Alzheimer’s is one of the most expensive diseases in America.

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

- In 2021, the cost of care is projected to total $355 billion, including $76 billion in out-of-pocket costs to those with dementia. Out-of-pocket costs are expected to increase 228% by 2050 to $250 billion (in today’s dollars).

- 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 those without dementia (32% versus 11%).

The duration of Alzheimer’s disease, combined with the high cost of care, means that most people with Alzheimer’s will ultimately need help from Medicaid.

- Among seniors with Alzheimer’s and other dementias, 27% have both Medicare and Medicaid (“dual-eligible seniors”), compared with just 11% of seniors without Alzheimer’s.

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

To qualify for Medicaid coverage of long-term services and supports (LTSS), seniors must meet both financial and functional eligibility criteria.

- Financial eligibility refers to the maximum amount of income and assets a senior can have in order to receive Medicaid benefits.

- Generally, states use Supplemental Security Income (SSI) eligibility limits to determine Medicaid financial eligibility — but many states are either more generous or more restrictive than SSI limits.

- Functional eligibility refers to a demonstrated need for assistance with activities of daily living (ADLs), such as bathing and dressing, and instrumental activities of daily living (IADLs), such as shopping and cooking.

- In assessing functional eligibility, states determine their own standards and tools.
Financial eligibility requirements can impose an undue burden on individuals with Alzheimer’s and their spouses.

- The strict income and asset limits on qualifying for Medicaid LTSS mean that older adults are only eligible if they have low incomes or have already spent down their savings and other assets. By this time, home care may no longer be an option, requiring Medicaid to cover more expensive nursing home care.

- In determining eligibility, Medicaid considers a couple’s joint assets, not just the income of the individual applying. But, spouses caring for someone with dementia may need to live years or decades on their savings even after the individual with dementia has died.

- Federal rules requiring spousal impoverishment protections for home and community-based services under Medicaid — where a spouse is able to retain some income, assets, and home equity — can expire unless Congress extends this provision.

Most state-established functional assessments for Medicaid HCBS do not recognize the unique challenges caused by Alzheimer’s.

- Medicaid functional assessments often do not weigh cognitive impairments at all or weigh them lower than physical impairments, even if they produce virtually the same level of functional difficulty. This focus on physical capabilities potentially excludes people with dementia, which delays their access to care and support.

- Functional eligibility criteria often do not explicitly address issues related to supervision and monitoring of behavioral symptoms or decision-making that results from impaired judgment.

What Can States Do?

- Set functional eligibility criteria to include and properly weigh cognitive impairment issues, particularly with regard to prompting, monitoring, and supervision of daily activities.

- Require dementia-specific training for anyone who performs assessments that determine functional eligibility.

- Set the income, asset, and home equity limits at the federal maximum and extend spousal impoverishment protections to those receiving home and community-based care.

- Elect the Medicaid “209(b) option,” which allows states to provide coverage to individuals whose income exceeds federal Supplemental Security Income (SSI) limits but is less than the federal poverty line.

- Adopt the “special income rule” for people who require long-term services and supports, thus allowing Medicaid eligibility for those earning up to 300% of SSI limits.

States have flexibility under Medicaid to establish eligibility requirements that better meet the circumstances of those living with Alzheimer’s.

- In determining functional eligibility, states have the authority to set their own standards and rules, and states determine what tools will be used in assessing function.

- In addition, several federally-approved options are available to states to adjust their financial eligibility rules, including extending spousal impoverishment protections to those receiving HCBS and increasing the income limits up to 300% of the SSI limit for those who need LTSS.