



January 26, 2016

The Honorable Orrin Hatch
Chairman
Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member
Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Johnny Isakson
United States Senate
131 Russell Senate Office Building
Washington, DC 20510

The Honorable Mark Warner
United States Senate
475 Russell Senate Office Building
Washington, DC 20510

Dear Chairman Hatch, Ranking Member Wyden, Sen. Isakson and Sen. Warner:

On behalf of UsAgainstAlzheimer's, a national movement committed to stopping Alzheimer's by 2020, I am writing to offer the following comments on the Chronic Care Working Group (CCWG) policy options put forward by the Finance Committee in late 2015.

UsAgainstAlzheimer's is powered by families – husbands, wives, children, sisters, brothers and friends – who have felt the devastating impact of Alzheimer's disease and other dementias first-hand. We have seen parents no longer recognize their own children, we have seen spouses become shells of their former selves, we have seen other friends and family become dependent on 24/7 care and support and we have seen families driven into poverty as a result of the costs of caring for loved ones with this disease. Today, more than five million Americans are suffering from Alzheimer's disease and from other forms of dementia, and millions more are directly impacted as their informal or family caregivers. Many of these caregivers are reducing their hours worked or leaving the workforce altogether; they are jeopardizing their own physical, mental and emotional health and they are carrying a tremendous load caring for the needs of their loved ones. Sadly, the perfect storm of an aging population, an underutilized long-term care insurance market, and changing family dynamics are threatening to cause even greater challenges, leading us to the point at which Alzheimer's disease and related dementias will cost the nation collectively more than \$1 trillion annually in the coming decades.

The surest way to prevent this travesty from occurring is by developing effective and safe disease-modifying therapies and treatments. The nation has established a national goal of preventing and effectively treating Alzheimer's disease by 2025. UsAgainstAlzheimer's has been relentless in urging that such a time-bound goal be set so appropriate resources can be committed against a clear plan to achieve that goal and that all stakeholders, public and private, do all they can to reduce the time, cost and risk of therapy development. While this remains a top priority, we recognize that persons with Alzheimer's and related dementias need support today and tomorrow.

We applaud the CCWG and Finance Committee for recognizing the need for a comprehensive and bipartisan initiative to address the current and looming challenges posed by chronic illnesses like Alzheimer's. This recognition will hopefully lead to enactment of a meaningful set of reforms this year. UsAgainstAlzheimer's is pleased to offer the following specific comments for the Committee's consideration going forward:

Establish a Medicare Benefit to Support Family Caregivers of Persons with Alzheimer's & Related Dementias

A body of evidence suggests that a specific set of counseling interventions delivered to the family (non-paid) caregivers of persons with Alzheimer's disease and related dementias can improve the well-being of caregivers, enabling the person with Alzheimer's disease to remain at home for significantly longer periods of time. **A seminal project in this space, the New York University Caregiver Intervention (NYUCI), has been evaluated in a randomized controlled trial over more than two decades and has been found to delay placement in an institutional care setting by an average of 18 months compared to the usual care control group.** The NYUCI model focuses on improving the well-being of the primary caregiver by improving emotional and practical support for other family members. By reducing depressive symptoms and stress and improving the physical health of the primary caregiver, the NYUCI achieved this remarkable delay in residential care placement and the corresponding decrease in costs. The NYUCI has been evaluated in additional settings in the United States and internationally and has been shown to deliver similar results in terms of delayed or reduced use of institutional care and improved caregiver well-being.

The NYUCI mode is divided into two phases. The first is an active phase that delivers a half-dozen counseling sessions to the primary caregiver and extended family unit within a short period of time to improve support for the primary caregiver. This phase is followed by an ongoing maintenance phase involving support groups and access to counseling via telephone as needed. A related but not identical approach has been developed and tested by the Department of Veterans Affairs. Known as the Resources for Enhancing Alzheimer's Caregivers Health or REACH program, it has also achieved some success in terms of improving quality of life for caregivers.

