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December 13, 2019

Mark Ghaly, MD, MPH  
Secretary, California Health and Human Services Agency  
1600 Ninth Street, Suite 460  
Sacramento, CA 95814

Dear Secretary Ghaly:

On behalf of the 2.3 million Californians living with or supporting loved ones with dementia, the Alzheimer's Association is eager to comment on the Master Plan For Aging process now underway. These comments supplement the outstanding work of the stakeholder advisory committee, public meetings held throughout the state and the workgroup process.

We are entering the decade of dementia. Between 2020 – 2030, California's population impacted by Alzheimer's and all dementias will soar 64 percent. We commend the Newsom Administration for multiple, concurrent efforts to plan and prepare for this historic demographic shift. With this Master Plan, the Governor's Alzheimer's Task Force and CalAIM, our state has the opportunity to lead the nation as a 21<sup>st</sup> century model for aging in America.

**The Alzheimer's Association priorities are as follows:**

- 1. Increase opportunities for Californians with Alzheimer's to receive a diagnosis at the earliest signs of cognitive impairment**
- 2. Improve the network of care so that persons with dementia and their care partners can easily access local services and supports**
- 3. Ensure that all Californians have access to quality care through public investment that helps families with the high financial and emotional cost of Alzheimer's**

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The priorities outlined above are progressive. First, all Californians must access a timely and accurate medical diagnosis. Currently, just 45 percent have the benefit of a comprehensive assessment and documented diagnosis. Within communities of color, the outcomes are far worse. Without this critical information, the majority of Californians are adrift in a complex health/long-term care delivery system. The lack of timely, accurate diagnosis precludes persons from accessing care planning and care coordination. In fact, less than 1 percent of Medicare beneficiaries have been offered the covered dementia care planning benefit. Improving screening, detection, diagnosis, documentation and care planning requires a multi-pronged strategy. The Alzheimer's Association urges strong consideration of the following:

- **Launch a comprehensive, statewide, culturally competent public education campaign.** Existing examples abound, including the recently released bi-lingual Ad Council “Our Stories” campaign emphasizing communication within families about changes in behavior. Additionally, the Alzheimer's Association offers an evidence-informed campaign focused on the early warn signs of the disease. Other states, including Wisconsin, have tailored campaigns to their residents.
- **Build public health infrastructure in support of risk reduction and early intervention.** The \$5 million in state General Fund dollars approved by Governor Newsom and the Legislature enables six pilot counties to test new local models. Grant awards will be announced in February 2020. With federal funding for the BOLD Act expected, California is exceptionally well positioned to serve as a nationwide Center of Excellence for the U.S. Centers for Disease Control's Healthy Brain Initiative. As we enlarge our thinking about aging beyond Medi-Cal, California's public health infrastructure – in 58 counties and three cities, is an untapped resource for planning.
- **Equip primary care physicians with tools and training to deliver timely and accurate diagnoses.** The majority of our state is a “neurology desert.” Alzheimer's expertise is highly concentrated in urban, academic centers. We need to accelerate efforts to prepare community-practicing primary care physicians with evidence-based tools, including the California Department of Public Health's “Assessing Cognitive Complaints Toolkit” and the 2017 Alzheimer's Clinical Care Guideline. Learnings from Cal MediConnect should be adopted in CalAIM, and applied broadly to managed care plans beyond Medi-Cal.

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Once an individual overcomes systemic barriers to receive a timely and accurate diagnosis – typically enduring symptoms for years without answers, the quest for services and supports begins. The Alzheimer's Association has offices in 21 local California communities, witnessing wide variations between state programs and huge gaps in services in both urban and rural areas. To overcome these deficits, we advocate for network adequacy as demonstrated by:

