Introduction

The number of Californians living with dementia will increase significantly in the next decade, creating economic, healthcare, and societal challenges. But California Advancing and Innovating Medi-Cal (CalAIM) holds promise to be an essential partner in reducing these problems.

CalAIM is transforming the state’s version of Medicaid by dramatically expanding the tools and partners available beyond the traditional health care systems’ to address the social determinants of health, improve health outcomes, and more efficiently use California taxpayers’ money.

One of the 10 populations eligible for coordinated health care and social services under CalAIM is Medi-Cal beneficiaries at risk of long-term care institutionalization. Within this population, the largest group is people living with dementia – who, because of their cognitive decline, have serious impairments in their self-care activities (activities of daily living), that can easily exceed the capability of their caregivers. However, most people and families would prefer to keep someone at home or in a more home-like setting if support were available.

CalAIM will make that more possible. Its new programs, enhanced care management and community supports, are supposed to add integrated care management, personalized care plans, multicomponent interventions, and caregiver support into health care. These efforts are consistent with evidence-based best practices for dementia care – reducing health system utilization, delaying institutionalization, and improving the quality of life of both people living with dementia and their caregivers.

Commissioned by Archstone Foundation from experts in dementia care at UCSF, this report reviews available evidence regarding services and supports that can delay or prevent nursing home placement and reduce other burdensome and costly care such as hospitalizations and emergency room visits for people living with dementia. It crosswalks these services with the new CalAIM benefits (especially Enhanced Care Management and Community Supports) – detailing the overlaps so that managed care plans and others understand which services and types of organizations are most likely to decrease institutionalization and other costly and unnecessary care.

What follows is intended to build a common understanding among managed care plans, health care organizations, and social support providers about how their roles in caring effectively for Californians living with dementia, and their families, can be changed for the better by CalAIM. While each case is unique, we already know a great deal about what is and is not effective in changing the life trajectories of people living with dementia and their caregivers.

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California’s Dementia Challenges

Dementia is different from normal, age-related cognitive decline. Instead, it is a syndrome defined by a progressive loss of cognitive abilities, such as memory or language, severe enough to limit ability to perform everyday activities. Dementia symptoms vary, but these cognitive and functional declines are almost always progressive.

Many neurodegenerative diseases can cause dementia but Alzheimer’s disease is the most common, accounting for 60 to 70 percent of cases. There is no curative treatment for all causes and, while some newly approved treatments may slow Alzheimer’s disease specifically, they are not routinely available because of the special diagnostics and frequent monitoring required. Detection and diagnosis are important because there are many ways to alter behavior to slow dementia’s progression. And patients prefer to be diagnosed as soon as possible.

The need to confront this challenge in California is urgent because:

• Its population older than 65 is projected to surge by 50 percent in the next decade, to 9 million.
• One in nine Californians older than 65 has dementia now, and the share among those 85 and older is one in three.
• The number of Californians diagnosed with dementia is projected to reach 1.3 million in 2040, a doubling since 2020.
• Two in five older adults with probable dementia (39.5 percent) go undiagnosed and one in five (19.2 percent) are unaware of their diagnoses.

For those who are diagnosed, Medi-Cal is a vital provider of care:

• A quarter (24 percent) of older Californians living with dementia are eligible for both Medi-Cal (Medicaid) and Medicare.
• People in this group are three times as likely to have dementia as those only eligible for Medicare.
• Between 10 percent and 20 percent of “dually eligible” in the state have dementia (150,000 to 300,000 of the roughly 1.5 million duals served by Medi-Cal).

