

ATI Advisory

ROSALYNN **FOR**
CARTER **CAREGIVERS**
INSTITUTE 

WHITEPAPER:

Guiding the GUIDE Model Toward Stronger Caregiver Supports

September 2023



Executive Summary

Caregivers of persons living with dementia (PLWD) face unique challenges and strain in managing dementia care for their care recipient (or person). ATI Advisory in partnership with the Rosalynn Carter Institute for Caregivers (RCI) sought to explore the evidence and needs of dementia caregivers that might inform a Medicare model test related to dementia care. On July 31, 2023, the Center for Medicare and Medicaid Innovation (CMMI) released the Guiding an Improved Dementia Experience (GUIDE) Model that includes explicit support for caregivers and is set to launch in July 2024.

As part of our research, we explored current leading dementia models focused on caregiver support interventions and quality of evidence. We also conducted interviews with clinical experts and family caregivers of PLWD. Through this research, we analyzed the challenge of serving caregivers within the current Medicare structure and identified components of effective caregiver supports from four innovative models.

The caregiver components of the GUIDE Model align well to existing dementia care models and offer a strong foundation for improving dementia care and supports for dementia caregivers. We offer key

considerations through the family caregiver lens to inform the GUIDE Model's design and evaluation. Specifically, we recommend:

- **Adding** a small, time-limited payment to maintain consistency in caregiver support for beneficiaries who transition to long-term care during the Model performance period.
- **Testing** and refining methods of obtaining consent and documenting caregiver contact information.
- **Evaluating** the impact of varying care navigation models implemented within the Model.
- **Obtaining** perspectives from participating dementia caregivers to adjust and assess impact of the Model.
- **Evaluating** health and other outcomes for dementia caregivers.
- **Disseminating** curriculum and best practices developed and refined under the Model to other non-participating stakeholders and sectors.
- **Monitoring** the impact of the GUIDE Model on Medicare enrollment decisions for individuals with dementia, including by subpopulation.

Together, these considerations will further improve alignment with caregiver needs, strengthen the evidence base for future caregiver support interventions, and broaden access and understanding of dementia care across the healthcare ecosystem.



Introduction

Dementia remains one of the costliest healthcare conditions in the United States.¹ An umbrella term used to describe a variety of neurological conditions affecting the brain, dementia progressively impairs a person's ability to remember, make decisions, and – in its most severe stages – carry out basic activities of daily living.² According to the Centers for Medicare and Medicaid Services (CMS), more than 6.7 million Americans ages 65 and older, or about 1 in 9 seniors, are affected by dementia in 2023.³ With a vast majority of these seniors enrolled in Medicare, the primary health insurance program for older adults in the U.S., CMS will spend an estimated \$157 billion on dementia care this year.⁴ With an aging population and longer life expectancies, the number of people living with dementia in the U.S. is expected to rise dramatically, impacting afflicted individuals, their families, and the healthcare and aging systems at large. By 2050, the number of Americans ages 65 and older with diagnosed dementia is expected to reach 12.7 million, or about 1 in 7, translating to an estimated \$458 billion in Medicare spending.⁵

While indicative of dementia's significant financial toll on the Medicare program, these figures fail to capture the complete cost of comprehensive dementia care in the U.S. Of the total lifetime cost of caring for persons living with dementia (PLWD), an estimated 70 percent of costs are borne by families, either through out-of-pocket health and long-term care expenses or from the value of unpaid care.⁶ Caregivers – broadly defined as family members, friends, neighbors, or others who provide assistance to a person who is aging, ill, or disabled – help to manage care challenges and mitigate healthcare costs associated with dementia. More than 11 million Americans provided an estimated 18 billion hours of care for PLWD in 2022, a contribution valued at nearly \$400 billion.⁷

Despite the condition's high prevalence and implications for the PLWD-caregiver dyad (“dyad”), variable and often poor diagnostic sensitivity results in dementia being underdiagnosed and underreported. Findings from a 2017 cross-observational study indicated that among Medicare beneficiaries with probable dementia, 58.7



11M+

Americans provided an estimated 18 billion hours of care for PLWD in 2022

- 1 <https://innovation.cms.gov/innovation-models/guide>
- 2 <https://www.cdc.gov/aging/dementia/index.html>
- 3 <https://www.hhs.gov/about/news/2022/12/19/hhs-emphasizes-addressing-disparities-and-risk-reduction-for-alzheimers-disease-and-related-dementias.html>
- 4 <https://portal.alzimpact.org/media/serve/id/62509c7a54845>
- 5 *Ibid.*
- 6 <https://www.alz.org/alzheimers-dementia/facts-figures>
- 7 <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>



percent were either undiagnosed (39.5 percent) or unaware of the diagnosis (19.2 percent).⁸ The distribution of dementia diagnoses also varies across different Medicare populations. Despite higher dementia prevalence among Black and Hispanic beneficiaries, these groups experience higher rates of missed or delayed dementia diagnoses (46 percent and 54 percent, respectively) compared to their white counterparts (41 percent).^{9,10} Without the formal diagnosis required to enroll in many dementia care models, caregivers must navigate additional barriers to care, alongside added caregiving and financial burden of caring for someone with dementia.

While Medicare currently covers costs associated with medical services and clinical treatments for PLWD, our research has revealed gaps within Medicare's

traditional fee-for-service payment methodology that often leave family caregivers ill-equipped and underprepared to care for someone with dementia. The federal government, including the Center for Medicare and Medicaid Innovation (CMMI or Innovation Center) has taken actions to identify and test models to better support beneficiaries with dementia and their caregivers. Established by Section 3021 of the Affordable Care Act, CMMI's purpose is to test innovative payment and service delivery models to reduce program expenditures while preserving or enhancing the quality of care for individuals receiving benefits from Medicare, Medicaid, or the Children's Health Insurance Program.¹¹ Models tested under CMMI authority are evaluated, and, if proven to be effective, can be expanded in scope or duration through rulemaking.

