

ON THE ISSUES: HEALTH REFORM & DEMENTIA

As Congress and the Administration work to improve health care outcomes and reduce costs, they must keep in mind the [Patient Protection and Affordable Care Act of 2010](#)ⁱ (ACA) provisions that support more than five million people living with Alzheimer's disease or another form of dementia and their families.

Alzheimer's Disease Protections at Risk Under the ACA Reform

Expanded Access to Health and Social Care for People with Dementia and Their Caregivers

- The Medicare Annual Wellness Visit including the cognitive assessment to measure memory loss
- Coordination of care for dually-eligible beneficiaries under Medicare and Medicaid
- Expanded access to Medicaid insurance
- Reduced out-of-pocket medication costs for beneficiaries in the Medicare Prescription Drug Plans coverage gap
- Health insurance for young adults up to age 26, who are caring for loved ones with dementia
- Services and outreach through the Alzheimer's Disease Initiative under the Prevention and Public Health Fund

Support for Dementia Research and Clinical Trial Participants

- Health insurance coverage for clinical trial participants with life-threatening illnesses
- CMS Innovation Center Pilot Programs which identify new models of care that will yield lower costs and better outcomes
- Patient-centered and patient-powered research for Alzheimer's through the Patient-Centered Outcomes Research Institute (PCORI)

Consumer Protections for the Most Vulnerable and Their Family Caregivers

- Non-discrimination policies to protect individuals with pre-existing conditions
- Coverage for essential health benefits, such as preventative services and emergency care
- Spousal asset protections for family caregivers living in the community
- Improved nursing home regulations that require transparency and improved quality of care



Expanded Access to Health and Social Care for People with Dementia and Their Caregivers

Medicare Annual Wellness Visit

Medicare beneficiaries can receive a personalized prevention health plan each year, including a [free Annual Wellness Visit with a cognitive assessment](#)ⁱⁱ, if the patient has had the Part B benefit for longer than 12 months. Beneficiaries do not pay co-pays or co-insurance for preventative care received during these visits, which helps people with cognitive impairment also manage comorbid conditions such as depression. In 2015 alone, [nearly 9 million people](#) received services through the Annual Wellness visit.ⁱⁱⁱ There are many advantages of a preventative, annual cognitive screening including:

- People with cognitive impairment can receive an accurate and timely diagnosis of dementia, if present, and begin planning for their future.
- Physicians can begin to implement a course of treatment, including recommending lifestyle changes that may improve quality of life.
- People and families managing dementia can use the diagnosis to seek home and community-based services and long-term care supports.
- Researchers relying on Medicare data will have a better picture of the pathway for dementia patients, due to earlier diagnosis.

National non-profit organizations such as The Gerontological Society of America and the Alzheimer's Association have recognized the Annual Wellness Visit as a critical tool to help reduce chronic under-diagnosis and improve early detection.^{iv}

Coordinating Care for Dually-Eligible Beneficiaries Under Medicare and Medicaid Through the Integrated Care Resource Center

The Integrated Care Resource Center^v grew out of ACA provisions requiring coordination between Medicare and Medicaid. The ICRC helps the states to coordinate medical care, behavioral health, and long-term services and supports for dually-eligible Medicare and Medicaid beneficiaries. This outreach aligns with the [National Alzheimer's Plan \(2013 Update\)](#) that recognized that the care coordination provisions of the ACA can reduce duplication of services, avoid errors, and improve overall health.^{vi}

Medicaid Expansion and Community First Choice

The ACA expanded the availability and eligibility of the Medicaid program, which a majority of states have adopted as of 2017.^{vii} Almost a quarter of adults with dementia (24%) living in the community are Medicaid beneficiaries,