- **Investment in a comprehensive, standardized, statewide Information and Assistance platform to aid consumers in all areas with current, reliable, culturally competent resources.** The individuals and families we serve don't know where to start, who to trust or how to access basic information. The resources they need on the ground aren't provided by Medicare or their family physician or health plan. And the population's needs are progressive, episodic and ongoing, necessitating a "one-stop" or "No Wrong Door" approach as consumers navigate the system over many years' time. The Alzheimer's Association is a strong partner to state and local efforts with our 24/7 Helpline and robust community resource finder in collaboration with AARP. Yet, many local entities are unaware or don't refer out to private, nonprofit organizations, denying free resources, e.g. care consultations, support groups, caregiver education, to clients in need, thereby placing more burden on state services.
- **Expand the network of available and accessible direct services and supports.** In many parts of the state, Californians living with Alzheimer's and their families – especially those who don't qualify for Medi-Cal, have no local supports. For example, 23 counties do not have a single Community Based Adult Services (CBAS) site offering adult day health care. Statewide, only 34 social day programs focused on Alzheimer's exist, down from 42 a decade ago. The Medi-Cal Assisted Living Waiver is capped at approximately 5,000 slots and unavailable to beneficiaries in 43 counties. Even the Area Agency on Aging (AAA) and Caregiver Resource Center (CRC) networks are limited to multi-county regions. Financial and regulatory incentives are needed to expand offerings statewide, including new models that rely on technology enhancement to deliver services remotely. The pending California Health Interview Survey (CHIS) on LTSS will provide much-needed data on utilization, gaps and need at the community level.
- **Examine barriers to care in the setting of choice.** For persons with Alzheimer's and all dementias, residential care is a preferred setting to skilled nursing. Yet, Medicare doesn't cover the cost of assisted living/board and care, and Medi-Cal provides limited coverage to only a small percentage of residents. California's regulatory framework needs to integrate and embrace persons with dementia rather than drive eviction or transfer to higher levels of care. Thoughtful work is underway – and needs to continue – with the Department of Social Services on the critical topics of wandering, medication management, behaviors, use of psychotropic/antipsychotic medications,

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hospice/palliative care and other common occurrences that precipitate high volume 9-1-1 calls, emergency room visits, hospital admissions and skilled nursing placements.

- **Integrate mental and behavioral health for older adults.** The safety net for seniors in need of crisis mental and behavioral health services is virtually non-existent. The lack of community-based interventions overburdens first responders and hospitals. In fact, persons with Alzheimer's in California visited emergency rooms nearly one million times in 2015, averaging 1.5 visits annually per person. Mental and behavioral health needs drive many ER visits, often exacerbating the presenting condition with the trauma of a hospital stay and discharge. Oftentimes, it is the overburdened and overwhelmed family caregiver seeking support. We encourage the elevation of efforts already underway by the Agency's Alzheimer's Disease Advisory Committee, the County Welfare Directors Association and the California Commission on Aging.

Finally, once a diagnosis is documented, a care plan is in place and community options are identified, California families face crushing financial costs that exhaust personal resources, drain retirement savings, deplete home equity, and lead to Medicaid eligibility and impoverishment. The average lifetime cost of Alzheimer's – the most expensive disease in America, is nearly \$350,000 per person. This year, Medicare and Medicaid combined will spend \$195 billion on beneficiaries with Alzheimer's, more than heart disease and cancer.

- The Alzheimer's Association is proud to partner with the California Aging and Disability Alliance (CADA) to identify a long-term, financial solution to help all California families living with acute, chronic and disabling conditions. We strongly recommend pursuit of a public long-term services and supports benefit that is person-centered, allowing Californians to access the help they need, when they need it, to maximize independence, promote choice, and enhance dignity. It is paramount that any public benefit include cognitive impairment as a qualifying condition for eligibility. Early investments in CHIS data and an actuarial study will provide the data needed to proceed with the Governor, Legislature and voters.

Lastly, each of the aforementioned recommendations necessitate a sufficient supply and adequately trained workforce. Alzheimer's disease is labor intensive. Whether the care is provided by unpaid family members, paid family members or a wide range of job types from unlicensed home care aides to specialty neurologists, the need for training is essential. Alzheimer's is not normal aging. Evidence strongly suggests that education on the disease process improves outcomes. The Alzheimer's Association is committed to working with our community colleges, California State University and University of California systems to prepare the workforce for an aging population. Further, we look forward to collaborating with the

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Office of Statewide Health Planning and Development and state licensing boards to build dementia capacity and competency among health professionals.

Thank you for the opportunity to provide detailed comment and recommendations at this critical juncture in the Master Plan For Aging process. Should you or your team have questions or require additional information, please reach out to our California Government Affairs Director, Jared Giarrusso ([jagiarrusso@alz.org](mailto:jagiarrusso@alz.org)) at 916-447-2731 or myself.

Sincerely,

*Susan DeMarois*

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California Policy Director

Cc:

Sonia Angell, MD, MPH, Director, California Department of Public Health

Bob David, Director, Office of Statewide Health Planning and Development

Richard Figueroa, acting Director, Department of Health Care Services

Kimberly Johnson, Director, California Department of Social Services

Kim McCoy Wade, Director, California Department of Aging