

OLDER INDIANS NEWSLETTER

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DEMENTIA CAREGIVING: THE LAST 10 DAYS

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The last ten days, I had a front-row seat to dementia caregiving when my husband's mother came to stay with us as she was transitioning into a memory care apartment near us. It was a close-up view not just into dementia caregiving but also into broken "systems" and missing support.

My husband is the primary caregiver for both his mom and her brother. He is also the only one of his generation left in the immediate family, the only child and grandchild. His mom has moderate-severe vascular dementia that has taken a turn for the worse in the last several months. She had been staying in the family home with her 72-year-old intellectually disabled brother. He passed away unexpectedly during the ten days she was with us. Their mom died two years ago, right at the start of COVID. My husband was also her primary caregiver until she passed. So, not his first caregiving rodeo.

My husband managed their care from our house a couple hours away, routinely driving back and forth for everyone's doctor's appointments. He also took care of the upkeep for both houses and the bills for his mom and uncle. His mom receives a small pension from her state job. His grandmother had thankfully put some money aside to help cover long-term care needs for both of their children. Otherwise, I have no idea what their living situation and our lives would look like.

His mom and uncle had amazing caregivers (not formally trained) who came in to help almost around the clock that my husband coordinated. When the paid caregivers needed time off, it usually meant my husband had to take time off from his job or spend the weekend there. Taking on everyday tasks like meals, meds, and bathing. His mom suffers from incontinence. So, every morning includes a big load of laundry, trash runs, scrubbing bed covers and floors, and a lot of effort to try to convince her a shower is a good thing. I swear, it is like listening to the "dementia whisperer" when he talks to her. If he can't convince a person to do something with his kind, soothing voice, nobody can. Sadly, a shower is/ was never in the cards most days. At least not without dozens of attempts, hours passing, or a battle of wills. Thanks to the challenging behavior changes that have taken hold from dementia. Apathy. Depression. Resistance.

It's a lot. Some days I can see he just barely keeps it together. He is not alone. According to the [National Institute on Aging](#), more than 40 million people provide unpaid care for someone each year. [One in three \(1 in 3\) American Indian and Alaska Native adults are caregivers](#). That is more than the general population. Like my husband, more than half of those folks have provided care for more than two years.

[Research has found](#) that while caregiving is rewarding, it is a challenge and presents a lot of long-term risks and challenges, including: depression, anxiety, heart disease, cancer, diabetes, acute injuries (e.g., sprains or strains).



DEMENTIA CAREGIVING: THE LAST 10 DAYS (CONTINUED)

Dementia caregiving is tough and takes more than a mental and physical toll. A [2015 article](#) estimated that families of people with dementia spend \$61,522 a year in the last 5 years of life— almost twice as much as those who died of other causes. Minorities, people with lower education and lower incomes, are more likely to have higher out-of-pocket costs from dementia. My husband had to take an unpaid leave of absence last month to help care for both his uncle and his mom. This was after using up all of his paid sick and vacation leave for the year, mostly taking care of them. He is still out of work.

The caregiving role is tough, but the worst part is how almost impossible it is to find help and access supports and services. Trying to navigate both the health care and aging “systems” most days was (and is) almost more than my husband can stand. Getting a live person just to answer the phone or return a call in less than a week is a miracle. What he really needs is a live person to give him time, answers, and follow-through. Not a form letter eight weeks later from Medicaid notifying him that his uncle’s application was finally approved. A week after he passed away.

The one bright spot in the hunt for services and supports has been memory care facilities. Yet, few families have the resources to afford them. Safe, accessible spaces; meaningful socialization; emotional support; appropriate therapies; trained staff; interdisciplinary approaches to care coordination. These shouldn’t be considered luxuries for people living with dementia and their caregivers.

We can do more, and we can do better for caregivers and people living with dementia. For all caregivers really. Consider doing one thing today: read an article, pick a program or service you can start, engage in community conversations with caregivers, or just pick up the phone when caregivers call.

Check out some of the following resources or trainings for ideas.

