

March 17, 2020

The Honorable Pat Toomey
Chairman
Senate Finance Subcommittee on Health Care
United States Senate
Washington, D.C. 20515

The Honorable Debbie Stabenow
Ranking Member
Senate Finance Subcommittee on Health Care
United States Senate
Washington, D.C. 20515

Re: AGS Comments to Senate Finance Subcommittee on Health Care on Improving Care for Alzheimer’s Patients

Dear Senators Toomey and Stabenow:

The American Geriatrics Society (“AGS”) appreciates the opportunity to provide input to the Senate Finance Subcommittee on Health Care on improving care for patients with Alzheimer’s disease and related dementias, which are a major threat to the health and independence of older adults. Founded in 1942, the AGS is a nationwide, not-for-profit society of geriatrics healthcare professionals dedicated to improving the health, independence, and quality of life of older people. Our nearly 6,000 members include geriatricians, geriatric nurses, social workers, family practitioners, physician assistants, pharmacists, and internists who are pioneers in advanced-illness care for older individuals, with a focus on championing interprofessional teams, eliciting personal care goals, and treating older people as whole persons. The Society provides leadership to healthcare professionals, policymakers, and the public by implementing and advocating for programs in clinical care, research, professional and public education, and public policy that can support us all as we age.

We appreciate the committee’s focus on this important issue and welcome the opportunity to work with you to improve care for older Americans with Alzheimer’s disease. We have responded to your specific questions below.

Care Coordination in Federal Health Care Programs

The subcommittee is asking for feedback on how to improve access to comprehensive care planning services for individuals with Alzheimer’s and related dementias. As noted in the request for comments, the Centers for Medicare and Medicaid Services (CMS) implemented a new Medicare benefit (CPT code 99483) in 2017, however, update of the code has been slow. The AGS led the development of this CPT code and has outlined the following recommendations regarding increasing usage of the code.

- Disseminate information about the CPT code to all clinicians, expanding the audience for the information and how it can be provided.

- Help clinicians, especially primary care providers, see the potential benefits of using this service on their patients and their caregivers. Using the code will help their patients and caregivers along with benefiting their practice overall.
- Show potential benefits for practices by consolidating evidence that dementia care planning saves dollars and for whom. The claim has not yet been compelling for health system administrators.
- Develop standardized training for generalists, providing continuing medical education (CME), and making training free or low cost.
- Simplify and standardize documentation requirements. Currently some billers flag these codes and find deficiencies that prevent them from billing CMS.
- Create standardized formats for Electronic Medical Records (EMR) modification that can be imported into major providers off the shelf. Template standardization currently requires investment on the part of each system that wants to implement the code on a wide scale. Health systems should be compensated for the costs of doing this and rewarded for uptake.
- Incentivize health systems to develop dementia care teams, starting with an inventory of their staffing patterns in primary care to identify staff who will do the necessary assessments for review by the clinician.
- Incentivizing staffing for individual chronic care management (CCM) once a care plan has been established, such that each element of the plan translates to an element tracked by the CCM staff (nurse or social worker).

Improving Detection and Care

The subcommittee is seeking feedback on how to better utilize the existing “Welcome to Medicare” initial exam and Medicare annual wellness visits (AWVs) to screen, detect, and diagnose Alzheimer’s in addition to how best to incentivize detection and high-quality care.

The AGS recommends the following steps:

1. Increase support for services for those with dementia, particularly personal care to help people stay at home. Currently help with personal care continues to be paid for privately by the majority of individuals.
2. Survey health systems for uptake of the annual wellness visit (AWV) in their population. AWV uptake remains in the 30-45 percent range even for systems that prioritize it – increasing gradually (slowly) since 2011-12. There is a current need to engage health systems and their clinical administrative/policy directors to better understand their thinking about what would 'turn their heads' toward making this a standard of care/universal practice. Find out why they don't use the AWV, and what would convince them to change
3. Require that the Welcome to Medicare exam and the AWV include an objective test for cognitive impairment. While some systems already do this, CMS does not require it, and does not require specific documentation of this element. There are disagreements

about the best tests, but the approach worked relatively well when depression screen rates became a quality measure.

4. Link use of the AWW to indicators of care quality. Some health systems have linked use of AWW to immunization rates for older adults – this works well because it's simple and easily tracked/measured. For cognitive impairment, there is no simple quality link; one approach is to make scheduling a 'brain health visit' (with a specific code – e.g. the care plan code) the outcome of interest. Simply measuring rate of new cognitive impairment diagnoses after AWW is quite flawed. While most systems can do this with relative ease, the validity of the outcome is much harder to establish.
5. Link cognitive assessment and care planning to 'preventable' hospitalizations or rates of delirium in hospitalized patients.
6. Bring together all organizations and governmental agencies currently (or previously) engaged in crafting dementia care quality standards and outline what should be measured.