8 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6025653/>

9 <https://www.nia.nih.gov/news/data-shows-racial-disparities-alzheimers-disease-diagnosis-between-black-and-white-research>

10 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7552114/>

11 <https://innovation.cms.gov/data-and-reports/2022/rtc-2022>



As shown below, there has been an increasing interest in dementia care models, including caregiver supports, over the past decade:

Through the CMMI Health Care Innovation Awards (HCIA) that began in **2012**, CMS provided funding to five dementia care pilot projects to inform future CMS models and programs.¹²

CMS hosted a Dementia Care and Services listening session in **May 2022** intended to inform the agency's approach to better supporting people with dementia and their caregivers in ways that optimize healthcare outcomes.¹³

At a roundtable convened by the John A. Hartford Foundation in **October 2022**, representatives of CMMI joined national healthcare leaders and dementia care experts to discuss scalable payment models for comprehensive dementia care.¹⁴

Two months later, in **December 2022**, the Department of Health and Human Services (HHS) updated their National Plan to Address Alzheimer's Disease with new strategies and actions intended to support dementia dyads.¹⁵

In **April 2023**, President Biden released an Executive Order that directed the Secretary of HHS to "consider whether to select for testing by CMMI an innovative new health care payment and service delivery model focused on dementia care that would include family caregiver supports such as respite care."¹⁶

Most recently, on **July 31, 2023**, CMMI announced the Guiding an Improved Dementia Experience (GUIDE) Model (discussed in more detail later). Through this voluntary nationwide model, CMS will test an alternative payment for participating providers who deliver comprehensive care and coordinated supports to Medicare beneficiaries living with dementia and their caregivers.¹⁷

12 <https://innovation.cms.gov/data-and-reports/2022/dementia-care-synthesis-1989-2020>

13 <https://www.cms.gov/files/document/transcriptoalistingessiondementiacareandservices05242022.pdf>

14 <https://www.johnahartford.org/dissemination-center/view/roundtable-convening-comprehensive-dementia-care-models-and-payment-reform>

15 <https://aspe.hhs.gov/sites/default/files/documents/59cefdd628581b48b2e389891a675af0/napa-national-plan-2022-update.pdf>

16 <https://www.whitehouse.gov/briefing-room/presidential-actions/2023/04/18/executive-order-on-increasing-access-to-high-quality-care-and-supporting-caregivers/>

17 <https://innovation.cms.gov/innovation-models/guide>



Why Dementia Care is Different

The intricate interplay of cognitive, medical, and social factors associated with dementia makes it a uniquely complex – and costly – condition. According to CMS, more than 95 percent of individuals diagnosed with dementia have at least one other chronic condition.¹⁸ Compared to individuals without dementia, PLWD are 4.4 times more likely to have six or more other chronic conditions.¹⁹ The presence of comorbidities complicates the management of dementia, as it requires a comprehensive and coordinated approach to address both the cognitive decline and the associated health conditions. In turn, average per-person Medicare payments for beneficiaries with dementia are nearly three times greater than payments for those without dementia.²⁰ Much of these increased costs derive from significantly higher rates of hospital admissions among PLWD. Notably, prior research suggests that many admissions among PLWD are potentially avoidable through more robust outpatient dyad support.^{21,22}

Unlike many other illnesses, dementia affects an individual’s physical health and cognitive abilities. As a PLWD’s capacity to manage their own care declines, their

reliance on their caregivers and the healthcare and aging systems grows. PLWD become increasingly dependent on their caregivers for assistance in meeting basic everyday needs, requiring support in Activities of Daily Living (ADLs) such as bathing, dressing, and mobility, and help with Instrumental Activities of Daily Living (IADLs) such as managing finances, preparing meals, and arranging transportation. Dementia caregivers spend more hours per week providing a wider variety of care assistance, including more ADLs and IADLs on average compared to non-dementia caregivers.²³

The combination of dementia and comorbidities often requires a higher level of medical and personal attention, requiring caregivers to navigate the complexities of multiple conditions and their respective treatments. Caregivers often need to coordinate appointments with various specialists across disparate health systems, manage multiple medication regimens, and address the unique needs, limitations, and progression patterns of each condition. Through the progression of dementia, many caregivers eventually find themselves unable to continue caring for

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“Expecting a PLWD to live without a caregiver is like expecting a quadriplegic to live without a wheelchair [...] I don’t know how you could live with the disease without another mind helping you manage.”

- PHYSICIAN AND
ALZHEIMER’S DISEASE
RESEARCHER

18 <https://innovation.cms.gov/innovation-models/guide>

19 <https://www.cms.gov/files/document/transcriptoalistingssessiondementiacareandservices05242022.pdf>

20 <https://portal.alzimpact.org/media/serve/id/62509c7a54845>

21 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7811187/>

22 <https://pubmed.ncbi.nlm.nih.gov/28886338/>

23 https://www.caregiving.org/wp-content/uploads/2020/05/Dementia-Caregiving-in-the-US_February-2017.pdf



their person at home, due to the declining health of their person or concerns about their own health. This often accelerates transitions among PLWD to long-term care settings, the biggest source of out-of-pocket costs for dementia caregivers and a significant source of CMS expenditures.²⁴

Many caregivers prioritize the increasingly overwhelming and time-consuming demands of dementia care management, often to the detriment of their own health. A national poll administered by the University of Michigan found that one in four (27 percent) of dementia caregivers delayed or did not do things they should to maintain their own health, and two-thirds (66 percent) of respondents said caregiving interfered with their ability to take good care of themselves or go to the doctor when they have a health problem.²⁵ Data from a Health and Retirement Study indicated that compared to other spousal caregivers of similar age,

caregivers providing care to a spouse with dementia had 40.5 percent higher odds of experiencing increased frailty during the time between becoming a caregiver and their spouse's death.²⁶ This reliance on caregivers, and its associated burden, is especially pronounced in the non-white PLWD population. Black and Hispanic PLWD are more likely to rely on family caregivers and less likely to use nursing homes than their white counterparts.²⁷

We recognize that caregiver experiences are not homogenous, and to date are largely categorized by the disease state or condition of the care recipient. While condition can be critical to shaping experience, RCI has partnered with Duke University to research and develop a series of caregiver "typologies," or similarities or differences across caregiving experiences, which can be used to develop and target more effective programs and policies in the future.

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“I didn't think I had a problem, I just thought, you know, my grief was so strong and so deep and so hard, and then being so exhausted from caregiving during that time. I went a whole year before seeing my primary care provider, [at which point they identified a medical issue].”

- DEMENTIA CAREGIVER

24 <https://innovation.cms.gov/guide/faqs>

25 https://www.healthyagingpoll.org/sites/default/files/2017-10/NPHA_Caregivers-Report-PROOF_101817_v2.pdf

26 <https://pubmed.ncbi.nlm.nih.gov/25161263/>

27 <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2793180>



Current Gaps In Dementia Care Support Under Medicare

PLWD and their caregivers need support that goes beyond the care provided in formal clinical settings. Regular dementia care is primarily covered by Medicare Part B (outpatient care) and Part D (prescription drug coverage). While traditional Medicare benefits cover essential services such as physician visits, diagnostic tests, and medication access, current Medicare policies do not address the holistic social needs of the dementia dyad.