People with dementia use the health system more than people without dementia:

• Their average hospital stay is longer (5.1 days vs. 4.5 days).
• Their 30-day hospital readmission rate is higher (23 percent vs 18 percent).
• Their visits to emergency rooms increased 28 percent in the decade ending in 2018.
• Seventy-five percent of them (but just 4 percent of the general population) are in nursing homes by the time they are 80.
Dementia imposes outsized costs on society, the healthcare system, and the government:\textsuperscript{2,3}

- Total payments in 2023 on care for people living with dementia are estimated at $345 billion. (This does not include the value of unpaid care or disease-modifying therapies.)
- Medicare and Medicaid are expected to cover $222 billion, or 64 percent.
- Out-of-pocket spending by patients’ families is expected to be $87 billion, or 25 percent.
- Caring for an older person with dementia averages $43,444 annually – triple the cost of caring for other people older than 65.
- Thirty-one percent of money spent on caring for older people with dementia goes to nursing homes.
- Medicaid spends 22 times more on annual payments to those with dementia ($6,739) than on those without ($303).
- Nearly half (48 percent) of caregivers of older adults nationwide are caring for someone with dementia – and 83 percent are not paid for that work. Nearly 1.9 million Californians provided an estimated $44 million in unpaid care in 2022.

Glaring racial and ethnic disparities and inequities mark the prevalence of, and care for, persons living with dementia:

- Black people are twice as likely to develop dementia as white people.\textsuperscript{2}
- Black patients with dementia have a 37 percent higher hospital readmission rate than white patients.\textsuperscript{11}
- Hispanic people are one-and-a-half times as likely as white people to develop dementia.\textsuperscript{2,3}
- Hispanics with dementia are more likely than others to remain undiagnosed.\textsuperscript{8}
- Hispanics with dementia are more likely to reside in under-resourced nursing homes.\textsuperscript{13}
- People with dementia who identify as Black or Black Hispanic have higher-than-average hospital mortality rates.\textsuperscript{13}
- Lower-income women of color are the most likely to provide unpaid care to people with dementia.\textsuperscript{13}
A review of recent academic studies reveals that current thinking about the best practices for caring for people with dementia – practices that focus on personalized care, contain costs, and delay or minimize institutionalization – reveal these often-cited approaches:

- Embrace collaborative care
- Develop care plans with multicomponent interventions
- Promote community living arrangements and support
- Do more to support caregivers

**Embrace collaborative care**
Models of collaborative care – professionals with an array of specialties working as a team to look after people living with dementia – have shown significant success. A comprehensive review in the American Journal of Geriatric Psychiatry in 2020 of primary-care-based models of collaborative care concluded they are likely to reduce behavioral symptoms, improve functioning, reduce use of acute medical services, enhance quality of life, decrease the burden on caregivers, and raise patient and family satisfaction. The review concluded these models either cost the same as the current standard of care or saved money, in part because primary care providers reported more confidence in their management of dementia and so made fewer specialty referrals.14

Central to successful models is that the primary care provider (PCP) coordinating the team centers patients and caregivers in the decision-making, and the PCP receives adequate support for implementing components of care plans including patient and caregiver education, psychosocial assessments, coordination of transitions of care, and referrals for specialty care and community services. Most models use clinical algorithms to ensure quality during both planning and implementation. The models rely on both in-person primary care infrastructures and remote connections or telemedicine, with team members sometimes allowed to access patients’ electronic health records. Some models also provided training of PCPs in the management of people with dementia and how to address sensitive topics in ways that lead to evidenced-based care.14

One significant challenge is that Medicare and Medicaid do not always support the use of such models, although efforts are underway to change the payment systems so that happens.15,16
Six Notable Models of Care

Here are six collaborative care models that have demonstrated success in caring for people with dementia

**Care Ecosystem** at the University of California-San Francisco deploys teams led by non-licensed, trained navigators and including advanced practice nurses, social workers, and pharmacists. The team uses telephone and video calls to create and implement care plans using clinical algorithms. In randomized control trials, teams improved quality of life for dementia patients and reduced caregiver depression to 8 percent from 13.4 percent. In a 12-month period, the program prevented 120 emergency department visits, 16 ambulance usages and 13 hospitalizations leading to a $600 average estimated saving per patient.\(^{14}\)

**The Alzheimer's and Dementia Care (ADC)** program at the University of California-Los Angeles has teams of advanced practice nurses, social workers, and non-licensed staff members providing telephone-based care. In a randomized control trial, the program showed a 40 percent reduction in nursing home placement compared to the control group, and a reduction of $284 in net costs per member per quarter.\(^{17}\)

