

## Supporting Diverse Family Caregivers: Spotlight on Alzheimer's Los Angeles

For the nearly one in four older adults dually eligible for Medicare and Medicaid with Alzheimer's disease or related dementia (ADRD),<sup>1</sup> family caregivers provide significant physical, emotional, and financial support. The level of support is substantial; each year, family caregivers provide an estimated \$470 billion in unpaid help.<sup>2</sup> To meet the needs of family caregivers, providers and health plans may benefit from strategies for supporting caregivers through services such as respite care, counseling, and training and education.

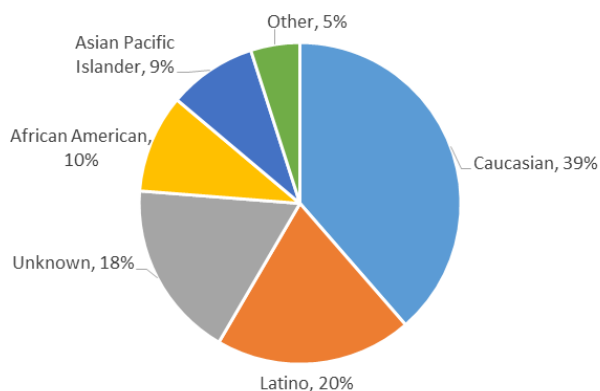
While many caregivers come from diverse cultural and linguistic backgrounds, health plans report challenges providing supports that meet the cultural needs and preferences of family caregivers from diverse backgrounds.<sup>3</sup> This Spotlight, showcasing Alzheimer's Los Angeles, is part of a series highlighting innovative programs supporting diverse family caregivers.

**Alzheimer's Los Angeles** has supported individuals with Alzheimer's disease and their family caregivers in the Los Angeles area for over 35 years. Alzheimer's Los Angeles provides caregiver education, advocacy, financial support to increase research on Alzheimer's disease, and training for health care professionals. Alzheimer's Los Angeles has also partnered with Medicare-Medicaid Plans in California to outreach to caregivers of individuals dually eligible for Medicare and Medicaid (see [Partnerships with Health Plans](#) for more details).

### Target Population

Alzheimer's Los Angeles' efforts supporting diverse family caregivers began in 1989 through partnerships with organizations serving the Latino community. In 1991, they began a project, known as El Portal, to improve care for individuals with dementia and their families in a primarily Latino area of Los Angeles through support groups, workshops, bilingual care management services, and other services. They have since expanded their efforts to reach African American and Asian Pacific Islander communities in Los Angeles, identifying similar needs in these communities.

2017 Alzheimer's Los Angeles Consumers by Ethnicity



<sup>1</sup> The Medicare Payment Advisory Committee (MedPAC) and the Medicaid and CHIP Payment and Access Commission (MACPAC). (January 2018). *Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid*. Retrieved from [https://www.macpac.gov/wp-content/uploads/2017/01/Jan18\\_MedPAC\\_MACPAC\\_DualsDataBook.pdf](https://www.macpac.gov/wp-content/uploads/2017/01/Jan18_MedPAC_MACPAC_DualsDataBook.pdf)

<sup>2</sup> Reinhard, S., Fox-Grage, W. & Friss Feinberg, L. (2016). *Family caregivers and managed long-term services and supports*. Retrieved from [https://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1080\\_FSandMLTSS\\_REPORT\\_WEB.pdf](https://www.aarp.org/content/dam/aarp/ppi/2016-08/AARP1080_FSandMLTSS_REPORT_WEB.pdf)

<sup>3</sup> Reinhard, S., et al. (2017). *Emerging Innovations in Managing Long-term Services and Supports for Family Caregivers*. *AARP Public Policy*. Retrieved from [http://www.longtermscorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/AARP1202\\_EI\\_EmerInnovationLTSS\\_Oct31v2.pdf](http://www.longtermscorecard.org/~media/Microsite/Files/2017/2017%20Scorecard/AARP1202_EI_EmerInnovationLTSS_Oct31v2.pdf)

## Innovative Educational Programs and Materials Supporting Diverse Family Caregivers

Alzheimer's Los Angeles develops a variety of educational resources and support programs tailored to the communities they serve. Their resources, described below, include family caregiver tip sheets, a *telenovela* series, trainings, and classes.

### *Family Caregiver Tip Sheets*

Family caregivers who want to learn more about

Alzheimer's and its symptoms may face barriers if educational materials are not available in their preferred language and at the appropriate literacy level. To support caregivers, Alzheimer's Los Angeles developed 15 tip sheets in four languages: English, Spanish, Chinese, and Japanese. The tip sheets cover topics relevant to caring for loved ones with Alzheimer's, including specific tasks (e.g., medication management, bathing, toileting) and managing behaviors associated with dementia (e.g., paranoia, hallucinations, sundowning). One side of the printed versions of the tip sheets is in Spanish, Chinese, or Japanese, and the opposite side is in English for reference by English-speaking family members. The tip sheets are available here: <https://www.alzheimersla.org/alzheimers-los-angeles-services/professional-training/caregiver-tip-sheets/>.

### *Telenovela Series*

Alzheimer's Los Angeles produced a four-part *telenovela* series called *Lost Memories/Recuerdos Perdidos*. The *telenovela* series, available in both English and Spanish, delivers creative Alzheimer's education tailored to the Latino community. *Lost Memories/Recuerdos Perdidos* tells the story of a family whose grandmother exhibits signs of Alzheimer's disease. In the series, the family confronts the diagnosis, works with providers, and learns to manage their grandmother's behaviors associated with the disease. Alzheimer's Los Angeles hosts *telenovela* screenings and leads facilitated discussions in the community. Social workers also use the *telenovela* to provide education and facilitate discussions with families in similar circumstances. The series is available here:

<https://www.alzheimersla.org/videos/>.

