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Payment For Comprehensive Dementia Care: Five Key Recommendations

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More than 6.5 million older Americans are living with Alzheimer's disease <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf> today, a number projected to double by 2050. Alzheimer's is the most common type of dementia, accounting for 60 percent to 80 percent of those living with dementia <https://www.cdc.gov/aging/dementia/index.html> . Related dementias include vascular dementia, Lewy body dementia, frontotemporal dementia, and mixed dementia. Alzheimer's and related dementias (ADRD) are among the most expensive conditions affecting our nation. The Alzheimer's Association <https://portal.alzimpact.org/media/serve/id/62509c7a54845> estimates that Medicare spent $146 billion on Alzheimer's disease in 2022—meaning that more than one in every

six Medicare dollars will have been spent on someone with ADRD. Medicaid spent another $60.8 billion caring for these individuals.

Because of the cognitive and behavioral manifestations of dementia, the scope of disease management is often broader than health care management of chronic diseases and includes social, legal, and financial issues. This complexity affects caregivers (see note 1) enormously, with up to 40 percent developing depression <https://www.jamda.com/article/S1525-8610(15)00607-6/ppt> . Moreover, the effects of caregiver burden often translate to costlier care for the person with dementia, such as hospitalization and placement in nursing homes <https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/abs/dementia-caregiver-burdens-predict-overnight-hospitalization-and-hospice-utilization/529DC61AF73E8488F02A761C60AA97C8> . Yet, to date, the Centers for Medicare and Medicaid Services (CMS) does not have a comprehensive, coordinated way to pay for the unique challenges associated with dementia care <https://www.ajmc.com/view/chronic-disease-management-why-dementia-care-is-different> .

We, the authors, believe care could be vastly improved, and costs could be reduced, if all community-dwelling Medicare beneficiaries living with dementia could enroll in a comprehensive dementia care program <https://nap.nationalacademies.org/read/26026/chapter/1> that addresses the needs of both the persons living with dementia and their caregivers. Congressional leaders <https://www.congress.gov/bill/117th-congress/senate-bill/1125?s=1&r=93> and dozens <https://milkeninstitute.org/sites/default/files/2021-11/Comprehensive%20Dementia%20Care%20Models.pdf> of experts have urged the Center for Medicare and Medicaid Innovation (the Innovation Center) to test a nationwide alternative payment model (APM) to provide comprehensive care to those living with dementia. Recently, CMS Administrator Chiquita Brooks-LaSure and her deputies have indicated that improving dementia care is a high priority for CMS <https://www.cms.gov/files/document/transcriptoalisteningsessiondementiacareandservices05242022.pdf> , specifically the Innovation Center.

As momentum grows for implementing a new payment model, The John A. Hartford Foundation <https://www.johnahartford.org/about> and the Education Development Center <https://www.edc.org/> convened a group of experts on October 24, 2022. The convening was designed to address essential questions for those interested in participating in a new payment model for comprehensive dementia care. Here, we lay out

the evidence around comprehensive dementia care models and offer five recommendations for a new comprehensive dementia care APM.

Reviewing Evidence And Recognizing Heterogeneity

Comprehensive dementia care models that focus on both persons living with dementia and caregivers have been developed <https://www.ajgponline.org/article/S1064-7481(18)30494-9/fulltext> and <https://www.ajgponline.org/article/S1064-7481(19)30460-9/fulltext> tested with promising findings <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.16807> on achieving the quintuple aim <https://jamanetwork.com/journals/jama/article-abstract/2788483> of better care, improved outcomes, lower costs, workforce satisfaction, and health equity. These interventions share many common elements, including assessment and care planning, psychosocial interventions, and care coordination. Nevertheless, care models differ in staffing, delivery method and site (for example, telephone versus in-person, home versus clinic), scope of services, intensity, and cost. Exhibit 1 compares the structure, process, and benefits of the six most widely studied comprehensive dementia care models.

Exhibit 1: Comparison of six dementia care models

Comparison of Six Dementia Care Models						
Structure and Process	Benjamin Rose Institute Care Consultation	Care Ecosystem	Maximizing Independence at Home	Eskenazi Healthy Aging Brain Center	UCLA Alzheimer's and Dementia Care	Integrated Memory Care Clinic
Key personnel	Non-licensed, SW, RN, MFT	Non-licensed care navigator, CNS, SW, Pharmacist	Non-licensed staff, RN, MD	Non-licensed staff, MD, SW, RN, Psychologist	NP, PA, SW, non-licensed staff, MD	NP, SW, RN
Key personnel base	CBO or health system	Health system or community	Community or managed care organization	Health system	Health system	Health system
Face-to-face visits	No	No	Yes	Yes	Yes	Yes
Access 24/7/365	Optional	No	No	Yes	Yes	Yes
Communication w/ primary care physician	Mail, fax, phone	Fax, phone	Phone, mail, fax	EHR, phone, mail	EHR, phone	N/A
Order writing	No	No	No	Yes	Yes	Yes
Medication management	No	Yes	No	Yes	Yes	Yes
Benefits						
High quality of care	N/A	N/A	N/A	Yes	Yes	Yes
Patient benefit	Yes	Yes	Yes	Yes	Yes	Yes
Caregiver benefit	Yes	Yes	Yes	Yes	Yes	Yes
Cost of the program	+++	++	+++	+++	++++	++++
Cost savings, gross	++	++	+++ (Medicaid)	++	++++	++++