**Partners in Dementia Care**, a version of Benjamin Rose Institute’s Care Consultation program, is a telephone-based model delivered by partnerships of Department of Veterans Affairs medical centers and Alzheimer's Association chapters. Social workers or nurses act as care managers. In controlled trials, it was associated with beneficial changes in psychological outcomes for veterans with dementia, such as decreased symptoms of depression and reduced embarrassment about memory problems. It also reduced both caregiver burden and social isolation.\(^{18,19}\)

**Aging Brain Care** is a program of Eskenazi Health, which runs the public hospital in Indianapolis with the Indiana University School of Medicine, that uses an interdisciplinary team in collaboration with a primary care provider who manages comprehensive care coordination. In a case-controlled trial, the program reduced behavioral symptoms 29 percent and produced per-patient savings of $3,474 in 12 months – about 53 percent of it reduced inpatient costs and the rest from reduced emergency department and outpatient expenses.\(^{20,21}\)

**Maximizing Independence at Home** is a care coordination program of Johns Hopkins Medicine that assembles teams of non-licensed personnel, registered nurses, and physicians. Participants are seen about every 30 days and care plans consider 13 areas of care. In a randomized control trial, after 18 months participants were 15 percent less likely to permanently leave home or die than the control group and also remained in their home 11 percent longer (496 days).\(^{22}\)
The Integrated Memory Care Clinic (IMCC) of Emory Healthcare is a patient-centered medical home led by nurse practitioners who provide comprehensive primary care as well as dementia care. Over a 3-year period, patients in the IMCC have a 2 percent hospitalization rate for ambulatory-sensitive conditions, much lower than the 13 percent average in patients with dementia in the country, on average.39

<table>
<thead>
<tr>
<th>Structure and Process</th>
<th>Benjamin Rose Institute Care Consultation</th>
<th>Care Ecosystem</th>
<th>Maximizing Independence at Home</th>
<th>Eskenazi Healthy Aging Brain Center</th>
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**Benefits**

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<td>Caregiver benefits</td>
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<td>Cost of the program</td>
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<td>+++(Medicaid)</td>
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Source: Updated and adapted from Haggerty Kt, Epstein-Lubow G, Spragens LH, Stroteckle RJ, Everston LC, Jennings LA, et al. Recommendations to improve payment policies for comprehensive dementia care, 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.

Reprinted with author permission. Table of evidence-based interventions
Develop detailed care plans
Several practices embraced by many collaborative care models, including the six described above, should be aspects of all models for high-quality dementia care.

Personalized and comprehensive care plans need to be created and regularly updated. Their three areas of focus should be treatment and care management, medication management, and caregiver support.23

Care plans should also include multicomponent interventions – in other words, more than one component is necessary to achieve the intervention’s goals – that are particularly relevant for people living with dementia. Two notable examples are:

Safety interventions, which often include but are not limited to decision aids, technology assistive tools, occupational therapy evaluations and interventions, and toolkits that guide caregivers in making homes safer for people with dementia. Such modifications are shown to significantly reduce risky behavior and accidents.24 Occupational therapy assessments improve the safety and quality of life of both patients and caregivers and have shown to be cost effective by decreasing the need for formal care and delaying institutionalization.25

Physical activity and cognitive therapy interventions, which lead to clinical improvements and reduced use of services.25 Tai chi and community-based group activities have shown to improve dementia symptoms and cognitive functioning.26 And one study of found that spending no more than $1,820 on three months of community-based therapy saved $2,600 compared with the usual cost of care for older patients with dementia.27

Promote community living arrangements and support
Several studies show that remaining in community – in small-scale homelike settings, dementia villages, or dementia-friendly initiatives – is effective in supporting people living with dementia.

