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 resourcesAccurate informationAdvance Care PlanningAnticipatory GuidanceCaregiver educationCounselingFollow-upHealth educationInitial point of contactKnowledgeable personnelOnline, on-demand resources (24/7 for caregivers and out of area or out of state support)Peer-to-Peer supportPromptingProximity – local connectionsSupport groupsTools & tipsTriageWarm hand-off | Abuse and neglect preventionADL/Functional AssessmentAdvance Care PlanningAdvocacyCare ConsultationCare CoordinationCare PlanCaregiver educationCase ManagementComprehensive AssessmentDirect ReferralsHealth educationHousingInitial AssessmentLegal AssistancePerson-centered planningRisk AssessmentSafety assessmentTreatment PlanTransportation | Abuse and neglect preventionAdvance care planningChronic disease managementDrivingEarly detectionHealth educationHospice careLifestyle modificationsMedicare annual wellness visitMedicare care planning benefitMedication managementMental and behavioral healthPalliative careParticipation in researchScreeningTimely and accurate diagnosis |
| Workforce | Workforce | Workforce |
| AttorneysCommunity Health WorkersFamily CaregiversGerontologistsMSWs/MFTsPromotoresPsychologists | AttorneysCertified Nurse AidesDementia Care ManagersFamily CaregiversGerontologistsLicensed Vocational NursesMarriage and Family TherapistsNurse PractitionersPhysician AssistantsPsychologistsPublic Health professionalsRegistered NursesSocial workers | Certified Nurse AidesFamily CaregiversGeriatriciansHome careHome healthLicensed Clinical Social WorkersLicensed Vocational NursesMarriage and Family TherapistsNeurologistsNurse practitionersPharmacistsPhysician AssistantsPrimary Care doctorsPsychologistsPsychiatristsRegistered nursesSpecialty physicians  |
| Best Practices | Best Practices | Best Practices |
| 2-1-1 in select areasAging and Disability Resource CentersAlzheimer’s Association 24/7 HelplineArea Agencies on AgingCaregiver Resource CentersDisability Rights CaliforniaIndependent Living CentersPatient and caregiver interventionsRegional Centers | Alzheimer’s Day Care Resource CentersCare consultationsCaregiver education (Savvy Caregiver)Community-Based Adult ServicesMSSP/LinkagesPACEUCSF Dementia Ecosystem | 2017 Alzheimer’s Clinical GuidelineAssessing Cognitive Complaints Toolkit California Alzheimer’s Disease CentersCal MediConnect Dementia projectCDC Healthy Brain InitiativeResidential Care Facilities for the ElderlySelect Kaiser Memory ClinicsSkilled Nursing FacilitiesUCLA 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)