



## **Statement for Hearing on**

### **“Alzheimer’s Awareness: Barriers to Diagnosis, Treatment, and Care Coordination.”**

**Submitted to the  
Senate Finance Committee**

**November 20, 2019**

Alzheimer’s Disease is the most common form of dementia.<sup>1</sup> As of 2019, 5.8 million Americans are living with Alzheimer’s Disease, with this number projected to increase to 14 million by 2050.<sup>2</sup> Alzheimer’s Disease and other dementias cost the United States more than \$290 billion, with more than 16 million Americans providing unpaid care for this population.<sup>3</sup> With the increasing number of people and their families affected by Alzheimer’s Disease and the high costs associated with caring for this population, it is essential that we work to improve care by ensuring stable funding for patient care and maintaining an appropriate workforce. America’s Health Insurance Plans (AHIP)<sup>4</sup> and our member health insurance providers are committed to finding solutions to these issues, and we support the Committee’s focus on addressing Alzheimer’s awareness and their commitment to caring for the people living with this disease and their caregivers.

#### **Funding Care for those with Alzheimer’s Disease**

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<sup>1</sup> <https://www.cdc.gov/aging/aginginfo/alzheimers.htm>

<sup>2</sup> <https://www.alz.org/alzheimers-dementia/facts-figures>

<sup>3</sup> <https://www.alz.org/alzheimers-dementia/facts-figures>

<sup>4</sup> AHIP is the national association whose members provide coverage for health care and related services to millions of Americans every day. Through these offerings, we improve and protect the health and financial security of consumers, families, businesses, communities, and the nation. We are committed to market-based solutions and public-private partnerships that improve affordability, value, access, and well-being for consumers.

People struggling with Alzheimer’s Disease deserve high-quality care. The care they need can often be expensive and be required for several years. In fact, the total cost of care for someone with Alzheimer’s or other forms of dementia is estimated to be \$341, 850.<sup>5</sup> America needs real solutions to provide for these patients’ needs from diagnosis and treatment to long-term care, including funding for the long-term care services they require. Expanding access to long-term care insurance can provide this financial security and peace of mind. Solutions to make long-term care insurance coverage more available include:

- Launching a national educational campaign to help consumers understand both the need for and benefits of long-term care coverage.
- Providing tax incentives for employers to offer long-term care coverage to employees. Incentives may include:
  - Making long-term care coverage available through Internal Revenue Code (IRC) Section 125 cafeteria plans and Flexible Spending Arrangements (FSA);
  - Allowing tax-free premium payments for long-term care policies either from or within their 401(k)s, 403(b)s, IRAs, and other retirement plans; and
  - Permitting employees to make additional contributions to their Health Savings Accounts (HSA) to pay for long-term care premiums.
- Allowing patients to access long-term care insurance benefits that support healthy, independent living and aging in place before they are technically eligible.<sup>6</sup>
- Allowing for different types of financial protections against inflation for long-term care policies; this would encourage more innovation among long-term care insurers as they design new types of policies for consumers<sup>7</sup>.

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<sup>5</sup> <https://www.alz.org/media/Documents/2015FactsAndFigures.pdf>

<sup>6</sup> Currently, providing these types of benefits may cause LTC insurance policies to forfeit its tax qualified status. Issuance of legislation or regulatory guidance that allows for these benefits would help consumers remain healthy and independent longer.

<sup>7</sup> HIPAA and many states require LTCI policies to offer a benefit that automatically increases a policyholder’s benefit at an annual compounded rate of 5 percent. This inflation protection offer is expensive and discourages consumers from seeking protection altogether. Eliminating or revamping inflation protection would meet the diverse needs of consumers. Given that “one-size-fits-all” solutions do not work for everyone, it is important for consumers to have a variety of products and options from which to choose when evaluating their LTC protection needs.

Enacting these policies will offer individuals with Alzheimer and other forms of dementia, as well as others with long term care needs, a new pathway to independence and financial security, while ensuring the best use of taxpayer dollars that are spent on care.

### **The Role of Federal Programs in Funding Alzheimer’s Care**

**Medicare.** Medicare covers eligible services for individuals with Alzheimer's Disease or other dementias. Those services include cognitive assessments, home safety evaluations, planning for care, and hospital stays.<sup>8</sup> Medicare Part D also covers many prescription drugs for beneficiaries with Alzheimer’s Disease and other dementias.<sup>9</sup>

Starting with plan year 2019, CMS expanded the definition for primarily health-related supplemental benefits, permitting MA plans to offer benefits such as adult day care services, in-home support services, respite care, and home and bathroom safety devices and modifications.<sup>10</sup> Via these new flexibilities, MA plans are able to offer additional benefits to address unmet medical and social needs for these individuals.