The Alzheimer's or dementia village is a relatively new model for delivering person-centered care and optimizing the cognitive, physical, social, and environmental aspects of care. Most villages use community volunteers to assist residents with physical activities and entertainment. Limited studies have shown promising results on the physical functioning, social participation, and quality of life of people living in small-scale communities compared with people in conventional nursing homes. No quantitative evaluation on dementia villages has yet been published.28 Another review found that group living can be beneficial for individuals who are close to needing institutionalization.30
For people with dementia still living in their own homes, the delivery of meals – both medically-tailored and not – has shown benefits. One study found that food deliveries for six months resulted in fewer emergency department visits and ambulance usage, saving an average of $220 in health care costs monthly for those receiving medically tailored meals and $10 for those with non-tailored food deliveries.\textsuperscript{29,30} Another, decade-long study found that every $25 in increased spending on home-delivered meals yielded a 1 percent reduction in the number of nursing home residents with low-care needs.\textsuperscript{31}

**Do more to support caregivers**

As highlighted elsewhere, high-quality care for people with dementia must include support for their caregivers.

This often begins with a direct assessment of caregivers’ understanding of dementia and its progression, their ability to support medication management, their connection to community services, and their level of care-related strain and depression. Those assessments may identify particular needs: to be educated about dementia and their role in its management; to be introduced to programs that can offer them respite, such as adult day health centers and nursing homes that allow brief stays; or to be referred for psychosocial therapy.

Both caregivers and the people living with dementia being cared for can benefit from respite care and psychosocial therapy, as noted in a systematic review of the value of supportive care by Guzzon and co-authors.\textsuperscript{30} They categorize adult day care and respite care into any kind of arrangement that provides short term relief to a primary caregiver. Though evidence on the positive effects of adult day care is limited, long-term utilization can reduce the time a caregiver spends on symptom management and increase the time available to work in other jobs. One study found psychosocial therapy for caregivers had a 99 percent chance of being cost-effective and improved their quality of life by reducing depression and anxiety.
In January 2022, the state's Department of Health Care Services announced the launch of CalAIM, the shorthand for California Advancing and Innovating Medi-Cal. The program will transform the state's version of Medicaid by the end of 2027, principally by providing coverage of more social services. While its reach is intended to help all beneficiaries, many of the reforms are focused on improving care and quality of life for those with the most complex and costly needs – and older adults are among the targeted populations. (An estimated 1.2 million low-income older Californians, many from marginalized communities, qualify for Medi-Cal as well as Medicare.)

With an increased reliance on managed care plans willing to pay per-beneficiary monthly amounts to their contractors – and which will be obligated to create a statewide consistency of benefits and processes – CalAIM’s goal is to reduce health care disparities by increasing access to a standard set of services and providing the highest payments and levels of service to those with the highest needs, especially populations historically excluded from or underserved by the system.

To that end, CalAIM provides several opportunities to mitigate the limitations and challenges faced by people with dementia and their caregivers:

- Coordinated medical and social service benefits
- Additional benefits for support services
- Funds to train dementia care specialists
- Extra help for dual eligibles
- New opportunities in Medicare

**Coordinated medical and social service benefits**

Enhanced Care Management (ECM) is the name for the new Medi-Cal managed care benefit that provides enhanced coordination of health and social services to address both the clinical and nonclinical needs of beneficiaries in CalAIM’s 10 “populations of focus.”

One of those populations is “adults living in the community and at risk for long-term care institutionalization.” Two types of people are eligible: Those who meet the criteria for a skilled nursing facility’s level of care; and those who require lower-acuity skilled nursing and have at least one complex social or environmental factor challenging their health – such as poor or inadequate caregiving, communication difficulties, or challenges with such activities of daily living as eating, dressing, bathing, walking, and using the toilet – but are able to remain in the community if wraparound supports are provided. Importantly, residential care and assisted living facilities are considered community living. Also, a diagnosis of dementia is not required, so many people with identified cognitive issues may qualify for ECM benefits.
The state is in the process of estimating how many Californians are living in the community but at risk of long-term care institutionalization. It has recommended that ECM social services for these adults be provided by community-based adult service centers, local agencies on aging, home health agencies, centers for independent living and community-based Alzheimer’s organizations.

These five aspects of the ECM program most importantly reflect best practices in dementia care:

- **Team structure.** While there are no licensing or professional requirements for staff members, ECM teams must have a lead care manager who serves as the beneficiary’s primary point of contact with all team members. Care managers are responsible for coordinating all aspects of care, including other CalAIM programs such as Community Supports (CS), detailed in the next section. This structure is well-aligned with the needs of a successful collaborative care model for people with dementia.