Improving Quality of Life & Reducing HealthCare Costs

The evidence at present indicates that these interventions:

- Enable persons with Alzheimer's disease to remain in their home for longer periods of time.
- Allow informal family caregivers to better manage the physical, mental and emotional stresses of caregiving so they can better support the person with Alzheimer's or another form of dementia at home.
- Delay and reduce public and private costs of Alzheimer's disease by delaying beneficiary admission into an institutional care setting.

With one year of care in a nursing home costing between \$80,000 to \$90,000 on average¹, and with the Medicaid program the single largest financer of nursing home care, a cost-effective intervention able to

¹ See: <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>

delay institution care could bring about sizeable reduction of such costs. One analysis of the potential cost savings impact of the NYUCI, published in *Health Affairs* in 2014, suggests that if rolled out broadly in the state of Minnesota the direct medical cost savings could be \$996 million over a 15 year period, with a range of nearly \$100 million to \$2.64 billion depending on the rate of adoption of the intervention.²

Kirsten Hall Long and Steven Foldes, the authors of the *Health Affairs* analysis, extended their work to estimate program costs based on data from the original implementation of the NYUCI and its application in a Minnesota setting. Caregiver program cost per family unit in year one of the program were estimated to be approximately \$1,500 to \$2,000, assuming on-line or in-person counseling, respectively, and reduced to about \$600 in subsequent years. **The substantial potential savings and modest program costs suggest enhanced caregiver support would likely produce a positive return on investment.**

A Medicare Pilot or Demonstration Project

Given the body of evidence that exists today, now is the time for CMS to evaluate the broader potential impact of such an intervention by conducting a rapid pilot or demonstration project of a Medicare Alzheimer’s Disease Caregiver Support Benefit. Such a pilot or demonstration would ideally be a first step that would ultimately lead to more widespread translation throughout the Medicare program if warranted by the results. Criteria for the intervention and eligible providers should be stipulated, and the Medicare program should be tasked with implementing the project and with publishing initial findings within three years. A more rapid turnaround is consistent with recent desires to more rapidly implement, evaluate and, if shown to be effective, translate more broadly promising care and payment interventions, and would help make such supports available more broadly if they are determined to be cost effective. We urge the Committee to recognize this body of evidence and to include a provision authorizing such a provision within your legislative package.

A Need to Increase Early Detection and Diagnosis of Alzheimer’s Disease

Adequate support for Medicare beneficiaries with Alzheimer’s and their families is simply not possible absent the timely and appropriate diagnosis upon which a clear post-diagnostic care plan can and must be developed. Unfortunately, too many patients and families have endured tortuous odysseys before arriving at the point of a diagnosis. We are encouraged that the working group has included within its options package a proposal to provide a one-time visit to code the diagnosis of Alzheimer’s disease. We see this as a necessary step toward filling this gap, and we urge the Committee to not only to include this provision within its legislation but to add a requirement that the diagnostic assessment be recorded in the beneficiary’s health record as well.

This proposal recognizes the complexity associated with delivering a diagnosis like Alzheimer’s disease or other serious illnesses. Such a diagnosis is not something a doctor can convey in a matter of minutes. Rather, it requires adequate time for the provider to fully deliver the diagnosis, including any treatment options that might fit the specific patient as well as other health and related planning activities the

² See *Health Affairs*: Translating Research Into Practice: Case Study Of A Community-Based Dementia Caregiver Intervention. Vol 33, no. 4, April 2014: <http://content.healthaffairs.org/content/33/4/587.abstract>

patient and family should consider. For example, if a patient is deemed to be a fit for currently approved medications that address symptoms of Alzheimer's – or for the disease-modifying treatments we hope will soon become available – a physician can speak to this important point during such a meeting. Similarly, physicians could use this time to educate the beneficiary and his or her caregivers about community resources that could support families navigating a diagnosis of Alzheimer's or about care support or other interventions to which they may have access.