To fully understand the limitations of dementia care delivery under existing Medicare policy, we conducted nine interviews with dementia subject matter experts, including clinical providers, family caregivers, and organization leaders providing community-based services to PLWD, their caregivers, and their families. Respondents agreed that while Medicare plays a crucial role in providing coverage for clinical aspects of dementia care, deficits within the existing Medicare fee-for-service payment structure limit PLWD and their caregivers from accessing meaningful dementia care management and social support services.

Below we outline three challenges reiterated throughout our discussions with subject

matter experts that limit the ability to provide comprehensive dementia care to PLWD and their caregivers under existing Medicare policies. Notably, the GUIDE Model directly addresses many of these existing gaps, aiming to improve the quality and experience of care for PLWD and their unpaid caregivers under the Medicare program.

LACK OF CAREGIVER EDUCATION AND TRAINING:

Dementia caregivers often assume their role with little to no prior experience with caregiving or familiarity with the complexity of dementia. Amidst processing the personal implications of their persons' prognosis, caregivers are thrust into unfamiliar territory and struggle to comprehend how their lives will be impacted, what to expect as symptoms progress, and where to access the resources they need. Our interviews with caregivers revealed an inverse relationship between caregiver instruction and their self-reported burden, indicating that when equipped with dementia education and training, caregivers feel more prepared to effectively manage care for their person



with dementia.^{28,29} Medicare does not currently provide payment for caregiver training programs or education, though CMS has recently issued a proposal to offer this service.³⁰ The clinical experts and dementia caregivers we interviewed indicated unanimous agreement that caregiver education and training are invaluable supports from which all caregivers could benefit.³¹ Without Medicare payment for caregiver education and training, providers are currently financially disincentivized from furnishing these important services to caregivers.

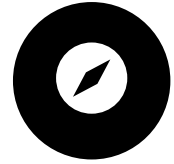
UNCOORDINATED CLINICAL CARE:

Managing medical and functional support for PLWD requires navigating fragmented healthcare and social support systems. Comprehensive dementia care often involves multiple healthcare providers, including primary care physicians, neurologists, geriatric specialists, and mental health professionals. Caregivers of PLWD report playing a care coordination role, often juggling multiple appointments, dealing with varying insurance requirements, and navigating different care settings – demands that grow increasingly complex as the condition progresses. This care fragmentation makes communication and integration among providers more challenging, increasing the potential for delayed services and inappropriate or unnecessary medical treatment.³² In an

interview with a geriatrician and emergency department (ED) physician, we learned that emergency physicians are frequently missing context as to why PLWD have been sent to the ED or PLWD are missing dementia diagnoses, hindering their ability to provide appropriate or necessary care. A lack of integration across providers and care settings leaves caregivers responsible for bridging the information gaps, particularly when PLWD themselves are no longer able to communicate clearly and accurately.

LACK OF CAREGIVER SOCIAL SUPPORTS:

Caregivers report that access to services such as individual counseling, peer support groups, respite care, and assistance with daily activities meaningfully contribute to their personal health and well-being and directly impact their ability to provide effective and sustained care to PLWD.³³ Under Medicaid, many states have a range of these services available to qualifying beneficiaries, and support provided from other federal agencies like the Department of Veterans Affairs and the Administration for Community Living provide funding for various non-medical supports for PLWD and their caregivers. Social supports and non-medical services are generally not covered in Medicare's current payment



Managing medical and functional support for PLWD requires navigating fragmented healthcare and social support systems.

28 <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2751946>

29 Subject matter expert (SME) interviews

30 In the CY 2024 Medicare Physician Fee Schedule proposed rule, CMS proposes to establish new billing codes to allow treating practitioners to bill for training furnished to a caregiver in strategies and specific activities to assist the beneficiary in carrying out their treatment plan.

31 SME interviews

32 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2787842/>

33 SME interviews



methodology, however, and remain out of reach for many dementia caregivers.³⁴

For many caregivers, especially those in rural areas, access to caregiver supports is limited at best, and in some communities is not available. As a result, other national, state, and local organizations try to fill this gap and provide a variety of sought-after services to caregivers. By way of example, one California-based community-based organization (CBO) reported leveraging philanthropic and grant funding to offer \$2,000 in annual voucher credits to dementia caregivers for adult day services.³⁵ Adult day services offer PLWD the opportunity to participate in social

activities within a safe environment while providing caregivers temporary respite from their caregiving responsibilities. As one of the few respite service providers in the area, the California-based CBO is unable to meet the growing demand for these vouchers in the absence of Medicare reimbursement pathways, with a waitlist last year of nearly 5,000 caregivers.³⁶ Despite the demand for these programs, limited federal and state financial assistance and reliance on philanthropic donations and grant funding to sustain caregiver support services restricts the availability and accessibility of these services to many dementia caregivers.

34 Medicare Advantage (MA) plans have additional authority to offer supplemental benefits that can provide support for family caregivers, such as providing direct respite care, counseling, training, or support lines for caregivers. Some example benefits that plans can offer are Supports for Caregivers of Enrollees, In-Home Support Services (IHSS), and Adult Day Health Services. Benefit eligibility can vary based on certain member characteristics and funding can limit the total number of hours or dollars available to provide these services.