The Bipartisan Budget Act of 2018 (Public Law No. 115-123) also included a provision that expanded the types of supplemental benefits that MA plans can offer to eligible chronically ill enrollees. These benefits are referred to as Special Supplemental Benefits for the Chronically Ill (SSBCI). The SSBCI do not have to be primarily health-related, but the item or service offered must have a “reasonable expectation of improving or maintaining the health or overall function of the chronically ill enrollee.”<sup>11</sup> Examples of benefits covered under the SSBCI criteria include food and produce deliveries, transportation for non-medical needs, social needs benefits, and general supports for living. These recent benefit flexibilities allow MA plans to offer important, valuable services.

As a result, health insurance providers are offering services specifically tailored to those with Alzheimer’s Disease. For example, Tufts Health Plan in Massachusetts is working with the local

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<sup>8</sup> <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/Downloads/Medicare-and-Medicaid-Benefits-for-People-with-Dementia.pdf>

<sup>9</sup> <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/Downloads/Medicare-and-Medicaid-Benefits-for-People-with-Dementia.pdf>

<sup>10</sup> CMS HPMS Memo. Medicare Advantage Organizations and Section 1876 Cost Contract Plans. April 27, 2018.

<sup>11</sup> CMS HPMS Memo. Implementing Supplemental Benefits for Chronically Ill Enrollees. April 24, 2018.

chapter of the Alzheimer's Association to help those with Alzheimer's Disease and their caregivers.<sup>12</sup> Within the program, a Tufts Dementia Care Consultant directly connects patients to resources at the Alzheimer's Association. Resources include: referrals to community resources, care planning, educational materials, answers to disease-related questions, information on support groups, and more.<sup>13</sup> This model has seen success and is now being replicated in other parts of the country.

Aetna's Resources for Living Program also aims to fill the gaps in caring for those with Alzheimer's Disease by providing access to at-home services such as cleaning and cooking, caregiver support services such as help with childcare and respite care, and social activities such as transportation and classes for skills and interests.<sup>14</sup>

**Medicaid.** In addition to Medicare, Medicaid covers a broad range of services for people with Alzheimer's Disease and other dementias. In fact, 27% of people with Alzheimer's Disease or other dementias who have Medicare also have Medicaid.<sup>15</sup> For people with both Medicare and Medicaid, Medicaid coverage wraps around their Medicare benefits, covering Medicare cost sharing and long-term services and support (LTSS) like nursing facility and home- and community-based services. For people covered only by Medicaid, Medicaid covers important services like assessments, physician and diagnostic services, LTSS, care management, hospital stays, and prescription drugs.

Services health insurance providers serving Medicaid eligible members with Alzheimer's Disease include: community-based services such as therapeutic care, personal care, meals, speech therapy, and occupational therapy.<sup>16</sup> In some cases, Medicaid also covers respite care and supportive services for family members who provide unpaid care for relatives with Alzheimer's Disease who are enrolled in Medicaid. Respite care allows family caregivers time to attend to their own lives and personal affairs, helping to reduce caregiver "burn-out."

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<sup>12</sup> <https://www.ahip.org/board-spotlight-tom-croswell-president-ceo-of-tufts-health-plan/>

<sup>13</sup> <https://www.tuftsmedicarepreferred.org/members/caring-loved-one/alzheimer%E2%80%99s-association-partnership-tufts-health-plan-members>

<sup>14</sup> <https://www.aetnamedicare.com/en/live-well/resources-for-living.html>

<sup>15</sup> <https://www.alz.org/media/documents/alzheimers-facts-and-figures-2019-r.pdf>

<sup>16</sup> <https://www.molinahealthcare.com/members/ca/en-US/mem/medicaid/medical/coverd/lts/Pages/cbas.aspx>

One example of the kinds of supports provided by Medicaid health insurance providers to members and their caregivers is Centene's Caregiving Collaborations Program which provides tools for informal caregivers such as: information on balancing needs; a Caregiver Journal to stay organized and track daily routines; a Caregiver Portal for authorized caregivers to view the member's care plan and other information; resources on early symptoms and managing illnesses; and other resources to increase collaboration between caregivers and Centene's medical teams.<sup>17</sup>

Commonwealth Care Alliance (CCA) is another example; CCA provides members of their Senior Care Options plan personalized care designed to expand as the member's needs increase over the course of their disease. Members receive ongoing health and functional assessments, assistance with health care appointments and personalized comprehensive care plans which include individualized goals identified by the member and their caregivers.