- **Essential roles.** ECM requires enhanced coordination of care, transitional care services, and coordination of referral to community and social support services. In a collaborative care model, evidence shows these are essential roles to support both the primary care provider and the patient with dementia in executing the care plan.

- **Updated plans.** ECM care planning is based on clinically appropriate frequency, not the calendar. And a dementia care best practice is to have personalized and comprehensive care plans that get updated regularly, especially when people develop an urgent need or change their goals. CalAIM discourages managed care plans from reassessment policies based on timelines and encourages the use of data sharing and chart audits to review beneficiary progress. When adults at risk of long-term care institutionalization develop the need for long-term services and supports, their care plans must be developed by people trained in person-centered planning, using a person-centered process.

- **Plan components.** ECM provides health promotion and family support which may include caregiver support. Team members, particularly lead care managers, are strongly encouraged to educate caregivers about aspects of dementia including management of stressors, medication management, self-management, and community resources. But ECM does not cover the costs of prescribing staff, a best practice in dementia care programs, so a way to provide access to medication management for people with dementia must be developed. One option is determining the location of ECM teams (such as within a healthcare system, primary care, or ancillary specialty team) creating partnerships with home health or primary care services.
• **Referral generation.** A key ECM component is outreach and engagement that generates a referral and enrollment base. An opportunity for this would be working with dementia-friendly initiatives, which have a strong understanding of dementia and are engaged with people with dementia living in community and their caregivers. An example would be a partnership between an ECM provider and a dementia village program to support higher-risk village participants with referrals for ECM services.

The overlap between Enhanced Care Management and best practices in dementia care are detailed here.

<table>
<thead>
<tr>
<th>ECM component</th>
<th>Dementia care best practice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outreach and engagement</strong></td>
<td>★ Partner with dementia friendly initiatives to generate referrals</td>
</tr>
<tr>
<td><strong>Comprehensive assessment and care management plan</strong></td>
<td>★ Defined care manager role</td>
</tr>
<tr>
<td></td>
<td>★ Personalized and comprehensive care plan that is regularly updated according to the patient’s needs</td>
</tr>
<tr>
<td></td>
<td>★ Care plan includes treatment and care management</td>
</tr>
<tr>
<td></td>
<td>⚠ Care plan includes medication management</td>
</tr>
<tr>
<td><strong>Enhanced coordination of care</strong></td>
<td>★ Defined care manager role</td>
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<tr>
<td><strong>Health promotion</strong></td>
<td>★ Caregiver education includes dementia education including managing stressors, medication management, self-management and community resources.</td>
</tr>
<tr>
<td><strong>Transitional care services</strong></td>
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<tr>
<td></td>
<td>★ Care plan includes caregiver support</td>
</tr>
<tr>
<td><strong>Member and family supports</strong></td>
<td>★ Caregiver support includes education on self-management</td>
</tr>
<tr>
<td></td>
<td>⚠ Caregiver assessment</td>
</tr>
<tr>
<td><strong>Coordination of and referral to community and social Support Services</strong></td>
<td>★ Defined care manager role</td>
</tr>
</tbody>
</table>

Overlap Opportunity Limitation
Additional benefits for support services

Community Supports (CS) – which CalAIM sometimes refers to as In Lieu of Services – are optional benefits that managed care plans are encouraged to offer to all who would benefit, both within and outside of Enhanced Care Management. The plans are strongly encouraged to offer as many CS services as possible and to contract with a variety of providers to meet the needs of diverse populations. These 14 services address health-related social needs and social determinants of health. They support central CalAIM goals, which are delivering care in the least restrictive possible setting and allowing beneficiaries to remain in their communities as long as medically appropriate. And as mentioned above, some evidence shows benefits from partnering with dementia-friendly initiatives.