Source: Updated and adapted from Haggerty KL, Epstein-Lubow G, Spragens LH, Stoeckle RJ, Evertson LC, Jennings LA, et al. Recommendations to improve payment policies for comprehensive dementia care

<https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.16807> . *2020;68(11):2478-85. Notes: CNS is clinical nurse specialist. MD is medical doctor. MFT is marriage and family therapist. NP is nurse practitioner. PA is physician assistant. SW is social worker. RN is registered nurse. + is least cost savings. ++++ is most cost savings.*

The population of persons living with dementia is diverse with respect to needs for care and resources. To increase efficiency and contain costs, services and payments must be designed to meet the care needs of all persons in the population (for example, high-intensity comprehensive dementia care for those with high use or care needs [typically 20 percent of the population] and lower intensity services for those who have few complications and low use [typically 80 percent of the population] <https://journals.lww.com/academicmedicine/Fulltext/2019/09000/The_Population_Health_Value_Framework__Creating.26.aspx>).

Recommendations

Based on review of the available evidence; detailed discussion of APM design elements at the October convening; and our combined clinical, policy, and funding expertise, we recommend that the Innovation Center test a new comprehensive dementia care APM that contains five key design components.

1. **The payment model should cover comprehensive dementia care that meets quality outcomes measures.**

Previous papers <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.16807> have identified <https://milkeninstitute.org/report/dementia-care-models-scaling-comprehensive> eight core elements of comprehensive dementia care (see exhibit 2). Programs that contain these elements have been shown to reduce emergency department (ED) use, the length-of-hospital stays <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2751946> , and admissions to nursing homes <https://www.uclahealth.org/sites/default/files/documents/The-Effects-of-Dementia-Care-Co-Management-on-Acute-Care-FULL.pdf> . While not all the evidence-based models contain each element, we believe the APM should pay for all eight elements, especially for beneficiaries with higher-level needs.

Exhibit 2: Eight core elements of comprehensive dementia care

Source: Haggerty KL, Epstein-Lubow G, Spragens LH, Stoeckle RJ, Evertson LC, Jennings LA, et al. Recommendations to improve payment policies for comprehensive dementia care <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.16807> . 2020;68(11):2478-85.

Minimum quality standards must be required for all APM participants. Some new payment models, such as those focused on palliative care <https://milkeninstitute.org/sites/default/files/2021-11/Comprehensive%20Dementia%20Care%20Models.pdf> , have scaled quickly. Yet, because there are no required quality standards, it is uncertain whether they are being delivered as intended or as previously demonstrated to be effective. Quality measures should include both processes of care (for example, caregiver stress assessment, Assessing Care of Vulnerable Elders (ACOVE) <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.14251> quality measures)

and use outcomes (for example, ED, hospital, and long-stay nursing home use). Ideally, standards should also include measures of care experience, such as those in the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey <https://www.cms.gov/medicare/quality-initiatives-patient-assessment-instruments/hospice-quality-reporting/cahps%C2%AE-hospice-survey> , which has been standardized for multiple situations, including hospice care.

Finally, the Innovation Center should establish guidelines or certification standards for participating programs, including training and education designed for clinicians, non-licensed staff, beneficiaries, and unpaid caregivers. Such training is consistent with the national Advisory Council on Alzheimer's Research, Care, and Services 2021 recommendation <https://aspe.hhs.gov/sites/default/files/documents/18454de4f0f9ef42dacef6ef167b1933/napa-2021-public-member-recommendations.pdf> to develop and disseminate new training models to increase workforce readiness nationally.

2. **The payment model should address both beneficiary and caregiver needs.**

Comprehensive dementia care focuses on both the person living with dementia and their caregiver(s). These programs coordinate care by providing health care, behavioral, psychological, and social services throughout the dementia care journey. Also, programs that actively engage people living with dementia and their caregivers in health care decisions as well as clinicians who honor and respect these decisions in their care coordination can reduce unnecessary ED visits, days spent in the hospital, and fragmented care <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.16667> .