CCA is able to wrap long-term services and supports around the member and their family consistent with the member's needs and goals; examples of those services include home making, tech enabled supports such as a "medication box" for medication management, home delivered meals, personal care services, Adult Family Care, Adult Day Health and home based health care delivered by a CCA Nurse Practitioner who collaborates with the member's primary care provider and other health care providers. These services that health plans provide their members are crucial to ensuring coordinated, effective care for those with Alzheimer's Disease and other dementias.

### **Addressing the Caregiver Shortage**

Research finds that 83% of help provided to older adults in the U.S. comes from family members, friends, and other unpaid caregivers.<sup>18</sup> In 2017, unpaid caregivers contributed 18.4 billion hours – valued at \$232 billion - in care to those with Alzheimer's Disease and other dementias.<sup>19</sup> As our population ages, the age of the individuals willing and able to provide uncompensated care is also increasing – putting this important part of the safety net at risk. A 2015 study found that the average age of unpaid caregivers was 49.2, and among them 34% were

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<sup>17</sup> <https://www.pahealthwellness.com/members/ltss/caregiver-resources/organizational-tools.html>

<sup>18</sup> <https://www.alzheimers.net/5-09-16-dementia-financial-costs-take-toll-on-families/>

<sup>19</sup> <https://www.alzheimers.net/5-09-16-dementia-financial-costs-take-toll-on-families/>

over the age of 65.<sup>20</sup> A 2013 study by AARP found that the nation would see a dramatic decline over the next 20 years in the caregiver support ratio: from 7 potential caregivers for every person in the high-risk years of 80-plus in 2010, to 4 for every person 80-plus in 2030.<sup>21</sup>

The United States must take steps to ensure a robust paid workforce to provide care for seniors. According to the Bureau of Labor and Statistics, approximately 4.5 million people are part of the direct care workforce, including personal care attendants, home health aides, and nursing assistants. The direct care workforce is expected to grow by 41% between 2016 and 2026.<sup>22</sup> Individuals who take on the job of direct care are tasked with providing some of the most important care needed by patients with complex medical needs. Direct caregivers assist patients with bathing, toileting, meal preparation, eating, and a variety of other services that are highly personal and essential to a patient's well-being.

Despite the importance of the work, compensation for these workers is low. From 2008 to 2018, these workers experienced little to no pay increases.<sup>23</sup> Caregivers often receive few of the benefits that other employers offer, such as paid leave. This combination of low pay and few or no benefits leads to low job satisfaction, high rates of caregiver burnout, and, consequently, high rates of turnover.

Understanding the physical and emotional toll caregiving can take, health plans are giving caregivers access to free nurse help-lines; [comprehensive educational programs](#) including information on enrollment timelines, plan benefits, differences between plan types, etc.; [caregiving overviews](#); incentives for preventive care services, and access to mental health services.<sup>24</sup> Health plans are committed to reducing the burden on caregivers and ensuring caregivers get the information and support they need.

In the coming years, aging Americans who require assistance, including those with Alzheimer's Disease and other forms of dementia, will continue to face even more significant challenges in

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<sup>20</sup> <https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>

<sup>21</sup> [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/lrc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-lrc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/lrc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-lrc.pdf)

<sup>22</sup> <https://www.americanprogress.org/issues/healthcare/reports/2019/04/10/468290/state-options-making-wise-investments-direct-care-workforce/>

<sup>23</sup> <https://phinational.org/policy-research/workforce-data-center/#tab=National+Data&natvar=Wage+Trends>

<sup>24</sup> "Let's Recognize the Importance of Family Caregivers." AHIP Blog Post. Published: November 11, 2019.

identifying and retaining caregivers. The decline in the availability of family caregivers coupled with the challenges of the paid workforce will place a significant burden on private financial resources, and stress publicly financed programs.

## **Conclusion**

AHIP thanks the Committee for focusing on the important issue of caring for Americans with Alzheimer's Disease. As our population continues to age rapidly, we must urgently address funding for long-term services and supports and ensuring an adequate caregiver workforce. We look forward to working with the Committee on solutions to ensure efficient and effective care for this population moving forward.