By creating a visit code, by providing an appropriate level of reimbursement for this code and by requiring a record of such diagnosis, CMS will send a clear message as to the importance of an accurate and timely diagnosis for Alzheimer's and other serious illnesses. The agency will also signal that participating providers will have the resources necessary to support their patients during such trying circumstances and that researchers will be able to accurately assess the prevalence and clinical precursors of the disease. As the working group considers refining this proposal further, we offer the following comments:

- As you consider which diseases should be covered under such a visit code, we strongly urge that you include Alzheimer's and related dementias. While every serious illness is probably deserving of such a focused and intensive discussion, the challenges of Alzheimer's, including the dearth of disease-modifying treatments and the impact of the disease on the beneficiary's cognitive functioning, makes an early and accurate diagnosis and related discussion critically important. In the case of a person with Alzheimer's, a beneficiary may have limited time to take certain care and related planning actions before his or her declining cognition make certain decisions impossible.
- In terms of required elements for each visit, there are considerable overlapping needs and interests from one serious illness to another. For example, it is reasonable that any visit would cover vitals such as:
 - A thorough overview of the illness being diagnosed, including the stage of illness, the typical pathology or prognosis and an overview of potential treatment options, including the benefits and risks associated with each;
 - A discussion of the illness and how it connects to the management of comorbidities, particularly chronic illnesses, the beneficiary may have;
 - An initial discussion around developing a patient-centered care plan, including an introduction to other healthcare providers who will be part of the plan and any transitions, if needed;
 - A frank discussion of the challenges the illness will bring to the patient's life, including significant decisions the patient may need to make;
 - Direction to evidence-based resources that the patient and his or her family may wish to access to learn more about the illness and its impact; and
 - A list of other non-clinical resources and supports the patient and his or her family may find helpful to navigate specific challenges or needs associated with the illness, including links to in-person and/or virtual support groups or other forums.

Ultimately, the statutory language must be clear enough to drive proper descriptions of the code and its intended use and purposes through the CMS rulemaking process to ensure the code achieves its intended impact. We would be concerned about any code that is seen as being too narrow and not permitting the necessary conversation on these topics. At the same time, we would be concerned about any codes that could be overly broad and present a potential for being billed without performance of the full scope of activities.

- With regard to the code's interaction with the current Chronic Care Management (CCM) code, we see a high degree of synergy. We would envision the visit code as being the logical first step in the spectrum for many beneficiaries as it would establish the diagnosis. From there, the beneficiary could then qualify for the support provided through the CCM code, though there may be cases where the beneficiary already qualifies for the CCM code and may already be receiving such services because of previously diagnosed chronic illnesses. The CCM code and the care management services it supports would ideally be informed by the diagnosis and other outcomes emanating from the visit code being considered today. We also see the caregiver support benefit that we are proposing as coming into play following the diagnostic visit. Once the diagnosis is provided, the beneficiary could then be eligible for the caregiver support benefit which would work in tandem with the CCM code on the clinical side.

UsAgainstAlzheimer's also urges the committee to bear in mind that for the diagnosis code to work for beneficiaries with Alzheimer's and related dementias, it must permit the beneficiary's informal caregivers to participate in any meetings with the diagnosing physician. This is particularly important for cases of moderate to severe dementia where the beneficiary's cognition is increasingly impaired.

In closing, we applaud the CCWG and Finance Committee for undertaking this most important topic and we hope you will give strong consideration to our recommendations. We also look forward to continuing this dialogue focused on the important issues of Alzheimer's and dementia diagnosis and support for beneficiaries impacted by the disease. If you would like additional information on any points contained in this letter or to schedule a meeting to discuss in greater detail, please contact Nick Manetto at 202.312.7499 or via nicholas.manetto@faegrebd.com.

Sincerely,



George Vradenburg
Founder and Chairman