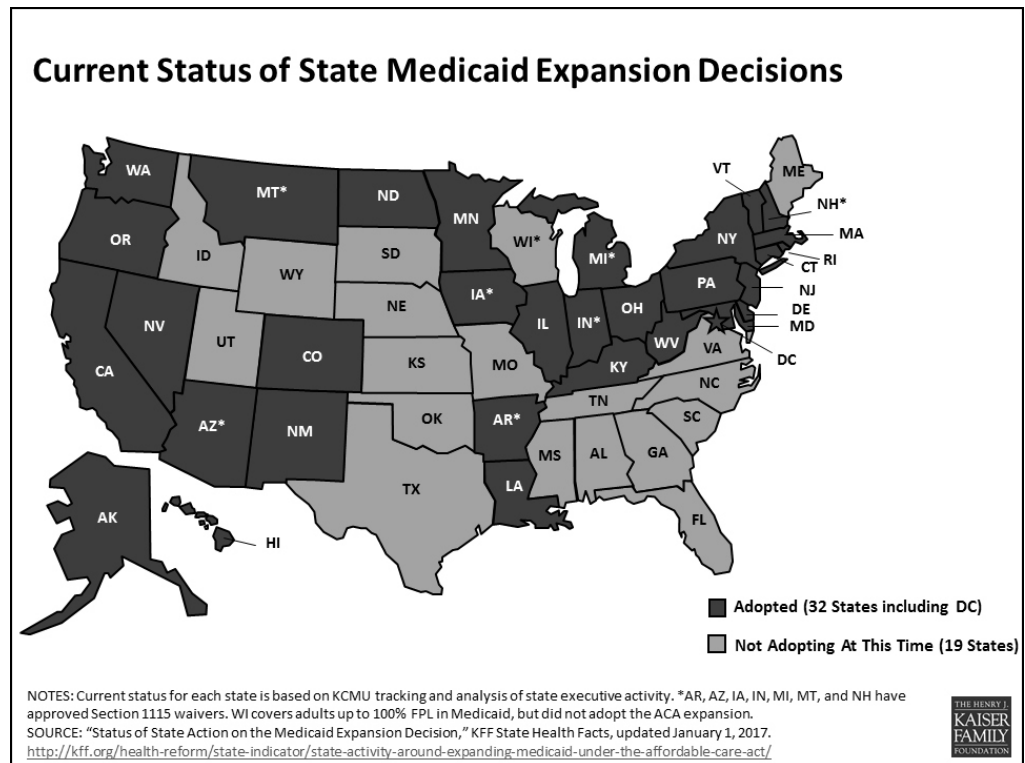


DID YOU KNOW?

The Medicare Annual Wellness Visit includes a multi-faceted Health Risk Assessment. When the physician assesses the cognitive health of the patient, they may also rely on input from family, friends, and other caregivers. This type of coordination reduces inefficiencies and is essential to person- and family-centered care.

Source
[CMS Guidance - The ABCs of the Annual Wellness Visit](#)

many of whom are living alone (45%), have fair or poor health (68%), and have three or more chronic conditions (90%).^{viii} Under the expansion, roughly 10.7 million Americans became eligible for health and long-term services.^{ix} For many, the expansion provided health care access to people with dementia and their unpaid, family caregivers for the first time and ensured access to long-term care.



The ACA's Medicaid reforms included the Community First Choice program, which allows states to provide community-based "attendant services and supports" to Medicaid beneficiaries.^x This program is key to keeping individuals with mild-to-moderate dementia independent and safe in their homes and communities, helping to delay costly institutionalization. Program participants include California, Maryland, Montana, Oregon, and Texas.

Reduced Out-of-Pocket Medication Costs for Beneficiaries in the Medicare Prescription Drug Plans Coverage Gap

Under the Medicare program, some beneficiaries on a prescription drug plan have a coverage gap, commonly called a "donut hole."^{xi} Individuals who have spent a certain capped amount on medications under their plans (\$3,700 in 2017) then must pay 100% of the cost of their medications until the costs reach a certain dollar limit. This policy put financial strain on many individuals with high-cost medications and multiple prescriptions as they entered the coverage gap. To reduce this burden, the ACA reduced the cost beneficiaries pay while in the coverage gap to approximately half of the drug's full retail



price (up to 40% for branded therapeutics and 51% for generics). Additional reductions in out-of-pocket costs will continue each year until 2020.

Health Insurance for Young Adult Caregivers

Over 10 million young adults are caring for a friend or relative, many of whom have cognitive impairment or dementia.^{xii} Under the ACA, parents may keep young adult children on their health insurance until age 26, providing indispensable support to those who are caring for an older adult. Many young adult caregivers would be unable to continue caregiving if they were required to seek traditional employment to secure employer-provided health benefits.

The Alzheimer's Disease Prevention Education and Outreach Program

The ACA established the Prevention and Public Health Fund, which supports public health programs to improve health outcomes and enhance care quality.^{xiii} The fund supports the Administration for Community Living's Alzheimer's Disease Prevention Education and Outreach program, also known as the Alzheimer's Disease Initiative (ADI). The ADI provides grants to states that offer specialized services to individuals with dementia and support stigma reduction campaigns along with public outreach to individuals with memory loss or early cognitive impairment.

Support for Dementia Research and Clinical Trial Participants

Health Insurance for Clinical Trial Participants

Currently, there is no proven way to prevent, slow, or cure dementia.^{xiv} Clinical trials are critically necessary to stop or treat dementia. The ACA protects individuals with dementia who want to participate in clinical trials and need health insurance.^{xv} The law prevents insurers from denying individual participation in an approved clinical trial "with respect to the treatment of cancer or another life-threatening disease or condition." It requires coverage of routine patient costs for items and services related to participation in the trial and prevents discrimination against the individual based on their participation in the trial. As many people living with dementia have other healthcare needs, these provisions allow them to contribute to critical research and still receive access to health care services.

Innovative Models of Care & Pilot Programs

Health policy experts have recognized that the complexity of caring for people with multiple chronic conditions can drive rising health care costs. Many people with dementia have [multiple co-morbidities](#)^{xvi} such as hypertension, chronic heart failure, or diabetes. Identifying new models of care coordination,

WHY IT MATTERS

- ❖ More than 5 million Americans have Alzheimer's disease or another form of dementia
- ❖ The annual cost to our economy exceeds \$200 billion

Sources

<https://www.cdc.gov/aging/aginginfo/alzheimers.htm>
<http://www.nejm.org/doi/full/10.1056/NEJMsa1204629>

COMPREHENSIVE CARE FOR PEOPLE WITH DEMENTIA

The UCLA Alzheimer's and Dementia Care Program developed a comprehensive care program to better integrate community-based organizations with formal health care providers. Program components include a dementia registry for patients and family caregivers, individualized dementia care plans (including assessment), and care management from a nurse practitioner. Preliminary data indicated that care plans should include referrals to support groups, a "safe return program," caregiver training, and information on medication management.

