

Rosa's Story

When my husband passed away a few years ago, I took over caregiving responsibilities for my 91-year-old mother-in-law with Alzheimer's disease.

My mother-in-law has some mobility issues and needs help with errands, paperwork, appointments, cooking, and cleaning, as well as medication management. Before her mobility issues became more pronounced, I was stopping by several times a week to check in on her. Now I share a duplex with her to make sure she's receiving all the care she needs. When it became clear that my mother-in-law needed full-time care, I made the choice to retire from my job in order to provide the care she needed. I have limited freedom to leave the house, and I have to manage the entirety of my mother-in-law's day. Even when I can find someone to take care of her for a few hours, she is wary of people she does not know and does not want them in her home.

A few months ago, my mother-in-law's health declined rapidly and she was unable to sit or eat by herself. Her health status has fluctuated since then, which has further limited my ability to leave the house. Sometimes my mother-in-law goes through periods of high energy and restlessness, and takes on more than she can manage. This makes me nervous, and sometimes I'm not sure how to best handle it.

My mother-in-law's health plan case manager referred me to Alzheimer's Los Angeles. I then connected with Juan, the social worker at Alzheimer's Los Angeles who works with me. Juan has helped me understand that my mother-in-law's periods of high activity were normal for someone with Alzheimer's. This explanation prompted me to learn more about my mother-in-law's disease and to better understand her behaviors. I attended Alzheimer's Los Angeles' *Savvy Caregiver Express* training¹, where I was able to ask questions and learn more about the disease. I also received materials to bring home and reference later. Although caring for my mother-in-law can be difficult, I know that I can reach out to Juan with any questions or concerns I have, and he will be able to connect me with helpful resources to improve not only my mother-in-law's quality of life, but also my own.

In the words of Rosa's Care Counselor, Juan...

I have worked with Rosa as her Care Counselor at Alzheimer's Los Angeles for two years. As a social worker, I support family caregivers by connecting them to services, helping them solve problems, providing disease education, and offering a supportive and empathetic ear. Each family caregiver is unique and family caregivers come from diverse backgrounds, with different languages, cultures, and histories. As a Spanish speaker, I often work with family caregivers who also speak Spanish, and I work with telephonic interpreters for family caregivers who speak other languages as well. As a Care Counselor and social worker, it is important to understand and be open to different cultural perspectives on disease, health, and the role of the caregiver. For example, the stigma against dementia in some cultures may make caregivers reluctant to reach out for help.

Taking a family-centered approach is important to provide support that is meaningful to the caregiver and their family, in a way that respects their needs and preferences. For Rosa, I listened to her and her mother-in-law's preferences. Rosa was interested in learning more about Alzheimer's, so I connected her with the *Savvy Caregiver Express* classes, where she learned more about the disease and heard from other caregivers in similar situations. Although she has limited social supports, she declined respite care, as her mother-in-law was not open to outside help. However, I still provide counseling to her to help her address any concerns. For example, as her mother-in-law is dually eligible for both Medicare and Medicaid, I help her navigate benefits available to her.

¹ For more information about Alzheimer's Los Angeles' training programs, including *Savvy Caregiver Express*, visit <https://www.alzheimersla.org/alzheimers-los-angeles-services/classes-and-workshops/>.

Strategies to Help Rosa

- **Learn about cultural attitudes towards disease, health, and caregiving.** Not all caregivers and families view caregiving and disease through the same cultural lens. Diseases such as Alzheimer's can carry significant stigma in some cultures and for some families, and not all families wish to receive outside help. Understanding that family caregivers come from different cultural backgrounds, Juan recommends being flexible, supportive, and offering, but not insisting families receive, help.
- **Offer a variety of caregiver support services.** While Rosa's mother-in-law did not want outside help, Juan connected Rosa to educational classes, which helped her manage her role as a caregiver, and provided peer support from other class attendees. Different caregivers prefer different settings, methods, and levels of support and offering multiple types maximizes the potential that each caregiver can receive support that meets their needs and preferences. For example, Alzheimer's Los Angeles offers a variety of services, including a helpline, personalized consultations and care counseling, online tip sheets, and support groups. For more information on Alzheimer's Los Angeles' family caregiver support programs, download the Spotlight on Alzheimer's Los Angeles here: *[insert link once final]*.
- **Provide trainings and resources to help caregivers understand Alzheimer's:** Teaching Rosa about behaviors associated with Alzheimer's through trainings and other resources helped her understand that her mother-in-law's unusual behaviors were related to Alzheimer's. A resource guide to teach caregivers about managing behaviors associated with Alzheimer's disease and related dementia is available on the Resources for Integrated Care website here:
https://resourcesforintegratedcare.com/sites/default/files/Dementia_Resource_Guide_for_Caregivers_0.pdf