California Health and Human Services Agency Secretary’s Alzheimer’s Disease and Related Disorders Advisory Committee

Maximizing the strengths and addressing the progressive needs of older Californians living with

memory loss, cognitive impairment, Alzheimer’s and dementia

***Planning for California’s Future***

***(November 2019)***

Alzheimer’s is a degenerative brain disease and the most common form of dementia. Until researchers discover the cause, cure or prevention of Alzheimer’s, it remains fatal, ranking as the second leading cause of death in California.

The symptoms of Alzheimer's disease worsen over time, although the rate at which the disease progresses varies. On average, a person with Alzheimer's lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors.

Alzheimer’s is not static. Because the disease is progressive, a person’s needs change over time. The committee recommends a life course perspective instead of a “moment in time” view. To guide our recommendations, we adopted six principles:

1. Person and Family-Centered Focus. As California plans for a future system of care intended to meet the needs of a growing population, we urge person and family-centered planning to guide the process. We want to seek opportunities for individuals with Alzheimer’s and all dementias to fully participate in decision making, including supported decision making, and exercise choice to the maximum extent possible.
2. Consistency. California should strive for a foundational system that supports high-quality, consistent, predictable and reliable services in all 58 counties.
3. Accessibility. Programs and services should be well known to the public and offered/delivered in a way that most consumers can readily access by phone, web or in person.
4. Sufficiency. The supply of home and community-based services throughout the state is inadequate, driving premature placement or prolonging institutional stays at high personal and public cost. Focused attention and new resources are needed to increase the availability of affordable Long-Term Services and Supports (LTSS) options to meet diverse needs.
5. Meet Diverse Needs and Promote Inclusion.Service systems must be responsive and available to individuals representing California’s vast language, culture, geographic and economic diversity, including focused attention on those who live alone.
6. Strategic Investment.Anticipating fiscal pressures due to population growth and increased demand for services, look to evidence-based/evidence-derived programs that emphasize prevention and risk reduction to mitigate against institutional costs.

For decades, California has led the nation on multiple fronts, be it consumer-directed IHSS, California Alzheimer’s Disease Centers, Alzheimer’s Day Care Resource Centers, Caregiver Resource Centers, Regional Centers, Independent Living Centers and Medicaid expansion. Our state can model, once again, how to plan and prepare for an aging population at high risk of Alzheimer’s and other disabling conditions. We have the opportunity to elevate and replicate best practices into a statewide standard of care. The programs, services, models – and lengthy reports, already exist. The grand challenge is creating a comprehensive system that anticipates and responds to consumer needs. The pieces exist; it’s time for leadership, decisions and action!

| **The progressive needs of older Californians living with memory loss, cognitive impairment, Alzheimer’s and dementia** | | |
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| Information, Assistance, Support and Referral | Care Planning, Care Coordination and Disease Management | Medical and Health Services |
| Access to resources  Accurate information  Advance Care Planning  Anticipatory Guidance  Caregiver education  Counseling  Follow-up  Health education  Initial point of contact  Knowledgeable personnel  Online, on-demand resources (24/7 for caregivers and out of area or out of state support)  Peer-to-Peer support  Prompting  Proximity – local connections  Support groups  Tools & tips  Triage  Warm hand-off | Abuse and neglect prevention  ADL/Functional Assessment  Advance Care Planning  Advocacy  Care Consultation  Care Coordination  Care Plan  Caregiver education  Case Management  Comprehensive Assessment  Direct Referrals  Health education  Housing  Initial Assessment  Legal Assistance  Person-centered planning  Risk Assessment  Safety assessment  Treatment Plan  Transportation | Abuse and neglect prevention  Advance care planning  Chronic disease management  Driving  Early detection  Health education  Hospice care  Lifestyle modifications  Medicare annual wellness visit  Medicare care planning benefit  Medication management  Mental and behavioral health  Palliative care  Participation in research  Screening  Timely and accurate diagnosis |
| Workforce | Workforce | Workforce |
| Attorneys  Community Health Workers  Family Caregivers  Gerontologists  MSWs/MFTs  Promotores  Psychologists | Attorneys  Certified Nurse Aides  Dementia Care Managers  Family Caregivers  Gerontologists  Licensed Vocational Nurses  Marriage and Family Therapists  Nurse Practitioners  Physician Assistants  Psychologists  Public Health professionals  Registered Nurses  Social workers | Certified Nurse Aides  Family Caregivers  Geriatricians  Home care  Home health  Licensed Clinical Social Workers  Licensed Vocational Nurses  Marriage and Family Therapists  Neurologists  Nurse practitioners  Pharmacists  Physician Assistants  Primary Care doctors  Psychologists  Psychiatrists  Registered nurses  Specialty physicians |
| Best Practices | Best Practices | Best Practices |
| 2-1-1 in select areas  Aging and Disability Resource Centers  Alzheimer’s Association 24/7 Helpline  Area Agencies on Aging  Caregiver Resource Centers  Disability Rights California  Independent Living Centers  Patient and caregiver interventions  Regional Centers | Alzheimer’s Day Care Resource Centers  Care consultations  Caregiver education (Savvy Caregiver)  Community-Based Adult Services  MSSP/Linkages  PACE  UCSF Dementia Ecosystem | 2017 Alzheimer’s Clinical Guideline  Assessing Cognitive Complaints Toolkit California Alzheimer’s Disease Centers  Cal MediConnect Dementia project  CDC Healthy Brain Initiative  Residential Care Facilities for the Elderly  Select Kaiser Memory Clinics  Skilled Nursing Facilities  UCLA Alzheimer’s Demonstration |

Sources:

* California State Plan for Alzheimer’s Disease: 2011- 2021 Action Plan
* California Task Force on Family Caregiving: 2018 Final Report
* California Future Health Workforce Commission final report
* National Alzheimer’s Project Act (NAPA)