Improving Access and Affordability to Long-Term Care Coverage

The subcommittee addresses in their request the high cost of long-term care services and requests feedback on ways to mitigate current costs of long-term care benefits and insurance and benefits. The cost of long-term care services can have a crippling effect on families and one's retirement savings. Long-term care insurance is a way to mitigate this cost by insuring against the risk of a long-term care event. The subcommittee seeks feedback on the share of patients receiving long-term care benefits pursuant to long-term care insurance, the share of patients paying for these services out of pocket, and the share of patients receiving benefits under Medicaid. The subcommittee also seeks feedback on the premium cost of long-term care insurance policies, and how various forms and features of the insurance policy impact the price. Lastly, the subcommittee seeks feedback on the extent to which traditional health insurance meets the needs of patients with terminal diseases that require home health care services.

The AGS stresses the need for support for personal care services to keep people at home. We also urge you to expand scope of practice issues so that nursing assistants at a basic training level can provide the following services: give medication in all states; give insulin as needed; and report to a family member information from a provider visit (whether that is a home visit or visit in a primary care or specialty setting). Currently this varies by state.

Additionally, we recommend that Medicare update their definition of homebound to allow greater flexibility in accessing benefits for home care. For example, functional status and access assessment should also be considered. Furthermore, hospice benefits have diminished substantially in recent years and often do not meet patients'/family needs. Health systems understaff for home care, which should be much better developed and much more widely available than it is now. Telemedicine liberalization may help this, but it remains to be seen to what extent remote connection can substitute for in-person care. With regard to long-term care insurance, it's driven by profit considerations, so adverse selection is almost certainly still a problem.

Encouraging Innovation

The subcommittee is requesting feedback on policy proposals that support research and development in innovative cures and policies for Alzheimer's disease that will reduce barriers and increase access to future innovative treatments and cures, while ensuring they remain affordable to patients and taxpayers.

In general, the AGS recommends focusing on efforts to increase the healthspan that could lead to a delay in onset of diseases; these efforts are the same as all primary preventive approaches: exercise, cognitive stimulation, management of cardiovascular disease, etc. Additionally, we strongly support the need for additional research on dementia within the context of multiple chronic conditions, primarily in terms of management and outcomes.

We also wish to call attention to the need for more research focused on improving healthcare decision-making for people living with AD and other dementias and their caregivers. We have outlined specific recommendations below:

1. We recommend more dissemination of findings related to best practices for families at the end of life for dementia patients (e.g. tube feedings and the use of treatments such as statins).
2. It is already difficult to define clinicians' decision making, let alone that of patients and families. A first step would be defining what good decision making is for clinicians, patients, and families. The context of dementia might be a good place to start working on a definition.
3. If we are going to consider offering specific treatment for putative causes of 'pre-dementia' (mild cognitive impairment with or without biomarkers) we should require that (1) the condition is persistent (since reversion to normal is not rare) and (2) evidence-based non-pharmacological approaches have been optimized before expensive treatment can be authorized.
4. We should consider requiring that clinical trials of drugs to treat Alzheimer's and related dementias include basic but individualized patient/family support prior to randomization throughout the study.

Care Coordination in Federal Health Care Programs

The subcommittee is seeking input on how best to increase care coordination efforts for individuals with Alzheimer's and related dementias in federally-funded programs that care for dual eligible beneficiaries as well as feedback on successes, challenges, and opportunities to improve the quality of care these programs provide.

Models and payment mechanisms are proliferated, but we need to establish fundamental goals that apply to all such programs and can be added onto either through private means or funded programs. Programs like PACE serve as an example of this.

Additionally, there is a significant healthcare workforce problem in meeting care coordination needs¹ and where there are programs that seek to help (e.g. geriatrics or dementia ECHO programs or dementia certification programs) they are in silos and are undersubscribed (e.g. RN gerontological certification) and are not part of any recognized career ladder. We need to establish realistic panel sizes and standards for care coordination – mostly panel sizes are too large. We need to further establish telehealth care coordination that works for recipients and continue to liberalize payment for remote technologies if keyed to quality outcomes.

The subcommittee also expressed interest in understanding how Medicare Advantage benefits, such as transportation, adult day care, meal delivery, and home and community-based services have impacted Alzheimer's patients and how we can better serve these beneficiaries. The subcommittee also seeks feedback on what the traditional Medicare program should cover in order to better serve individuals with Alzheimer's.

Traditional Medicare should cover substantial caregiver benefits, though this violates a fundamental rule of payment for healthcare services delivered only to the person with the disease. Dementia health care is at least triadic; payment mechanisms should reflect that reality. We don't know what we know about what Medicare Advantage plans are doing with this new 'benefit' – but the new dementia risk adjustment formula has cut back on values attributable to other conditions, with the goal of leaving the median score unchanged for a given population. That raises the question whether the 'extra' dementia benefit will be used for dementia care services.