CalAIM strongly encourages managed care plans to provide at least four CS services to people living in the community but at risk of long-term institutionalization:

- Home modifications, also called environmental accessibility adaptations
- Respite services
- Medically tailored meals or medically supportive food
- Personal care and homemaker services

*The California Health Care Foundation has a roster of organizations that provide these.*

Though no basis in evidence has appeared in the literature, managed care plans should cover personal care and homemaker services because that would lower barriers to services for people with dementia – among them eligibility requirements for in-home supportive-services that may exclude people with mild cognitive impairment and set limits for people needing around-the-clock caregiver support.

Coverage for transitioning to a nursing facility or diversion to an assisted living facility is another CS that would benefit people with dementia. Managed care plans could partner with small-scale homelike communities to offer this service. When considering recommended multicomponent interventions, many Medi-Cal beneficiaries will be able to obtain occupational therapy through ECM care coordination and referral to outpatient or home health services.
Funds to train dementia care specialists
To support execution of its policy changes, CalAIM will help community-based organizations with infrastructure improvements, personnel training, and technical assistance. The $1.85 billion program – called PATH, for Providing Access and Transforming Health – will subsidize the cost of contracting and payment processes, workforce development, and staff training connected to the upgrading of such delivery systems as certified electronic health record technologies, care management document systems, closed-loop referrals, billing systems and services, and onboarding and enhancements to health information exchange capabilities. Health systems and community-based organizations partnering with managed care plans may apply.
There are four major areas of funding in PATH. For ECM and CS providers working with people with dementia, the most relevant are Capacity and Infrastructure Transition Expansion and Development and Technical Assistance Marketplace. Money from either may be spent to train and certify people as dementia care specialists.36

**Extra help for people who are dually eligible**

A Dual Eligible Special Needs Plan (D-SNP) is a special Medicare Advantage plan providing care coordination and wrap-around services to people eligible for both Medicare and Medi-Cal. And last year, California and the federal government completed the Cal MediConnect demonstration project, creating one plan for the dually eligible combining both state and federal benefits and augmenting them with additional care coordination benefits. These are now known as Medi-Medi plans. CalAIM this year launched both exclusively aligned enrollment D-SNPs and Medi-Medi plans in the seven counties involved in the demonstration project, and five more counties will be added in 2024.37

The state recommends Medi-Medi plans provide integrated care management across Medicare and Medi-Cal, meaning managed care companies are responsible for providing ECM-like services. In addition, the state has highlighted the needs of people with dementia throughout its policies and procedures for these plans. For example, it requires these plans identify when a beneficiary has documented dementia care needs, at which point care plans will require teams include a dementia care specialist.38

**New opportunities in Medicare**

The federal government launched the GUIDE Model (Guiding an Improved Dementia Experience) in July 2023 in an effort to systematically improve how the traditional fee-for-service Medicare program cares for people with dementia and their unpaid caregivers. In addition, in California, the new Medi-Medi plan promises to produce more alignment with the needs of this population – including support for the specialized care workforce, assessment and data collection of dementia-specific needs, and integration of caregivers into assessment, data collection, and care plans.

This creates an opportunity to leverage ECM and CS services for a hybrid GUIDE and CalAIM program that provides robust care for dually eligible people living with dementia. However, GUIDE payments are only available in fee-for-service Medicare and applications are only being accepted this year (2023-24) for the next eight years.
Conclusion

California is challenged by how to care well for the growing population of people living with dementia, given the impacts on the economy, healthcare, and society.

Effective dementia care requires a comprehensive and integrated approach. People living with dementia need personalized care plans that incorporate treatment, medication management, and the needs of their caregivers. These plans have the added benefit of holding down costs when they rely on collaborative care teams centered in primary care. Several aspects of CalAIM – principally its new Enhanced Care Management and Community Supports benefits – provide opportunities, through care management and multicomponent interventions, to implement evidence-based and best-practices-infused collaborative care models for people living with dementia. CalAIM also sets requirements for Medi-Medi plans that will help improve care for many in this population.
References


15. “Payment For Comprehensive Dementia Care: Five Key Recommendations”, Health Affairs Forefront, February 7, 2023. doi:10.1377/forefront.20230206.835921


