ON THE ISSUES: HEALTH REFORM & DEMENTIA

As Congress and the Administration work to reduce health care costs and improve health outcomes for all Americans, including people with dementia and their families, policy makers and advocates should keep in mind the key provisions of the Patient Protection and Affordable Care Act of 2010 that support people with Alzheimer’s disease or another form of dementia.

In a Nutshell

The ACA provides vital support to people with cognitive impairment and their families through these provisions:

- **Medicare Annual Wellness Visit, with a cognitive assessment** to identify decline in brain function.
- **Protection for pre-existing conditions**, which supports adults with early-onset dementia and family caregivers.
- **Protections for essential health benefits**.
- **Innovative models of care**, which test new interventions for people with dementia and their caregivers.
- **Medicare-Medicaid care coordination**, which improves care for dually-eligible beneficiaries and reduces waste.
- **Medicaid expansion**, including Community First Choice and spousal impoverishment protections.
- **Funding for patient-centered research on dementia**, through PCORI and other quasi-governmental agencies.
- **New requirements for skilled nursing facilities**, such as increased transparency and quality of care goals.
- **Support for young adult caregivers**, through extended health insurance for adult children under age 26.

DID YOU KNOW?

- More than 5 million Americans have Alzheimer’s disease or another form of dementia
- The annual cost to our economy exceeds $200 billion
- By mid-century, total annual costs of care may be more than $1 trillion

Sources
- https://www.cdc.gov/aging/aginginfo/alzheimers.htm
Key Policies for People with Dementia & Their Families

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, if the patient has had the Part B benefit for longer than 12 months. 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 in older adults with cognitive impairment.

Protection for Pre-Existing Conditions
Under the ACA, insurance companies cannot refuse coverage 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. It also supports the family caregivers who are caring for someone with dementia and receive health insurance through the Marketplace.

Protection for Essential Health Benefits
In addition to protecting individuals from discrimination based on pre-existing conditions, the ACA protects ten essential health benefits for health insurance enrollees in individual and small group markets. While details 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. These benefits are critical to improving care for people with dementia and their family caregivers.

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
**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 such as hypertension, chronic heart failure, or diabetes. Identifying new models of care coordination, 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 a new division within CMS, the Center for Medicare and Medicaid Innovation (known as CMMI or the CMS Innovation Center), 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.

The CMS Innovation Center funded new models of dementia care, such as:

- The UCLA Alzheimer’s and Dementia Care coordinated, family-centered program in California;
- The Living Rite - A Disruptive Solution for Management of Chronic Care Disease in Rhode Island; and
- Geriatric Emergency Department Innovations (GEDI WISE) in Illinois, New Jersey, and New York.

In addition, the CMS Innovation Center has tested several payment and delivery models that may improve care for those with Alzheimer’s disease or other dementias. For example, the Independence at Home Demonstration (IAH) project tested a new payment model for physicians and nurse practitioners that offered coordinated home-based primary care with long-term services and supports. The pilot program included a sub-group analysis of people living with dementia. Programs like IAH offer insight into innovative health care delivery models can be scaled to lower costs and improve care.

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

The Integrated Care Resource Center grew out of ACA provisions requiring coordination between Medicare and Medicaid. The ICRC helps 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) which recognized that the care coordination provisions of the ACA can reduce duplication of services, avoid errors, and improve overall health.\textsuperscript{xv}

**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.\textsuperscript{xvi} Almost a quarter of adults with dementia (24%) living in the community are Medicaid beneficiaries, many of whom are living alone (45%), have fair or poor health (68%), and three or more chronic conditions (90%).\textsuperscript{xvii} For many, the expansion provided health care access to people with dementia and family caregivers for the first time and ensured access to medical and long-term care.

The ACA’s Medicaid reforms also included the newly established Community First Choice program, which allows states to provide community-based “attendant services and supports” to Medicaid beneficiaries.\textsuperscript{xviii} This program is key to keeping individuals with mild-to-moderate dementia in their homes and communities and helps to delay costly institutionalization. California, Maryland, Montana, Oregon, Texas are participating. In addition, Medicaid expansion strengthened protections against spousal impoverishment to include
those caring for a loved one who receives home and community-based services. These protections support better long-term care for beneficiaries.

**Funding for Patient-Centered Research on Dementia**

The ACA established the Patient-Centered Outcomes Research Institute (PCORI) under the 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 at the Mayo Clinic, behavioral interventions for people living with dementia, and statewide caregiver supports.

**Improved Care in Skilled Nursing Facilities**

Adults with Alzheimer’s disease or another form of dementia make up more than half of adults who are using nursing home care. The ACA created new protections for skilled nursing facility residents, including new transparency requirements, programs to prevent abuse and other crimes against residents, and additional reporting to consumers on quality of care. The ACA requires training on dementia and abuse prevention, because undertrained direct care workers may misinterpret the behavior of someone with dementia as aggression. The ACA provides dementia training to facility staff, including avoiding the misuse of antipsychotic medications to sedate or chemically restrain people who are living with this disease.

**Health Insurance for Young Adult Caregivers**

Over 10 million young adults ages 18 – 25 are caring for a friend or relative, and many are caring for parents or grandparents with cognitive impairment or dementia. Under current ACA provisions, parents may keep their 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.

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**DID YOU KNOW?**

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

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

• Ensure federal law retains and strengthens each of the provisions identified in this issue brief supporting people living with dementia and their families.

• Expand capacity for federal programs for people living with Alzheimer’s disease and other forms of dementia, as appropriate, to meet the growing need.

• 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 disease.

About This Brief

This paper was authored by LEAD Coalition Advocacy & Communications Director C. Grace Whiting, with input and review from the Executive Director Ian Kremer, LEAD Coalition member organizations, and other national experts. Please note that this brief does not necessarily represent consensus of the organizations within the coalition. Share feedback and questions by emailing info@leadcoalition.org.

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. Learn more at www.leadcoalition.org.

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15 See n. vii, above.

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