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April 9, 2014

Rohini Khillan  
HHS Office of the Assistant Secretary for Planning and Evaluation  
Room 424E, Humphrey Building  
200 Independence Avenue, SW  
Washington DC, 20201

Re: Advisory Council on Alzheimer's Research, Care and Services Meeting  
4/29/2014

Dear Ms. Khillan,

I am submitting the enclosed 5-page statement to be read at the April 29, 2014 meeting of the Advisory Council on Alzheimer's Research, Care and Services. My statement addresses the importance of determining the cause of dementia when it is recognized in medical practice.

I am a geriatric and cognitive neurologist. My clinical activities primarily involve the evaluation and care of patients with cognitive deficits. I wish to provide greater insight from the perspectives of practicing clinicians, patients, and their families. I propose that the Council adopt two recommendations as outlined in my statement:

- The Council should unequivocally, firmly and explicitly recommend that when dementia is identified, its cause should be determined.
- The Council should prioritize research that expands the evidence base evaluating the value in clinical practice of knowing the cause of dementia.

I am sending this letter via USPS and email. Please confirm your receipt to me by email. My email address is [norman.foster@hsc.utah.edu](mailto:norman.foster@hsc.utah.edu).

Sincerely,

Norman L. Foster, M.D.

**Public Comments to the Advisory Council on  
Alzheimer's Research, Care, and Services  
Tuesday April 29, 2014**

US Department of Health and Human Services  
200 Independence Avenue, S.W., Room 800  
Washington, D.C. 20201

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Thank you for the opportunity to provide public comments to the Advisory Council. I am unable to attend today's meeting in person so I request that this statement be read to the Council. The content and motivations for this statement are entirely my own. Citations and conflicts of interest are listed in the written version of these comments I have submitted.

Thank you for the opportunity to provide public comments to the Advisory Council. I am a board-certified geriatric neurologist, Professor of Neurology and Senior Investigator in The Brain Institute at the University of Utah in Salt Lake City. I direct the Center for Alzheimer's Care, Imaging and Research and I am Chief of the Division of Cognitive Neurology. Over the past 30 years I have maintained an active clinical practice as a cognitive neurologist. My clinical activities primarily involve the evaluation and care of patients with cognitive deficits. Our Center has a unique role. We are the sole academic dementia program in the Intermountain West, and our Cognitive Disorders Clinic is the primary referral center for 10% of the geographic United States. This provides a unique perspective I hope you will find helpful in your deliberations.

The single most significant factor impeding the care of patients is the lack of consensus about the value of knowing the cause of dementia. **The Council should unequivocally, firmly and explicitly recommend that when dementia is identified, its cause should be determined.** Patients with dementia and their families deserve the dignity and respect of knowing the cause of their illness. It should no longer be acceptable to have their problems simply dismissed as "dementia".

I see in my practice daily the adverse consequences when the cause of dementia is not identified. Without a known cause, treatment is chaotic, fragmented, and ineffective. Without a known cause, prognosis is uncertain and there is little care planning or support. I recently saw a highly educated patient with diabetes that exemplifies this problem. Although his diabetes always had been well controlled with insulin, his doctors several years ago began to notice he wasn't paying attention to his blood sugars. No mental status was performed (after all cognitive screening isn't a recommended procedure). When his family became increasingly concerned about his memory problems, they were told he just had dementia and was put on Aricept. Perhaps because of his physician's uncertainty of this course of treatment, he provided no counseling about what to expect. His family discontinued this drug when his memory problems continued. Later, he was prescribed a scopolamine patch when he went on a cruise; treatment that would clearly be contraindicated in Alzheimer's disease. He became dramatically worse – his family never understood why. Meanwhile he continued to manage his own insulin. Predictably and unnecessarily if his dementia had been recognized as due to a progressive disease, he developed hypoglycemic seizures requiring emergency treatment and hospital admission. Just before I saw him a Medicare annual wellness visit was completed, but without an assessment of

cognition (this is very common, even though supposedly required). His family became uncomfortable with the lack of guidance they had received. By the time of his first visit with me, he had severe memory loss, hesitant speech, was unable to name simple objects, copy simple figures or draw a clock. Even though he had trouble dressing and became very anxious when his wife left the room, he continued to drive. (His physician hadn't restricted driving or indicated his abilities might change. His wife had no support in his care, his daughter accompanying him didn't know what she should do to help, and they had not contacted the Alzheimer's Association. My evaluation led to the conclusion that he has Alzheimer's disease dementia, but that 3 small previously unsuspected strokes also had likely contributed to his relatively rapid decline. Now we can begin appropriate care and help his family avoid future care crises and manage a progressive dementing disease.