Evidence-based <https://www.benrose.org/best-practice-caregiving> and standardized caregiver education and support should be required for all APM participants. Comprehensive dementia care programs recognize that family and other unpaid caregivers are essential members of the care team and that self-management skills for caregivers allow persons with dementia to remain independent as long as possible. For severe dementia, caregivers need training to support daily functional tasks, provide a safe and supervised living environment, and manage behavioral and psychological symptoms, such as verbal or physical aggression. They also need support; dementia caregivers are twice as likely <https://www.benrose.org/-/best-practices-in-dementia-caregiving-new-tool-helps-organizations-that-support-family-caregivers#:~:text=Best%20Practice%20Caregiving%20https%3A%2F%2Fbpc.caregiver.org%2F%2C%20a%20new%20web-based%20resource%2C,compare%20and%20select%20evidence-

based%20programs%20for%20dementia%20caregiving.> as other caregivers to report negative impacts on their physical and emotional health, finances, and personal relationships.

Upon enrollment, the beneficiary and caregiver should undergo individualized person-centered clinical assessments <https://www.cms.gov/cognitive> to determine the functional, physical, and behavioral needs of the beneficiary and the caregiver <https://www.johnahartford.org/dissemination-center/view/nac-caregiving-report#:~:text=The%20National%20Alliance%20for%20Caregiving%20%28NAC%29%20has%20released,the%20existing%20impact%20of%20incentives%20on%20caregiver%20services.> , including the caregiver's capacity to care for the beneficiary. These individualized assessments should be designed to integrate with the local health system environment, linking the beneficiary's and the caregiver's needs <https://www.ihi.org/communities/blogs/caring-for-the-caregivers-is-part-of-optimal-age-friendly-care> to the region's available evidence-based programs and community-based services and supports network. Both the beneficiary and caregiver should be reassessed periodically, at least annually.

3. **To be eligible, beneficiaries must have a diagnosis of dementia.**

To move forward, the Innovation Center must determine who is eligible for the program. After careful consideration, we recommend that all Medicare beneficiaries enrolled in the APM should have a diagnosis of dementia, and the APM should include a process for confirmation of the diagnosis upon enrollment.

Medicare should pay for diagnostic evaluation under primary benefits, not the APM. Because comprehensive dementia care has yet to be demonstrated effective for persons with a diagnosis of mild cognitive impairment (MCI), individuals with MCI should not be included in the APM; however, parallel systems should be in place to provide education and support and to routinely monitor them for the development of dementia.

Because the elements of comprehensive dementia care are largely included within the Program for All-Inclusive Care of the Elderly (PACE), beneficiaries enrolled in PACE should not be included in the APM. Individuals who experience severe dementia that results in residential nursing home care or enrollment in hospice should also not be included in the APM because comprehensive dementia care programs have been designed and tested with people living in the community who are not near the end of life.

4. **Comprehensive dementia care programs should be widely available to Medicare beneficiaries, especially those living in rural and underserved**

communities who have traditionally had difficulty accessing health care systems.

Comprehensive dementia care should be available to populations at increased risk for dementia, with particular emphasis on populations who have historically received inequitable care, such as Black and Hispanic populations <https://jamanetwork.com/journals/jamaneurology/fullarticle/2777918?resultClick=1> . This recommendation is consistent with CMS leaders' vision to put health equity at the center of care.

Most existing comprehensive dementia care programs operate within large health systems or academic medical centers. To expand access to disadvantaged populations, the Innovation Center should give small community health care providers and rural practices incentives to participate. For example, the Innovation Center could offer bonus payments to safety-net providers that meet quality standards. In addition, beneficiary and caregiver assessments could screen for the social determinants of health of the population served, and payments should be adjusted accordingly.

The services covered by the APM should have built-in flexibility to ensure providers can individualize care to meet the needs of various populations, especially those underserved. Model participants should partner or contract with trusted community-based organizations (CBOs) and leverage existing networks such as faith communities and community health centers.

