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Andy Slavitt
Acting Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
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September 6, 2016

Re: Medicare Program: Revisions to Payment Policies under the Physician Fee Schedule and Other Revisions to Part B for CY 2017; Medicare Advantage Pricing Data Release; Medicare Advantage and Part D Medical Low Ratio Data Release; Medicare Advantage Provider Network Requirements; Expansion of Medicare Diabetes Prevention Program Model

Dear Acting Administrator Slavitt,

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's disease care, support, and research. We are the Alzheimer's Association's National Early-Stage Advisory Group, a cohort of individuals from across the United States living in the early stage of Alzheimer's disease and other dementias. As advisors, we are leaders and spokespeople for the Alzheimer's Association and the cause. We provide guidance on appropriate programs for people living with early-stage Alzheimer's, raise awareness about early-stage issues, advocate to increase funding for research and support programs, and provide input to external groups regarding early-stage issues.

Today, there are more than 5 million Americans living with Alzheimer's disease, including approximately 200,000 people under age 65.¹ Although most persons under 65 are not yet Medicare beneficiaries, we are living with the disease and its profound impact. As individuals living with the disease along with our care partners who provide support, we applaud the Centers for Medicare & Medicaid Services' (CMS) proposal to pay physicians and other practitioners to assess and create care plans for beneficiaries with cognitive impairment and offer the following for CMS's consideration.

While the disease is progressive and ultimately fatal, it is possible to live a good quality of life after a dementia diagnosis. Having a plan, however, is central to that quality. Care plans should be individualized, comprehensive, and evolve with a person and his or her family as the disease progresses and needs change. They include the resources and supportive services that are just as important as medical services, which have not historically been linked to the provision of medical

¹ Alzheimer's Association. (2016). *2016 Alzheimer's Disease Facts and Figures*.

care. We thank CMS for this step in bridging the gap between medical care and non-medical resources and services.

While some of us--individuals living with the disease and our care partners alike--received documentation of diagnoses, most of us did not receive basic information about the disease, what to expect, or where to turn for help. This is consistent with the Alzheimer's Association's finding that fewer than half of people with Alzheimer's disease report being told of their diagnoses.² Nor did most of us receive care plans. We were left to do our own research and cobble together disparate resources to manage our daily lives--like how to deal with co-morbid conditions such as diabetes and coronary artery disease, and how to remain safely in our homes. We also have to consider future concerns like financial planning, powers of attorney, and local long-term care options. We need to maintain as much independence as possible in our homes and to know how to remain engaged with other people. We need help managing the range of emotions that we can experience. We need to know about clinical trials and choices about end-of-life care. Information is power over this disease.

We will have different needs at different stages of the disease. Thus, care plans must be tailored to individuals, they must be modifiable, and they must be flexible. A checklist or form will not achieve CMS's goal of high-quality care. A care plan should be a living document that evolves with a person as his or her needs change.

Those of us who have received informed and compassionate care know that the benefits of having a plan are tremendous. We can participate in decision-making while we are able and a plan can reduce stress and confusion for friends and family in the future. The teams of professionals involved in our care and these invaluable plans have been composed of physicians, social workers, psychologists, nurses and nurse practitioners, education specialists, skilled therapists, and more.

Caregivers and families are pivotal to the team. They help persons living with dementia with their daily lives, arrange appointments, find resources, manage medications, and negotiate family relationships that are often strained by the disease. They must also address their own physical and emotional health. Thus, we note with gratitude CMS's recognition of caregivers and their needs by including these in the proposed code.

Because caregivers' most significant role is managing the daily needs and health of persons living with dementia, it is crucial that they be able to communicate directly with health care providers to share insights and perspectives if the person with the disease is unable or not present. In order to manage our care, they must be able to have regular, ongoing communication with providers.

Finally, we ask that CMS develop a robust communication plan to educate its providers about dementia, about local resources, and about this code. Its implementation will not succeed without their education.

² Alzheimer's Association. (2015). *2015 Alzheimer's Disease Facts and Figures*.

Thank you for your efforts to improve the quality of care and of life for those of us living with dementia and the people who care for us. Please contact Laura Thornhill, Manager of Regulatory Affairs, at the Alzheimer's Association at 202-638-7042 or lthornhill@alz.org with any questions or should you wish to learn more from the National Early-Stage Advisors.

Sincerely,

Michael Belleville
Massachusetts
Living with Dementia with Lewy Bodies

Jeffrey Borghoff
New Jersey
Living with younger-onset Alzheimer's disease

Ken Johnson
Michigan
Living with mild cognitive impairment

Leo Landhuis
New York
Living with Alzheimer's disease

Charles McClatchey
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Tom Oestreicher
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