35 SME interviews

36 *Ibid.*

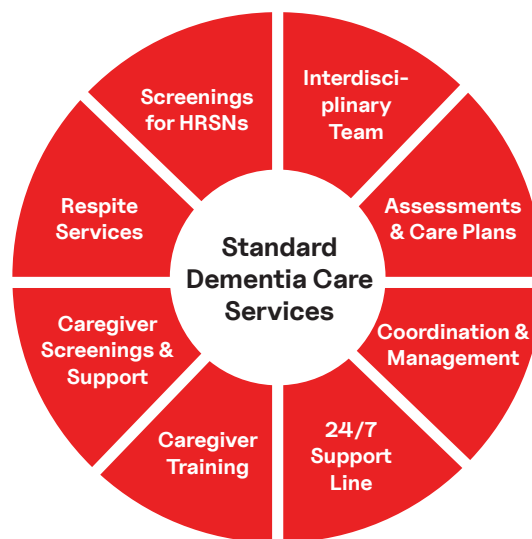


Improving Comprehensive Dementia Care Through the Guiding an Improved Dementia Experience (GUIDE) Model

On July 31, 2023, the CMS released the Guiding an Improved Dementia Experience (GUIDE) Model. A new voluntary nationwide model, GUIDE will focus on dementia care management and aims to improve quality of life for Medicare beneficiaries living with dementia, reduce burden and strain on their caregivers, and enable PLWD to remain safely in their homes and communities.³⁷ The GUIDE Model’s intended beneficiary population is community-dwelling Medicare fee-for-service beneficiaries, including beneficiaries dually eligible for Medicare and Medicaid, living with dementia. Throughout the Model’s eight-year performance period, CMS will test an alternative payment for participating dementia care programs that deliver the following set of standard dementia care services for beneficiaries and their caregivers:

- Care delivered by an interdisciplinary team that includes a clinician and a care navigator with required dementia training and proficiency
- Comprehensive, person-centered assessments and care plans
- Care coordination and care management
- 24/7 access to a support line

- Caregiver training and caregiver inclusion in the care team
- Screenings and support services to address caregiver needs
- Respite services made available in their home, at an adult day center, or at a facility that can provide 24-hour care for the purpose of giving the unpaid caregiver temporary breaks from their caregiving responsibilities
- Screenings for psychosocial needs and health-related social needs (HRSNs) and referrals to local, community-based providers to address these needs



The GUIDE Model is a vital step in CMS' efforts to support older Americans living with dementia and their caregivers nationwide. Providers participating in the Model will receive a per-beneficiary-per-month (PBPM) payment for providing dementia care management and supportive services to beneficiaries and their caregivers. Providers will also be able to bill for up to \$2,500 in respite services provided to certain dyads each year. Finally, certain safety net providers will be eligible for a one-time, lump sum infrastructure payment to support the

development of structural and care delivery capabilities necessary for successful Model participation.

The GUIDE Model builds from the evidence base of existing comprehensive dementia care models – many of which we included in our research and discuss in the following section – and offers CMS an unprecedented opportunity to pay for and evaluate the impact of key caregivers services and supports within the traditional fee-for-service Medicare program.

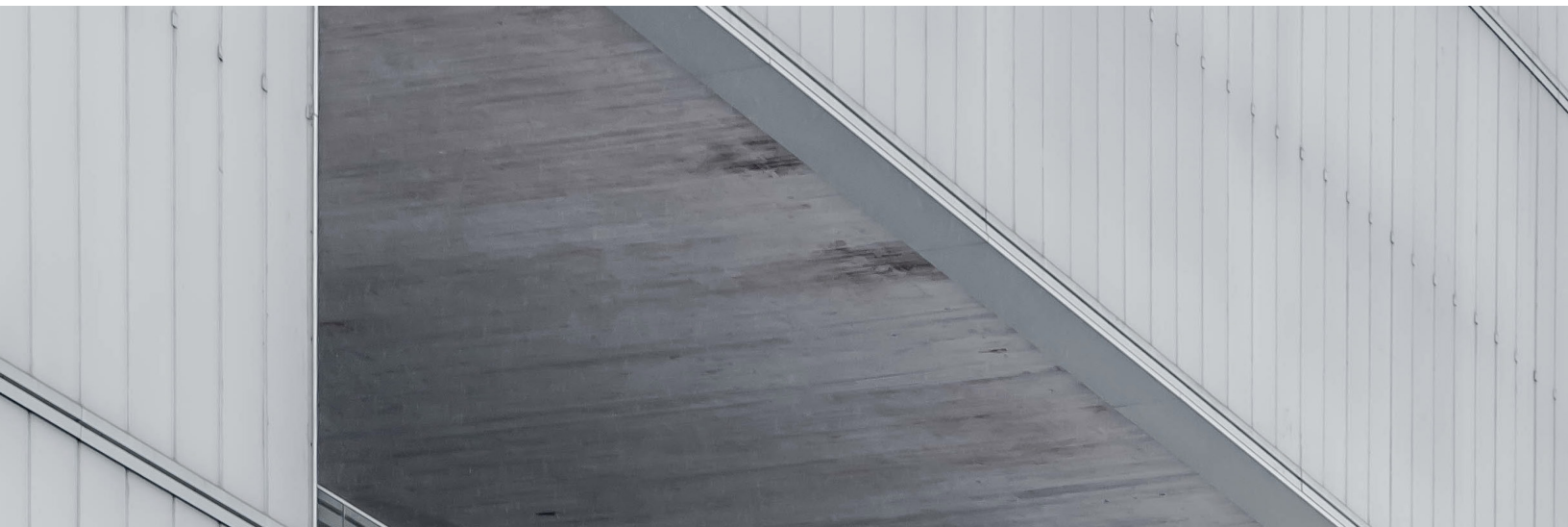


Existing Dementia Care Models Include Strong Focus on Caregivers

For the purposes of our research, we evaluated four existing dementia care models: 1) Indiana University’s Eskenazi Healthy Aging Brain Care (ABC), 2) UCLA’s Alzheimer’s and Disease Center (ADC), 3) UCSF’s Care Ecosystem (CE), and 4) Emory University’s Integrated Memory Care

Clinic (IMCC). We selected these models to study based on their comprehensive, interdisciplinary approach to dementia care and their emphasis on supporting caregivers. A summary of these models is provided in the table below, and more details are included in the Appendix.

Model	Acronym	Description
Eskenazi Healthy Aging Brain Care	ABC	Multidisciplinary approach to care with an emphasis on providing a caregiver support program
Alzheimer’s and Dementia Care	ADC	Co-management model providing individualized support for dementia patients and their caregivers
Care Ecosystem	CE	Telephonic support and education to persons with dementia and their caregivers
Integrated Memory Care Clinic	IMCC	Nurse-led, patient-centered model that provides both memory and primary care



To inform our understanding of dementia care models, we also looked at evidence-based caregiver interventions developed by the University of Pennsylvania's Alzheimer's Disease Research Center (ADRC) and the Benjamin Rose Institute on Aging (BRI), along with the Program of All-Inclusive Care for the Elderly (PACE) which serves many PLWD through an integrated, patient-centered care delivery model.