Dementia is not a medical diagnosis; it simply describes a syndrome that can be due to any of several dozen causes. It is inconceivable that a physician today would fail to determine the cause of chest pain, stroke, shortness of breath or any symptom as serious as dementia. Yet, this is the current state of affairs with dementia. Why? It is considered axiomatic that knowing the cause of a medical problem is necessary for appropriate treatment. Why isn't doesn't this seem to apply to dementia? Physicians usually vigorously pursue an accurate and precise diagnosis.

My clinical colleagues, health systems and insurers are all well aware that no existing guidelines require determining the cause of dementia. The American Academy of Neurology provides guidelines for what testing should be performed in a dementia evaluation, but offers no opinion regarding whether or not such a diagnostic evaluation should be undertaken (Knopman et al., 2001). Reportedly, this is because there is no supportive evidence from clinical trials! Who would suggest a randomized trial where a diagnostic evaluation is withheld from half of patients? Is there really equipoise about this question? The American College of Physicians and the American Academy of Family Physicians guidelines for treatment of dementia fail to mention evaluation and seem to assume that determining causation is unexpected and unnecessary since treatment is discussed only on in the context of dementia syndrome (Qaseem et al., 2008). The Council through its recommendations and influence can begin to change expectations so that the cause of dementia always is sought.

The consequences of diagnostic nihilism are everywhere manifest. The US Prevention Services Task Force has decided not to recommend screening to detect cognitive impairment in primary care (Moyer et al., 2014). Insurers often have failed to reimburse testing shown to increase the accurate and confident understanding of causation, justifying this with the belief that the effort has no value. In this environment, the Council's important recommendation of early recognition and evaluation is unlikely to be implemented. The concept of precision care, embraced in other fields, and critical

for improving quality, seems nearly unattainable unless we agree that cause of dementia is important.

Diagnostic nihilism also breeds therapeutic nihilism. If there is a feeling of “why bother” about determining the cause of dementia, then existing treatments also become dismissed. Needed services are not offered and we hear that there is no treatment for Alzheimer’s (even among some experts). This nihilism often extends to families and has huge implications for care. When causation is irrelevant dementia care becomes unlinked to medical practice. As a result doctors can feel that dementia is just a social problem not of their concern (Connell et al., 1996). They justify using drug treatments simply to “offer something” rather than treat a disease (Franz et al., 2007). Determining the cause of dementia is difficult and time consuming. As long as insurers, health systems and professional societies find it acceptable, doctors will find it easier and financially advantageous to opt out of investigating the cause of dementia. The price is paid in the quality of care patients receive. How can we expect treatment to improve when those providing care don’t even know what disease they are treating? How can patients and families make difficult life-changing decisions when they are uncertain about cause of the problem and its likely course?

The Council also can begin to change expectations through its recommendations about research. **The Council should prioritize research that expands the evidence base evaluating the value in clinical practice of knowing the cause of dementia.** Research centers should be encouraged to begin generating data addressing the relevance of improved accuracy and specificity of diagnosis. Validated measures of high quality care outcomes relevant to clinical care are necessary to change existing practice expectations among insurers and providers. Our concept of treatment should be expanded beyond drug treatments and to populations reflecting clinical practice, rather than highly selected groups needed for mechanistic and proof-of-concept studies.

We who are most committed to improving the quality of life of patients with dementia and their families must agree on the simple proposition that determining the cause of cognitive impairment should be a fundamental expectation in clinical practice. Peer expectations are critical in clinical practice. We must help define those expectations. Otherwise, our patients will be sentenced forever to poor quality care. Caring without knowing causation is well-intentioned kindness, but it’s not medicine.

## **Cited References**

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service providers in rural Michigan. *Am J Alzheimers Care Relat Disord Res* 1996;11:15-25.

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### **Conflicts of Interest for Norman L. Foster, MD:**

Dr. Foster receives a salary from the University of Utah as a faculty member through reimbursed clinical services, and for administrative and teaching activities. He provides unpaid services to the Alzheimer's Association, the American Academy of Neurology, the Society of Nuclear Medicine and Molecular Imaging, as a member of the Utah State Plan Task Force, the Working Interdisciplinary Network of Guardianship Stakeholders, and a number of other community organizations.

Within the past twelve months, Dr. Foster has received personal compensation from Bristol-Myers Squibb, GE Healthcare, the National Association for Continuing Education and Sanofi for consulting activities.

Within the past twelve months, Dr. Foster has received research support for clinical trials from GE Healthcare, the Center for Health Improvement, Merck, and Lilly.

Dr. Foster also has received research support within the past year from the National Institutes of Health, and the Veterans Affairs Office of Rural Health.

He is CEO and co-owner of Proactive Memory Services, Inc., a University of Utah for-profit start-up company developing a mobile application to improve the quality of care for cognitive concerns.