- [Visit the NIA for resources for your or those in your community for Alzheimer’s or dementia caregiving.](#)
- [Become a Dementia Friend for Indian Country or even better, a Champion to raise awareness about dementia in your community.](#)
- [Create an ongoing social media campaign with self-care tips and support for caregivers. Click here for some resources to get started.](#)
- [Download the Savvy Caregiver for Indian Country Training Manual or materials to bring this program that teaches about dementia staging to caregivers in your community.](#)
- [Contact Dr. Josea Kramer with the VA about free training for your community health staff on “Addressing Challenging Behaviors with Dementia.”](#)
- [Visit the American Indian and Alaska Native Resource Center for Brain Health Online Resource Library for more tools.](#)

If you are willing to share resources in our online resource library, please send them to admin@iasquared.org.



Upcoming Title VI Events

Title VI Webinar: Social Isolation

Join us for the Title VI Webinar on Social Isolation.

Wednesday, February 9, 2022 at 2:00 p.m. ET

Join on your computer or mobile app: [Meeting Link](#)

Call in: +1 206-420-5032, 967247174#

Phone Conference ID: 967 247 174#

Title VI Afternoon Chats

Join our weekly Title VI Afternoon Chats during which we explore and discuss a variety of topics that affect the Title VI community.

Thursdays at 3:00 – 4:00 p.m. ET

Dial-in details change weekly, check our ACL/AoA Weekly Update email blast or <https://olderindians.acl.gov/events> for details each week.

Title VI Program Basics Trainings

Bi-Weekly on Tuesdays at 4:00 – 5:00 p.m. ET

Next session: Tuesday, February 8, 2022 at 4:00 p.m. ET

If you're a new Title VI director, or an experienced director with some questions about your program, please come to our training series on program basics for Title VI directors. We will review how you can spend your Title VI funds, upcoming events and deadlines you should be aware of and much more. It will be an informal chance to get to know your program better, as well as get to know other Title VI directors. Access the meeting using the link or call-in information below:

Join on your computer or mobile app: [Meeting Link](#)

Call in: +1 206-420-5032, 390174608#

Phone Conference ID: 390 174 608#

For more information on Upcoming Events, visit <https://olderindians.acl.gov/events> or contact Melissa Szasz at Melissa.Szasz@teyaservices.com

Tribe of the Quarter

Eastern Band of Cherokee Indians of North Carolina



Nestled in the mountains of Western North Carolina is the home of the Eastern Band of Cherokee Indians. Among the myriad robust tribal services are Tribal In-Home Care and Tsali Manor Senior Services which serve the Cherokee community. As sister programs, we work hand in hand to provide care to some of the most vulnerable within our population.

Our mission is to provide quality care to the people of the Cherokee Indian Reservation through individualized care, with respect for cultural beliefs. The guiding principles and core values of the organizations include: group harmony, generosity, strong individual character, commitment to stewardship, respect for Cherokee Heritage, sense of humor interconnectedness, compassionate services, and valuing family.

Some key services we provide are: in-home caregiver respite by a certified nursing assistant, Alzheimer's support group, one-on-one in person counseling by a medical social worker, home delivered meals, nutritional supplement program, congregate meals, in-home caregiver and patient assessment by an RN, and individual member engagement education materials. Additionally, the team has worked with a local restaurant to provide full Thanksgiving meals to caregivers, which serves to promote oneness with family and reduces the stress associated with the holidays. Over the past 10 years, we have been able to provide these meals to 35 families on average annually. Each meal feeds approximately 20 family members. To overcome the challenges of a global pandemic, the team created a drive-through meal pick-up process to ensure that caregivers continue to receive this valuable service.

In 2021, the caregiver respite program provided 2,161 in-home visits and over 1,000 hours of inpatient caregiver respite. Each caregiver and patient were offered education on the importance of infection prevention and stress reduction. To ensure that members felt supported, telephone visits were made to caregivers by the medical social worker during the months of March and April 2021. This preventative measure allowed therapeutic conversation and the opportunity to voice any concerns in such uncertain times. Additionally, the Tsali Manor Senior center currently serves 107 daily home-delivered meals and approximately 100 congregate meals. The team members move from congregate to drive-through meal delivery as needed to ensure the safety and health of those in the community.

We continue to grow our community-based services, focusing on caregiver respite, Alzheimer's and dementia education, and surrounding the elders with services. Our partnership with Title VI funding greatly supports these efforts and is an asset to meeting the needs of the community.