Despite variation in care setting, workforce, and intensity of engagement across the four evaluated dementia care models, all models targeted the holistic needs of dementia dyads. The four core elements outlined below were seen consistently across evaluated dementia care models and are also mirrored in the GUIDE Model.

EDUCATION AND TRAINING

The provision of dementia education and caregiver training is included across all models included in our research and is a care delivery requirement for GUIDE Model participants. Within existing dementia care models, broad and ongoing education and training enables caregivers to sustain effective care delivery as their persons' condition evolves.

There are various mechanisms for delivering caregiver education and training. Existing models use a variety of methods for training: in-person, virtual, or asynchronously, to caregivers individually or in group settings. Under some models, caregivers are equipped with dementia education and printed materials relating to problem-specific information and general

caregiving tips,³⁸ while others provide caregivers with ongoing access to web-based training modules, webinars, and in-person education classes.³⁹ One model provides intensive weekend caregiver training "boot camps," deploying grant funds to provide adult day services to PLWD while their caregivers attend the educational sessions.⁴⁰ In addition to guidance on how to care for PLWD, programs provide caregivers with recommended strategies to care for themselves, designed to help recipients cope with the stress and burden of caregiving and protect their health and well-being.⁴¹ GUIDE Model providers are required to furnish continuous education and updated training services to caregivers throughout the dementia care journey via delivery methods deemed most appropriate or effective by the interdisciplinary care team.

CARE NAVIGATION

While composition of interdisciplinary care teams varies across existing dementia care models, a designated team member under each existing model serves as care navigator. They may be clinical (Nurse Practitioners, Physician Assistants, Licensed Clinical Social Workers) or non-clinical providers (coordination assistants, Community Health Workers), but those serving as care navigators have specialized training in dementia and serve as the main contact for caregivers. In existing models, care navigators serve as a bridge between caregivers and the clinical team, building and sustaining a feedback loop throughout the PLWD's care journey to develop individualized care plans, schedule



Within existing dementia care models, broad and ongoing education and training enables caregivers to sustain effective care delivery as their persons' condition evolves.

38 <https://www.capc.org/documents/download/554/>

39 SME interviews

40 SME interviews

41 <https://memory.ucsf.edu/caregiving-support/caregiver-well-being>



and manage required care plan activities and follow-ups, and ensure caregivers are adequately supported as the PLWD's condition progresses. Collectively, existing dementia care models demonstrate that PLWD and their caregivers benefit from dementia care navigation.⁴² However, because care navigation services have limited reimbursement under Medicare,⁴³ some programs have relied exclusively on grant funding or philanthropic donations to sustain these positions on their care teams.⁴⁴ Considered by one model as the "care team quarterback,"⁴⁵ care navigators are a central component of comprehensive dementia care models.

Similarly, the foundation of the GUIDE Model is the role of the care navigator.⁴⁶ Interdisciplinary care teams participating in the GUIDE Model will include a care navigator who has received specialized training in dementia, assessment, and care planning. Mirroring existing dementia care models, care navigators under GUIDE will help to integrate caregivers into the care planning and implementation processes and connect the dyad to clinical services and social supports. The extent of care navigator responsibilities in the GUIDE Model have yet to be specified. Successful dementia care navigation services include, but are not limited to, routinely administering person-centered assessments of dementia patients and their caregivers, coordinating

between caregivers and clinical teams to modify individualized care plans as needed, assisting with non-pharmacological behavior symptom management, assisting caregivers with advance care planning and care transitions, and maintaining communication with non-clinical service providers to whom caregivers are connected.

INTEGRATED CLINICAL- AND COMMUNITY-BASED CARE

We heard through our interviews that respite services, adult day programs, and peer support groups are among the most sought-after resources among caregivers, services for which traditional Medicare reimbursement is not currently available. As such, dyads enrolled across existing dementia care models are commonly referred to community-based entities to access these social and other caregiver support services. As CMS has previously acknowledged, these organizations provide meaningful social services to communities they serve and can complement care provided in a clinical setting.⁴⁷ Importantly, care teams maintain strong partnerships and open communication with the CBOs to bridge the gap between the clinical and social components of care that often remain siloed. In the GUIDE Model, CMS encourages dementia care programs to establish



Respite services, adult day programs, and peer support groups are among the most sought-after resources among caregivers.

42 <https://alz-journals.onlinelibrary.wiley.com/doi/10.1002/trc2.12408#trc212408-bib-0003>

43 In the CY 2024 Medicare Physician Fee Schedule proposed rule, CMS proposes a Principal Illness Navigation services payment to reimburse for health care navigation services provided by a patient navigator or certified peer specialist as part of the treatment plan for a serious, high-risk disease.

44 SME Interviews

45 SME interviews

46 <https://innovation.cms.gov/innovation-models/guide>

47 CY 2024 PFS proposed rule, <https://public-inspection.federalregister.gov/2023-14624.pdf>



partnerships with community-based providers to provide needed social and other services to dementia dyads and address beneficiaries' HRSNs under the GUIDE Model. Notably, the GUIDE Model goes beyond existing dementia care models to provide up to \$2,500 in annual payments for respite services for certain dementia caregivers – a unique opportunity for dementia caregivers to access respite within the traditional Medicare program.

MEASURES TO ASSESS CAREGIVER STRESS

Caregiver assessments are considered an essential component across nearly all dementia care models included in our research. Designed to evaluate the well-being, needs, and capabilities of caregivers, these structured assessments allow care teams to develop individualized care plans and inform subsequent referrals to external services and supports. Caregiver assessments vary across models but are often comprised of a variation or subset of validated caregiver self-reporting tools, including but not limited to the Zarit Caregiver Burden Interview, Dementia Burden Scale-Caregiver (DBS-CG), and caregiver portions of the Neuropsychiatric Inventory Questionnaire (NPI-Q), and often

paired with caregiver depression screens such as the Patient Health Questionnaire-9 (PHQ-9). Program teams readminister these assessments throughout the dementia care journey, evaluating gaps in caregiver support and modifying care plans to align with evolving dyad needs.

To assess levels of caregiver burden over time, GUIDE Model participants will be required to administer the Zarit Caregiver Burden Interview. Results from these evaluations will inform the beneficiary tiers into which dyads are placed and thus the intensity of care they receive under the Model. Beyond monitoring caregiver strain over the Model period, the results from the Zarit Caregiver Burden Interview along with other caregiver assessments should be used regularly by the dementia care team to evaluate caregivers' physical health and mental well-being, identify caregivers' capabilities and unmet needs, and develop individualized plans of care that also address needs of the caregiver, in addition to any needs for the PLWD. These assessments should be periodically readministered to allow GUIDE Model participant teams to monitor the impact of caregiver supports and identify new or existing needs that have not been addressed.