### *Family Caregiver In-Person Trainings*

Alzheimer's Los Angeles also reaches Spanish-speaking caregivers through an in-person training program called *Cuidando con Respeto*, adapted from the widely used *Savvy Caregiver* training. The *Savvy Caregiver* six-session evidence-based training, developed by researchers at the University of Minnesota<sup>4</sup>, teaches family caregivers strategies to reduce caregiver burden and improve their ability to understand challenging behaviors associated with the disease. The *Cuidando con Respeto*<sup>5</sup> curriculum, conducted through peer-to-peer sharing and discussion, spans eight hours. The

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From October 2018 to September 2019, Alzheimer's Los Angeles provided the following services:

- Education and training events attended by 14,331 individuals
  - Care counseling for 1,905 individuals
  - 137 caregiver support groups
  - Community outreach activities, with 45,523 people participating
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*The programs are an "opportunity to understand how dementia occurs, its stages, but most importantly – strategies to use during each stage of the program as the person travels through them."*

*-Maria*

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<sup>4</sup> Hepburn, K., Lewis, M., Sherman, C.W., & Tornatore, J. (2003). The Savvy Caregiver Program: Developing and Testing a Transportable Dementia Family Caregiver Training Program. *The Gerontologist*, 43(6), 908-15.

<sup>5</sup> To learn more about *Cuidando con Respeto*, visit <https://www.caregiver.org/cuidando-con-respeto>.

curriculum aims to improve caregiver quality of life and reduce depression and anxiety related to caregiving through disease education and skill building.

Alzheimer's Los Angeles also holds a condensed version of the *Savvy Caregiver* training program, called *Savvy Caregiver Express*. *Savvy Caregiver Express* spans three two-hour sessions. Fewer sessions allow caregivers with limited time to receive education aimed at improving their quality of life and reducing depression and anxiety. Alzheimer's Los Angeles plans to publish facilitator manuals for *Savvy Caregiver Express* training on their website soon.

#### *Family Caregiver In-Person Classes*

In addition to the trainings described above, Alzheimer's Los Angeles holds hour-long classes, available in Spanish and English, for caregivers on specific topics. The *Behaviors & Alzheimer's Disease: Are They Doing That to Annoy Us?* class covers approaches to managing challenging behaviors. The *Making Home Safe for a Person with Alzheimer's* class discusses ways caregivers can understand, manage, and mitigate safety risk factors at home in order to support an individual's ability to stay in their home for as long as possible.

#### **Partnerships with Health Plans**

Alzheimer's Los Angeles partners with local health plans to offer specific educational workshops for their members. Health plan staff, including care managers, as well as local providers, can also refer caregivers to Alzheimer's Los Angeles for counseling through a secure e-referral system. Through this system, Care Counselors from Alzheimer's Los Angeles contact interested caregivers to assess their needs, address urgent issues, develop a care plan, provide disease education, and connect families to additional services, such as legal assistance. Care Counselors also follow up with caregivers regularly to ensure they are receiving the services and supports they need.

#### **Collaboration with Community Organizations**

Caregivers may be more comfortable reaching out to their local community organizations rather than Alzheimer's Los Angeles directly. These organizations have firsthand knowledge of the issues facing their communities and may already have programs or connections to programs that support caregivers and their families. Over the years, Alzheimer's Los Angeles has partnered with hundreds of community organizations with the goal of increasing their capacity to provide dementia-related services and support. For example, Alzheimer's Los Angeles staff partnered with local African American and Latino churches to disseminate hand-held fans printed with information about Alzheimer's symptoms, behaviors, and caring for a loved one with Alzheimer's. Churches distributed the fans to their congregants during services. Alzheimer's Los Angeles also partners with community organizations to co-brand the family caregiver tip sheets and other resources. Co-branding enables partner organizations to target outreach in their communities. Alzheimer's Los Angeles also trains the staff of partner organizations to help them develop dementia capable care practices that are culturally and linguistically appropriate.

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*Caregivers who have taken Savvy Caregiver Express have demonstrated decreased depression and anxiety and improved ability to understand challenging behaviors associated with Alzheimer's disease.*

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*"I received great tips on how to deal with my mom and this difficult disease. Class participation and hearing other people's stories helped. I feel I'm not alone in this journey." -Frank*

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## Key Considerations to Support Diverse Family Caregivers

Alzheimer's Los Angeles' experience supporting diverse family caregivers highlights several key considerations for organizations seeking to create or refine programs to support caregivers:

- **Elicit community input.** Conduct focus groups, pilot testing of new resources, and work with community organizations to understand community needs and preferences to inform resource development.
- **Offer multiple formats for caregiver training and education.** Different caregivers prefer different settings, methods, and levels of support and offering multiple formats maximizes the potential that each caregiver can receive training and education that meets their needs and preferences.
- **Create accessible materials, adapted for varying literacy levels and languages.** Family caregivers speak many languages and have different literacy levels. Also, families may have members with different primary languages. Alzheimer's Los Angeles produces most materials at a sixth-grade reading level and makes them available in multiple languages, often including information in English along with information in other languages.

## Additional Resources on Dementia and Caregiving

Want to learn more? The [Resources for Integrated Care](#) website includes additional resources for providers and plans supporting caregivers of individuals with dementia.

**[Managing Behaviors Associated with Dementia Resource Guides](#):** These resource guides—one for caregivers and one for healthcare professionals—provide recommended trainings, toolkits, fact sheets, publications, and newsletters.

*The Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) seeks to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. This spotlight is intended to support health plans and providers in integrating and coordinating care for dually eligible beneficiaries. It does not convey current or anticipated health plan or provider requirements. For additional information, please go to <https://www.resourcesforintegratedcare.com/>.*