The subcommittee also asked for feedback on how programs, like those administered through the Older Americans Act, are reaching individuals living with Alzheimer's and other dementias and any gaps that may exist in these services.

Programs, such as those funded through the Older Americans Act, are often fragmented, overly bureaucratized services that require too much knowledge and effort to access. Care managers could pick this up if they became available and standard for all dementia patients/families. We also continue to struggle with barriers between health care and social care services and this is an impediment to both. We additionally reinforce our earlier comments about workforce and scope of practice.

While there are a number of models of community-based care for people with dementia and their families, one approach that should be considered is a variation on the Patient-Centered Medical Home. Two Institute of Medicine studies support person-centered care.^{2,3} Even earlier,

¹ Weiss J, Tumosa N, Perweiler, E et al. Critical workforce gaps in dementia education and training. J Am Geriatr Soc 68:625–629, 2020: <https://doi.org/10.1111/jgs.16341>

² Crossing the Quality Chasm: A New Health System for the 21st Century. Institute of Medicine 2001. Washington, DC: The National Academies Press.

³ Retooling for an Aging America: Building the Health Care Workforce. Institute of Medicine 2008. Washington, DC: The National Academies Press.

Kitwood proposed dementia care aligned with the personhood of the individual.⁴ The National Alzheimer's Project Act (U.S.) mandates coordinated care for people with dementia and expansion of caregiver support services.⁵

Dementia care interventions in clinical trials have been efficacious, but effectiveness in the community has been disappointing.^{6,7,8} With person-centered care as its foundation, the *Dementia Care Practice Recommendations* describe the goals of quality dementia care in these areas: detection and diagnosis, assessment and care planning, medical management, information, education, and support, ongoing care for neuropsychiatric symptoms (NPS), support for activities of daily living, staffing, supportive and therapeutic environments, and transitions and coordination of services.⁹

The Department of Geriatrics at Wright State University's Boonshoft School of Medicine is currently compiling 6-year outcome data on 40 households enrolled in a person-centered home for people living with dementia. Beginning in 2013 with 40 households (a dementia patient and at least one informal, unpaid caregiver), the interdisciplinary team (IDT) found that timely telephone access directly to a member of the person's care team prevented 3 emergency department (ED) visits/household/year, that the nature of calls varied by stage of dementia, and that cost of staffing 24/7 telephone access directly to an IDT member was \$40.00/household/month.¹⁰

As of 12/31/19, there had been 4 ED visits and 10 hospitalizations among enrollees. 32 had died with 24 receiving hospice care at the time of death. This simple low-tech, low-cost approach to person-centered care is associated with caregiver satisfaction, low utilization of more expensive resources (ED visits and hospitalizations), and high utilization of hospice services at the end of life.

⁴ Kitwood T. Towards a theory of dementia care: personhood and well-being. *Ageing and Society* 1992; 12(3): 269-287. <https://doi.org/10.1017/S0144686X00000647>

⁵ National Alzheimer's Project Act: PUBLIC LAW 111-375—JAN. 4, 2011. LEGISLATIVE HISTORY—S. 3036: CONGRESSIONAL RECORD, Vol. 156 (2010): Dec. 8, considered and passed Senate. Dec. 15, considered and passed House.

⁶ Callahan CM, Boustani MA, Weiner M et al. Implementing dementia care models in primary care settings. *Aging Ment Health* 2011; 15(1): 5-12. <https://doi.org/10.1080/13607861003801052>

⁷ Reuben DB, Evertson LC, Wenger NS, et al. The University of California at Los Angeles Alzheimer's and Dementia Care program for comprehensive, coordinated, patient-centered care: preliminary data. *J Am Geriatr Soc* 2013; 61(12): 2214- 2218. <https://doi.org/10.1111/jgs.12562>

⁸ Orrell M (Editor). *Support at Home: Interventions to Enhance Life in Dementia (SHIELD) – evidence, development and evaluation of complex interventions*. Southampton (UK): NIHR Journals Library 2017; Programme Grants for Applied Research.

⁹ *Dementia Care Practice Recommendations*. <https://www.alz.org/professionals/professional-providers/dementia-care-practice-recommendations>. Accessed 3/14/2020.

¹⁰ Lawhorne LW. Developing a person-centered medical home for people with dementia. Paper Presentation Public Health Session Alzheimer's Association International Conference. Boston, MA. July 15, 2013.

Thank you again for the opportunity to provide feedback. If you should need any additional information, please do not hesitate to contact Aimee Cegelka, Senior Manager of Education and Special Projects at acegelka@americangeriatrics.org or 212-308-1414.

Sincerely,

Handwritten signature of Sunny A. Linnebur in black ink.

Sunny Linnebur, PharmD, FCCP, BCPS, BCGP
President

Handwritten signature of Nancy E. Lundebjerg in black ink.

Nancy E. Lundebjerg
Chief Executive Officer