Caregiver assessments are considered an essential component across nearly all dementia care models.



Evidence Supporting Existing Dementia Care Models

Previous evaluations and studies reveal positive findings regarding the impact of existing dementia care models on health, spending, utilization, and care experience.

A snapshot of results from select model evaluations and peer-reviewed studies are listed in the table below.

Model	Study Design	Findings
Eskenazi Healthy Aging Brain Care (ABC)	Randomized control trials	ABC program demonstrated improved outcomes for PLWD and their caregivers and cost savings to the Medicare program. ⁴⁸
	Cost Analysis	The annual cost for the ABC program is around \$618 per patient and has led to net annual savings per patient of between \$980 and \$2,856. ⁴⁹
Alzheimer's and Dementia Care (ADC)	Large case series and cost comparisons with a matched control group	The ADC program demonstrated high quality care, delayed transitions to long-term care, improved end-of-life care, and improved patient and caregiver outcomes. ⁵⁰
Care Ecosystem (CE)	Randomized control trial	CE was shown to improve the quality of life of PLWD and decrease caregiver depression and burden. Compared to expected use based on usual care data, the CE intervention prevented 120 ED visits, 16 ambulance use events, and 13 hospitalizations over a 12-month period. Based on national average costs for provision of these services to PLWD, investigators estimated a mean cost savings of \$600 per PLWD across these 3 service types. ⁵¹
Integrated Memory Care Clinic (IMCC)	Longitudinal single-group cohort study	Several demonstrated improvements in neuropsychiatric symptoms among PLWD and caregivers' reactions towards those symptoms within their first 9 months of IMCC enrollment. ⁵²

48 <https://www.healthaffairs.org/doi/10.1377/hlthaff.2013.1221>

49 *Ibid.*

50 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3889469/>

51 <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2751946>

52 <https://www.sciencedirect.com/science/article/abs/pii/S0197457220301476>



CMS also conducted independent evaluations of the models tested under the Health Care Innovation Awards (ADC, ABC, CE). In those evaluations, CMS looked at claims-based outcomes available across models to assess 1) how model components fostered better health care for PLWD and their caregivers, 2) model effects on Medicare spending and service use, and 3) model effects on beneficiary and caregiver experience of care.

According to a report synthesizing results of these independent evaluations, CMS found that across all evaluated models 1) care navigators or other care team members helped address gaps in care for PLWD, 2) access to dementia care resources improved beneficiaries' and caregivers' experience of care, and 3) caregivers reported increased efficacy in their caregiving abilities and lower stress. Notably, the ADC program's reduction in long-term care facility use was the only statistically significant effect reported on Medicare spending and service use.⁵³

We acknowledge that lack of statistically significant findings from CMS' analysis does not fully align with other model-specific evaluations. For example, some longitudinal studies have found statistically significant

reductions in Medicare spending and hospitalizations among model participants, outcomes that showed non-significant reductions in CMS' evaluations. Variability in dementia severity, participant exposure to model interventions, and the follow-up periods during which effects were evaluated may impact consistency of findings. Some model evaluations have indicated cost savings associated with deferred patient transitions to long-term care, outcomes that were not included in CMS' evaluations. The GUIDE Model has a primary goal to reduce long-term nursing home placement where appropriate and anticipates that the majority of savings will come from reduced long-term nursing home placement through federal and state spending in Medicaid.⁵⁴

Despite differences in evaluation methods, measurements, and design, evidence from evaluated dementia care model findings trend positive and form the basis of the GUIDE Model. Evaluation of the GUIDE Model over its eight-year performance period will be critically important to improving CMS' ability to test and refine caregiver interventions throughout the progression of their person's dementia and evaluate interventions' impact on dyad outcomes.



The GUIDE Model has a primary goal to reduce long-term nursing home placement where appropriate.



53 <https://innovation.cms.gov/data-and-reports/2022/dementia-care-synthesis-1989-2020>

54 <https://innovation.cms.gov/guide/faqs>

Key Caregiver Considerations for the GUIDE Model

Caregivers play a central role in managing a person's dementia, assuming increasingly complex and all-encompassing responsibilities as the condition progresses. In the absence of meaningful services and supports, the residual effects of caregiving on the financial, emotional, and physical health of caregivers can become insurmountable. Collectively, this strain on caregivers may threaten the quality and longevity of their caregiving, and in many cases the ability for PLWD to remain in the community. We recognize that while a main goal of the GUIDE Model is to reduce long-term nursing home placement, there will be instances where placement in long-term care is the most appropriate course of action for dementia dyads.

The GUIDE Model meaningfully includes dementia caregivers in alignment with prior dementia care models and acknowledges the dementia dyad. In particular, the GUIDE Model addresses each of the four core elements we identified as being critical in existing dementia care models to support the caregiver:

- Education and training
- Care navigation
- Integrated clinical and community-based care
- Measures to assess caregiver burden

Our exploration of the dementia care landscape has informed our understanding of the role of caregivers in managing dementia and the impact of supportive services on caregiving quality and longevity. Building on existing evidence-based dementia care models, the GUIDE Model's approach to care delivery and inclusion of caregiver supports has the potential to inform and transform how dementia care and caregiver supports are addressed within the Medicare program in the future.

Our research revealed that dementia caregivers represent a broad and diverse cross-section of the population. Dementia caregivers are siblings, children, and spouses; they are neighbors and friends from within the community. Some caregivers may receive payments for the care they provide through existing mechanisms like self-directed Medicaid services or other state-funded programs. At times, caregivers may receive financial aid from other family members when caring for a person with dementia takes the place of a full-time job. As CMS aims to reduce the strain and burden shouldered by caregivers, GUIDE Model services and supports should be available to all those providing care to a person with dementia, and could also be informed by developing research on caregiver "typologies" building from findings from RCI's research.



