Alzheimer’s imposes a huge financial burden on families.

- The total lifetime cost of caring for someone with dementia, including the value of the care provided by family and friends, is about $350,000 — more than double the cost for someone without dementia.

- In the last five years of life, out-of-pocket costs represent a substantially larger proportion of total wealth for those with dementia than for people without dementia (32% versus 11%).

When incurring these costs, most individuals with Alzheimer’s will spend down their income and assets and eventually qualify for Medicaid.

- Among all seniors with dementia, 27% have both Medicare and Medicaid (“dual-eligible seniors”), compared with just 11% of seniors without dementia.

- Of all dual-eligible seniors, 23% have been diagnosed with dementia — and 58% of them have some cognitive or mental impairment.

- The result is that average per-person Medicaid spending for seniors with dementia is 23 times greater than average per-person Medicaid spending across all seniors without dementia.

- In total, caring for people with Alzheimer’s will cost Medicaid an estimated $51 billion in 2020, with those costs projected to reach $194 billion (in today’s dollars) in 2050.
Individuals with Alzheimer’s and other dementias have unique care needs.

- More than 95% of people with Alzheimer’s have at least one other chronic condition, and cognitive impairment often complicates the management and treatment of those conditions.

- While living at home, people with Alzheimer’s experience a wide range of needs, including home modifications, transportation, and financial management.

- Nearly 80% of older adults with dementia need help with a daily personal care activity such as bathing, dressing, grooming, eating, and getting to and from the toilet.

- The need for this care can last for years. It is not uncommon for a person to live for 20 years with Alzheimer’s.

- The intensity and duration of dementia caregiving places a physical, emotional, and financial toll on family caregivers that is greater than for caregivers of most other conditions.

Most state Medicaid programs, however, do not sufficiently meet the needs of individuals with Alzheimer’s.

- Individuals with Alzheimer’s who are on Medicaid often do not receive the services that would specifically address their auxiliary care needs.

- Services such as behavioral supports, financial services, transportation, and hospice care are not always available to Medicaid beneficiaries with Alzheimer’s.

- In addition, in dealing with a complex set of health conditions — exacerbated by the dementia — dual eligibles with Alzheimer’s and their families are often left to fend for themselves in a complicated system.

What Can States Do?

- Adopt a core set of dementia-specific home and community-based services under Medicaid.

- Establish coordinated care models, such as a dementia case manager program, that partner the state’s Medicaid program with health care organizations.

States need to ensure that individuals with Alzheimer’s and other dementias are effectively served by the Medicaid program.

- States have significant flexibility to modernize their Medicaid programs to best serve people with Alzheimer’s.

- A core set of dementia-specific home and community-based services should be covered. They should be guided by the principles of person-centered care and dementia competency, and should include:
  - Adult day services
  - Assistive technology
  - Behavioral supports
  - Caregiver supports
  - Home, environmental, and vehicle modifications
  - Financial services
  - Personal care
  - Transportation

- Establishing a dementia case manager program and implementing specialized training for case managers will better serve people with dementia by improving service coordination and the quality of care. It also has the potential to reduce Medicaid spending.