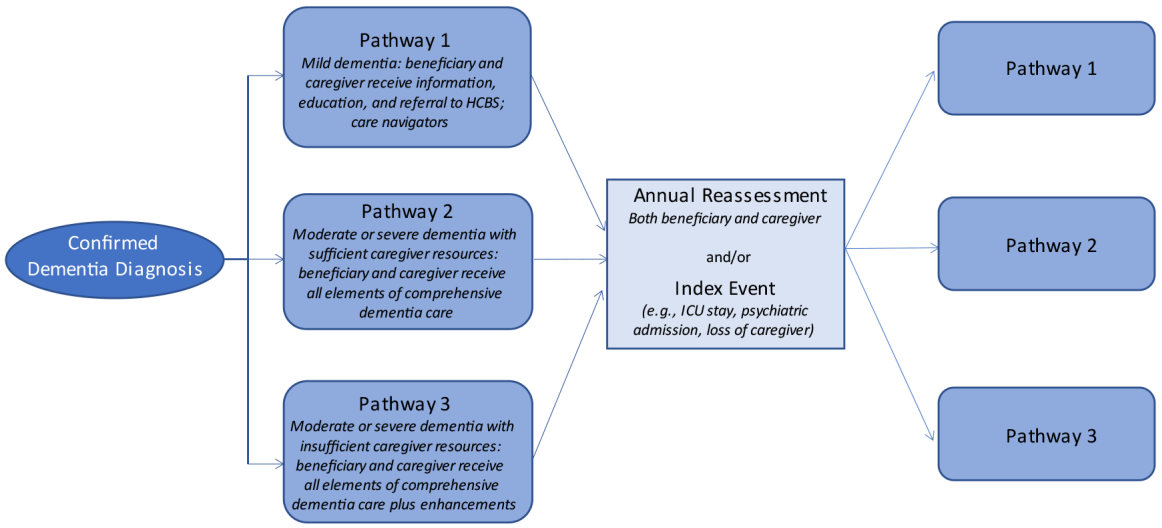
5. **The payment model should be capitated based on the severity of symptoms and available resources.**

While more codes for dementia care have been created and used, we believe existing codes are insufficient to provide the level of services necessary to deliver comprehensive dementia care, particularly services that do not fit within traditional fee-for-service payment structures (for example, care coordination, adult day health and other respite programs, caregiver interventions). Capitation provides the most flexibility for providers to manage care and assures CMS can meet budget requirements. A consistent payment stream to model participants will ensure that services are available when a crisis emerges.

The Innovation Center should include supportive caregiver services in the capitated amount. When CBOs provide home- and community-based services and caregiver support, the CBOs should be paid by the health care organization receiving capitation.

The APM should have at least three pathways for payment, recognizing differing needs at varying stages of dementia (see exhibit 3). The pathways should be based on use and clinical features. Most beneficiaries with mild dementia should track to a lower-intensity pathway. Beneficiaries with moderate or severe dementia (including significant cognitive symptoms, neuropsychiatric symptoms, or medication complexity) should receive all elements of comprehensive dementia care. The availability of caregiver resources should be a key determinant of whether the APM provides additional payment for more services. Insufficient caregiver availability and resources or a mismatch between caregiver resources and dementia severity place beneficiaries at risk of high-cost and poor outcome care; these beneficiaries should receive all elements of comprehensive dementia care plus enhancements, which may include additional services and more frequent follow-up.

Exhibit 3: Beneficiary pathway selection



Source: Authors' analysis. Note: HCBS is home- and community-based services.

The APM should include a reassessment of the beneficiary and caregiver dyad at regular intervals, such as every 12 months or after an index event (such as unexpected hospitalization, new serious comorbidity, or loss or illness of an essential caregiver). The APM should pay for the components that the Innovation Center wants to test as part of the model. For example, if the Innovation Center wants to test comprehensive dementia care that includes respite for caregivers (for example, through community-based services such as adult day health), payment must be adequate to cover these services.

The Innovation Center should put forward a stand-alone comprehensive dementia care APM for traditional Medicare rather than build on existing APMs. Dementia is more

complex and challenging to treat than other chronic conditions <https://www.ajmc.com/view/chronic-disease-management-why-dementia-care-is-different> covered by Medicare.

The Innovation Center should also encourage Medicare Advantage (MA) and Special Needs Plans to provide comprehensive dementia care services. Nearly half (48 percent) of eligible Medicare beneficiaries were enrolled in MA plans last year, and enrollment growth is expected to continue this year <https://www.kff.org/medicare/issue-brief/medicare-advantage-in-2022-enrollment-update-and-key-trends/> . MA plans already have flexibility under the value-based insurance design model and special supplemental benefits for the chronically ill. CMS could put out guidance that clarifies comprehensive dementia care programs are allowable or provide higher rebates for comprehensive dementia care.

A Call To Improve Dementia Care

As a nation, we are in an ever-increasing crisis over how to care for vast numbers of individuals living with dementia. Dementia care must improve and should be delivered by evidence-based programs that address the essential care processes—including supporting caregivers—leading to better outcomes and lower costs. As payers consider payment models for comprehensive dementia care services, attention to key design components can help ensure that this payment mechanism achieves its intended goals and promotes health equity. The need is critical; the time is now.

Note 1

In this paper, the term “caregiver” refers to family members and friends who provide significant assistance to a person living with dementia. The term “care partner” is often used as an alternative.

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