Distilling our key learnings to date, we offer the following caregiver-focused considerations that are intended to:

- **Inform** Model design to ensure incentives align with needs of caregivers
- **Strengthen** the ability to assess impact on PLWD and caregivers and build the evidence base for further caregiver support interventions
- **Broaden** access to information and understanding of dementia care across the healthcare ecosystem

INFORM MODEL DESIGN

- 1 **For beneficiaries who transition to long-term care during the Model performance period, GUIDE participants should receive a small payment to maintain caregiver support activities.**

A key goal of the GUIDE Model is to prevent or delay long-term nursing home care for as long as appropriate, and relatedly, individuals that reside in long-term nursing homes are ineligible for participation in the Model. Through our interviews, many clinical experts reiterated that long-term care may be the most appropriate setting for a PLWD enrolled in GUIDE given the progression of their needs over the course of the condition. We heard from family caregivers that this transition can be challenging and fraught with anxiety for the dyad. Importantly, the responsibility and burden shouldered by caregivers do not end with a transition to long-term care setting – in fact some studies estimate that caregivers continue to provide about 37 hours of household,

mobility, and self-care support each month to individuals who reside in long-term care settings.⁵⁵

As a result, it is likely that caregivers participating in GUIDE may benefit from continued care navigation and other supports during this time of transition. As such, for dyads enrolled in the GUIDE Model that see a transition to long-term care, we recommend that dementia care programs receive a reduced monthly payment to continue to provide supportive services to caregivers. While many caregivers would likely benefit from continued support throughout the duration of their person's stay in long-term care, we encourage CMS to provide GUIDE Model participants with payments necessary to sustain caregiver support services for no fewer than 6 months after they transition their person to long-term care.

- 2 **GUIDE Model participants should test and refine methods of obtaining consent and documenting caregiver contact information as part of this Model to help inform future CMS collection of caregiver information.**

Through this Model, GUIDE participants will need to obtain beneficiary consent for sharing diagnoses, treatment plans, and other care information with their identified caregiver(s). GUIDE participants will need to document, at minimum, the caregivers' name(s) and contact information for engagement with the care team, care coordination, linkages to supports and other assistance through the Model.



Individual providers may have processes for obtaining consent for sharing care information from the beneficiary and documenting caregiver names and contact information within their records. Currently, CMS does not have a defined process in place for collecting and/or documenting identified or consented caregivers on behalf of enrolled Medicare beneficiaries. As part of this process under the GUIDE Model, we recommend that CMS solicit input and pilot test options with GUIDE participants on how Medicare could collect caregiver information more broadly across the Medicare-enrolled population. Additionally, to best support the needs of PLWD and their unique situations and identified caregiver(s), we encourage CMS to test methods whereby multiple dementia caregivers could be identified and consented to participate in the Model and receive care information for GUIDE beneficiaries.

STRENGTHEN IMPACT ASSESSMENT

- 3 **To evaluate the impact of care navigation services, GUIDE Model participants should report on process and outcomes measures to CMS on a regular basis and identify key components of their care navigation model that may influence the efficacy and impact of a dementia care navigator.**

Care navigation is a key component of comprehensive dementia care and plays a central role in supporting the needs of the dementia caregiver. As discussed at length earlier, our review of existing dementia care models identifies variation

in the staffing credentials, training, and structure of care navigation services across programs. The GUIDE Model will require a standardized care delivery approach across all participants, but continued variation is expected in care navigation models implemented across GUIDE participants.

To ensure adherence to GUIDE requirements but to also inform CMS' evaluation of the Model, we recommend that CMS collect additional information from each dementia care program relative to their care navigation services. Firstly, we recommend that CMS establish specific process and outcomes metrics aligned with the care navigation role to ensure that the care navigators are adequately fulfilling the requirements and intent of the care navigation services within the GUIDE Model. Secondly, we recommend that CMS regularly collect key information about each dementia care program's care navigation program, such as staffing credentials, training requirements, supervision, and staffing ratios, so that GUIDE program evaluations can assess overall Model effectiveness based on varying GUIDE care navigation structures.

Importantly, many community-dwelling Americans living with dementia and their caregivers lack the financial resources needed to access long-term supports and services (LTSS), and a significant share of this patient population reside in communities where availability of LTSS remains limited. While GUIDE's care navigators will be responsible for connecting dyads with community based LTSS providers, the efficacy of these care navigation services may be hindered if dyads cannot access or afford these



Many community-dwelling Americans living with dementia and their caregivers lack the financial resources needed to access long-term supports and services.



services. By monitoring access issues to community and caregiver supports throughout Model's performance period, CMS can better understand and identify opportunities to address certain structural and access barriers that may lead to gaps in care navigation and caregiver support.

4 The GUIDE Model evaluation should include perspectives and input from participating dementia caregivers used to refine the Model over time.

To supplement CMS' quantitative evaluation of the GUIDE Model, CMS should collect qualitative feedback from participating dementia caregivers on a regular basis. Through GUIDE Model focus groups, caregivers could share their experiences participating in the Model, discuss the effect of GUIDE services on their lives, report barriers to accessing needed support or accessing long-term nursing home placement as necessary for the dyad, and highlight any concerns regarding dementia care program compliance. Similar in structure to Institutional Review Board panels, CMS could establish GUIDE advisory councils or learning collaboratives composed of dementia caregivers alongside clinical, home-based care, and other subject matter experts to review Model evaluations, identify gaps in required resources and areas for GUIDE improvement, and ensure caregiver needs are being adequately addressed under the Model. Collecting ongoing feedback from those most intimately involved in GUIDE will equip CMS with more timely indications of the impact of the Model on its intended outcomes and allow for targeted Model refinements over time.

5 The GUIDE Model evaluation should evaluate health and other outcomes for dementia caregivers.

Beyond enabling CMS to develop, test, and refine dementia care models over time, the GUIDE Model should be used as an opportunity to test meaningful services and supports for dementia caregivers, in addition to PLWD. Given the critical role of dementia caregivers in the quality and efficacy of dementia care provided under the GUIDE Model, the GUIDE Model evaluation should assess the impact of Model interventions on the quality of life, health outcomes, and financial health of dementia caregivers, in particular. Caregiver outcomes such as health deterioration, role captivity, and anxiety/depression are widely used across existing dementia care models to evaluate caregiver outcomes. There is also an opportunity to evaluate the impact of the Model on the financial health of caregivers, such as whether their role as a caregiver affected their ability to work or required a reduction in employment in order to balance the workloads of caregiving.

CMS has a unique and meaningful opportunity to assess impact on health outcomes and utilization for caregivers who are also Medicare beneficiaries. CMS should collect the names and Medicare Beneficiary Identifiers of caregivers in the GUIDE Model and conduct evaluations of impact on utilization and Medicare spending for the caregiver throughout the life of the Model. CMS may similarly analyze the respite care benefit to identify relationships between respite use and caregiver strain, emergency room or hospital admission, and long-term care admission. This may be particularly insightful, as respite care is not a core



offering of the four existing dementia care models included in our research.