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



health care delivery, and payment have been shown to simplify the complexity of caring for these patients and, in turn, reduce costs.

The ACA created the [Center for Medicare and Medicaid Innovation](#)^{xvii} (CMMI), to develop innovative health care models and test them through pilot programs and grant funding. If successful, these models can be scaled to the Medicare or Medicaid program at large.^{xviii} New models under this center included:

- The [UCLA Alzheimer's and Dementia Care](#)^{xix} coordinated, family-centered program in California;
- The [Living Rite - A Disruptive Solution for Management of Chronic Care Disease](#)^{xx} in Rhode Island; and
- [Geriatric Emergency Department Innovations \(GEDI WISE\)](#)^{xxi} in Illinois, New Jersey, and New York.

CMMI has tested payment and delivery models that may improve care for people with dementia. For example, the [Independence at Home Demonstration \(IAH\)](#)^{xxii} project tested a physician and nurse practitioner payment model that offered coordinated home-based primary care with long-term services and support, including sub-group analysis of people with dementia. Such programs advance scalable innovative health care delivery models to improve care and lower costs.

Funding for Patient-Centered Research on Dementia

The ACA established the Patient-Centered Outcomes Research Institute (PCORI) under the existing PCOR Trust Fund, which provides 80% of the funding to the PCORI network. As a public-private partnership, PCORI funds patient-centered research including research and pilot programs on dementia. Ongoing research programs include [The National Alzheimer's & Dementia Patient and Caregiver-Power Research Network](#)^{xxiii} at the Mayo Clinic, behavioral interventions for people living with dementia, and statewide caregiver supports.^{xxiv}

Consumer Protections and Support for the Most Vulnerable and Their Family Caregivers

Protections for Pre-Existing Conditions, Essential Health Benefits, and the Assets of Spousal Caregivers Living in the Community

Under the ACA, insurance companies [cannot refuse coverage](#)^{xxv} based on a pre-existing condition. This provision allows people with early-onset dementia who do not yet qualify for Medicare to purchase health insurance to mitigate the cost of care. The ACA also protects ten [essential health benefits](#)^{xxvi} for health insurance enrollees in individual and small group markets. While details



DID YOU KNOW?

The International Psychogeriatric Association consensus-based definition of “agitation” notes that a person living with Alzheimer’s disease may exhibit excessive motor activity, verbal aggression, or even physical aggression because of emotional distress. It’s important for medical professionals, such as nursing home clinicians, to receive training so that they understand how to provide safe and effective care for someone who is experiencing agitation.

Source
<https://www.ipa-online.org/news-and-issues/defining-agitation>

of the benefits vary by state, in general, plans must offer preventative and wellness services including chronic disease management, ambulatory and emergency services, and access to prescription drugs, among other services.

For spouses caring for a loved one with advanced illnesses, Medicaid expansion strengthened protections against spousal impoverishment to include those caring for a loved one who receives home and community-based services.^{xxvii} These protections support better long-term care by protecting the health and income of unpaid family caregivers, who typically provide care for five years or more.^{xxviii}

Improved Care in Skilled Nursing Facilities

People with Alzheimer’s disease or another form of dementia represent over half of adults receiving nursing home care.^{xxix} The ACA created protections for nursing home residents, including transparency requirements, programs to prevent abuse and other crimes, and strengthened quality of care consumer reporting.^{xxx} The ACA requires dementia and abuse prevention training, because undertrained staff may misinterpret behavior of someone with dementia as aggression.^{xxxi} The ACA provides dementia training to facility staff to reduce misuse of antipsychotic medications to sedate or chemically restrain people living with this disease.

Issue Brief Recommendations

- **Ensure that federal law retains and strengthens each of the provisions identified above to support people living with dementia and their caregivers.**
- **Expand capacity for federal programs for people living with Alzheimer’s disease and other forms of dementia, as appropriate, to meet the growing needs of an aging population.**
- **Continue to address inefficiency, waste, and poor care quality through new models of health care delivery and payment for older adults facing dementia and other chronic diseases.**



About the LEAD Coalition

Leaders Engaged on Alzheimer's Disease (LEAD Coalition) is a diverse and growing national coalition of more than 90 member organizations committed to overcoming Alzheimer's disease and other forms of dementia. The coalition works collaboratively to focus the nation's attention on accelerating transformational progress in: (1) care and support to enrich the quality of life of those with dementia and their caregivers; (2) detection and diagnosis; and (3) research leading to prevention, effective treatment, and eventual cures.

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About This Brief

The LEAD Coalition staff, member organizations, and other national experts authored the brief. Please note that this brief does not represent the consensus of the LEAD Coalition or coalition member organizations.

Share feedback and questions by emailing info@leadcoalition.org.

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