established by the National Alzheimer's Project Act (NAPA).

The last part of this paper contains a brief discussion of a grant program through which funding could be provided for the care of people with AD.

GENERAL COMMENT

I agree with the goals in the draft plan. I do not agree, however, with the distribution of funding for the goals. Of the $156 million dollars included in the draft plan, $130 million (83 percent) are allocated for research. Only $26 million are allocated for care. In my view, the funds for research and care should be reversed. At some point, everyone with either AD or another type of dementia is going to need care. That is where most of the federal funds and private funds should be spent.

The final plan should include more details for each of the goals. This includes the office responsible for each strategy and the tentative completion date, funds, and expected outcomes or products for each strategy. Without the details, there is no way to tract the progress on each strategy. The plan also should indicate who will provide oversight for each strategy.

SPECIFIC COMMENTS

1. Care

As mentioned above, I concluded several years ago that the only thing that I can do for my wife is to see that she is taken care of. For this reason, I believe that the first goal on Page 6 of the national plan should address care and that care should be the major theme throughout the plan.

I am not recommending that no research be done on AD. Certainly, research should continue on AD, but not at the funding distribution in the draft plan (i.e., 83 percent of the total amount in the draft plan). In my view, the only way to find a cure for AD is to find a cure for the aging process. This is highly unlikely.

2. Use of the Word “Disease”

In his book, Dr. Whitehouse concludes that Alzheimer’s is not disease. It is aging of the brain that can be caused by a number of factors (e.g., stroke, lifestyle, injury, or environmental exposure). Because it is not a disease, there is no cure for AD.

I recommend that the work “disease” no longer be used to describe Alzheimer’s dementia . Use of the word stigmatizes the person with AD often resulting in depression, loss of friends, and lack of understanding on what is really occurring. Even though the end result is the same (all persons with AD and other dementias need care), calling the condition what it really is (i.e., dementia) is a better approach for dealing with the condition. In his book, Dr. Whitehouse described an approach whereby the patient and the patient’s family are told that the patient has dementia and then given help through a team approach. The team consists of the doctor, a dietitian who helps the patient improve their diet, a physical therapist who works with the patient to increase their physical activity, and a social worker who emphasizes the importance of staying connected both mentally and socially. Use of the team approach is more compassionate then just telling the patient they have Alzheimer’s disease, and to take Aricept and come back for another doctor’s visit in six months, which is what happened to my wife. Using the word “disease” to describe AD implies there is a cure for AD. This gives the patient and the patient’s family false hope because, as previously mentioned, I do not believe there is a cure for AD.

3. Ethnic and Racial Minority Populations

During the eight years that I have had direct involvement with AD, I have never read anything or had any experiences that indicate ethnic and racial minority populations have higher cases of AD than the general population. Unless there is compelling evidence that those populations do experience disproportionate cases of AD, I recommend that this issue not be emphasized in the national plan. In my view, it is more important to spend funds on the care of all people with AD.

4. Assisted Living Facilities

The draft plan fails to recognize that a viable option for people with AD is care in a secure area at an assisted living facility. My wife has been cared for in such facility for three years and nine months, and I expect her to continue to be cared for in an assisted living facility for many more years (she is very healthy except for AD).

An issue related to caring for a person with AD in an assisted living facility is cost. Funds are not available from either Medicare or Medicaid for people who receive care in an assisted living facility. In my view, there is no difference between care of a person with AD in a nursing home and care of such a person in a secure area of an assisted living facility. This disparity needs to be addressed. An example of the cost of care in an assisted living facility is the $75,600 annual fee for my wife plus the cost of incontinence supplies and medications. At present, my long term care insurance pays for part of these costs and I pay the remaining part. When my long term care insurance expires, I will have to pay the total costs.

5. Strategy 2.A

Emergency Medical Technicians (EMTs) and emergency room personnel should be included in the healthcare providers who receive education in AD. In my experience, general physicians also need to be educated about AD. All too often, they just want to prescribe a medication. For example, seroquel often is prescribed for people with AD. Every article that I read on seroquel said that it is not recommended for people with dementia. When I told the doctor that, he said they give it to people with AD anyway.

6. Action 2.A.4

The training discussed in this action should be made available to all direct-care workers and not just workers in nursing homes. In particular, direct-care workers in assisted living facilities and those who provide home care should receive this training.

7. Action 2.B.2

My wife was diagnosed with AD through a process of elimination. In her first visit to a neurologist, she could not pass some simple tests. At later appointments, those same tests were given to her with worst results that the results of the earlier tests.

Eventually, the neurologist concluded she had AD. In my view, this process is most likely the only way to diagnose AD.

8. Action 2.E.2

In my experience, the cost of home care for a person with AD is not that much less than the cost of care in an assisted living facility. In addition, home care is much more difficulty for the primary care giver even with the help of direct-care personnel who come to the home. In too many cases, the primary care giver is the one who suffers the most when care is provided in the home.

9. Strategy 2.H

As mentioned above, I have not seen that racial and ethnic minorities are affected disproportionally by AD. All people with AD need care no matter what their race or ethic group. The available resources should be spent on improving care for all AD patients instead of focusing on any racial or ethnic group.

10. Action 3.D.1

It is extremely important that primary care givers understand the legal documents a person with AD should have. These include a general power of attorney, a medical power of attorney, a will, and, where appropriate, a trust. Also, the primary care giver should ensure their name is on the appropriate bank accounts. The importance of these documents should be stressed in the plan.

11. Goal 5

I agree that it is important to track progress on all of the strategies in the plan. As part of that effort, oversight on all strategies and actions must be provided. Without oversight, there is no way to assess progress.

CARE PROPOSAL

Throughout the above comments I have emphasized the importance of care for people with AD. To provide quality care, funding is required. One way to provide that funding is through a grant program.

To help defray the cost of care for people with AD, a grant could be provided to nursing homes, assisted living facilities, home heath care companies, and, potentially, to individuals. Such a program could be administered by the Department of Health and Human Services or funds could be provided to a state and they could administer the program. To receive a grant, specific requirements would have to be met. In addition, oversight would have to provided to ensure that the grants funds are spent properly.

Grant funds could be used to.

- Develop standards of the care of AD patients.
- Develop design standards for new facilities or modifications to existing facilities where care for people with AD is provided.
- Construct new facilities or modifications to existing facilities where care for people with AD is provided.
- Train direct-care workers
- Provide funds to increase the pay of direct-care workers. .
- Provide funds to defray the costs that family members have to pay for care.
- Provide funds for the oversight of the grant requirements and to ensure quality care is provided.

To receive a grant, an entity would have to submit an application to the agency who administers the grant program. The application would have to contain detailed information about on the facility and the care they provide.

Thank you for the opportunity to submit the above comments. Questions on my comments should be addressed to:

Robert M. Southworth
8054 Willboyd Court
Marshall, Virginia 20115
Telephone: (540) 222-0175