It is also important to note that given the progressive nature of dementia, some experts have identified that caregiver stress or health effects may increase even with caregiver supports as the severity of the condition increases. We recommend that CMS in its evaluation also monitor the health outcomes of caregivers that are not enrolled in GUIDE or other dementia care programs as a more realistic comparison group, in order to assess the impacts of the GUIDE Model on dementia caregivers. Systematic evaluations of caregiver impact conducted throughout the Model's 8-year performance period will strengthen the evidence base for effective caregiver interventions and inform future dementia care models.

BROADEN ACCESS AND UNDERSTANDING OF DEMENTIA CARE

- 6 Materials developed and refined under the GUIDE Model, along with CMS' GUIDE Model evaluations, should be disseminated broadly to other stakeholders and sectors not participating in the Model.**

Underlying structural capabilities (dementia education, diagnostic tools, care navigation, community integration) have not been sufficiently disseminated to sustain comprehensive care for the growing share of Medicare beneficiaries living with dementia. Existing dementia care models have developed program-specific curricula to support training of care navigators, education and training for caregivers, and

effective integration of community-based organizations and clinical dementia care. In addition, through our interviews with dementia caregivers and clinical experts, we heard that primary care providers (PCPs) often lack the resources and training necessary to identify early signs of dementia which limits their ability to ensure appropriate and timely referrals to dementia care specialists.

Existing dementia care models, and the implementation of GUIDE, provide a ripe testing ground for identification and sharing of best practices and present an opportunity to disseminate evidence-based dementia care materials across the entire healthcare ecosystem to help bridge these gaps and build the foundation needed to manage the complex care of this growing patient population. GUIDE intends to reach a portion of the Medicare fee-for-service enrolled dementia patient population through the Model's participating providers, but the learnings developed would have broader applicability across the healthcare system, including for beneficiaries enrolled in Medicare Advantage or PACE, or for beneficiaries receiving care from hospice or long-term care facilities. CMS, in partnership with other federal partners (such as the Administration for Community Living, National Institutes of Health, Centers for Disease Control and Prevention, and Agency for Healthcare Research and Quality), should leverage the investments in and evaluations of the GUIDE Model to develop, refine, and disseminate educational materials, trainings, scripts, and best practices from the Model to these additional settings to continue to raise awareness of dementia care best practices. The broad dissemination of evidence-



Some experts have identified that caregiver stress or health effects may increase even with caregiver supports as the severity of the condition increases.



based resources developed and tested under the GUIDE Model can help to reduce fragmentation across healthcare systems and strengthen the quality and continuity of comprehensive dementia care and caregiver engagement delivered throughout the United States.

7 CMS should monitor the effects of the GUIDE Model on rates of dementia diagnoses and Medicare enrollment decisions for individuals with dementia, including evaluating by subpopulation (race/ethnicity, income, etc.)

The implementation of the GUIDE Model offers a significant opportunity to provide comprehensive dementia care supports to eligible beneficiaries within the Medicare program. We recognize that dementia diagnosis is a barrier to Model enrollment, and as a result, we expect that rates of dementia diagnosis will increase in order to access the services available under the

Model and may have the effect of driving enrollment in traditional Medicare vs. Medicare Advantage.

As part of CMS' ongoing implementation of the Model, we recommend that CMS establish mechanisms to monitor the potential effect of the GUIDE Model on both dementia diagnoses and enrollment decisions. The ongoing monitoring should be segmented by subpopulation such as race/ethnicity, rural/urban status, and income levels as well to identify any inequities in access to the GUIDE Model among specific subpopulations. Specifically, we recommend that CMS monitor the rates of dementia diagnoses between populations participating in the Model and not, especially within minority populations that already experience delayed dementia diagnoses. In addition, it will be important to monitor program enrollment changes for those in the GUIDE Model, for example between Medicare Advantage and traditional Medicare as well as transitions to hospice, to understand any beneficiary selection patterns throughout GUIDE Model implementation.

In closing, these considerations will further improve alignment with caregiver needs, strengthen the evidence base for future caregiver support interventions, and broaden access and understanding of dementia care across the healthcare ecosystem. We look forward to additional GUIDE Model details on how the Model can meaningfully address and evaluate support for dementia caregivers.

Appendix

EXISTING DEMENTIA CARE MODELS STUDIED

Model	Description	Setting	Workforce	Intensity	Duration
Indiana University Eskenazi Healthy Aging Brain Care (ABC)	Multidisciplinary approach to care with an emphasis on providing a caregiver support program.	Virtual, Clinic, & Home	Interdisciplinary teams: MD, RN, SW, 2-3 care coordinator assistants (specially trained community health workers), medical assistant, & psychologist	Quarterly home visits with monthly contact between visits	Ongoing
UCLA Alzheimer’s and Dementia Care (ADC) Program	Comprehensive, coordinated, patient-centered dementia care management	Virtual & Clinic	Nurse Practitioners (NPs) as dementia care managers (DCMs) to collaborate with patients’ PCPs	Annual in-person clinic visits and quarterly phone check-in	Ongoing
UCSF Care Ecosystem (CE)	Telephonic support and education to persons with dementia and their caregivers	Virtual	Care Team Navigator (CTN, an unlicensed dementia care guide) supported/supervised by dementia-trained RN, pharmacist, & social worker (SW)	Varies from monthly to every 3-4 months depending on dementia acuity score	Dyad graduates after 1 year, ongoing contact with CTNs as needed
Emory University Integrated Memory Care Clinic (IMCC)	Nurse-led, patient-centered model that provides both memory and primary care	Clinic	Interdisciplinary team: NP, geriatrician, neurologist, SW	Weekly appointments with dementia care assistants offered	Ongoing



CAREGIVER INTERVENTIONS PROVIDED WITHIN THE STUDIED MODELS

Model	Caregiver Assessment	Education / Coaching	Peer Support	Care Planning	Clinical Liaison	Respite
Eskenazi Healthy Aging Brain Care (ABC)	✓	✓	✓	✓	✓	
Alzheimer’s and Dementia Care (ADC) Program	✓	✓		✓	✓	
Care Ecosystem (CE)		✓		✓		
Integrated Memory Care Clinic (IMCC)	✓	✓		✓	✓	



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