

Caring for the Caregiver: Navigating the Journey of Dementia with Self-Compassion

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**“We never
heard of
Alzheimer's
or dementia
before this”**



The number of Americans living with Alzheimer's is growing.

An estimated 6.7 million Americans are living with Alzheimer's.

Almost two-thirds of Americans with Alzheimer's are women.

Older Black Americans are about twice as likely to have Alzheimer's or other dementias than older non-Hispanic Whites.

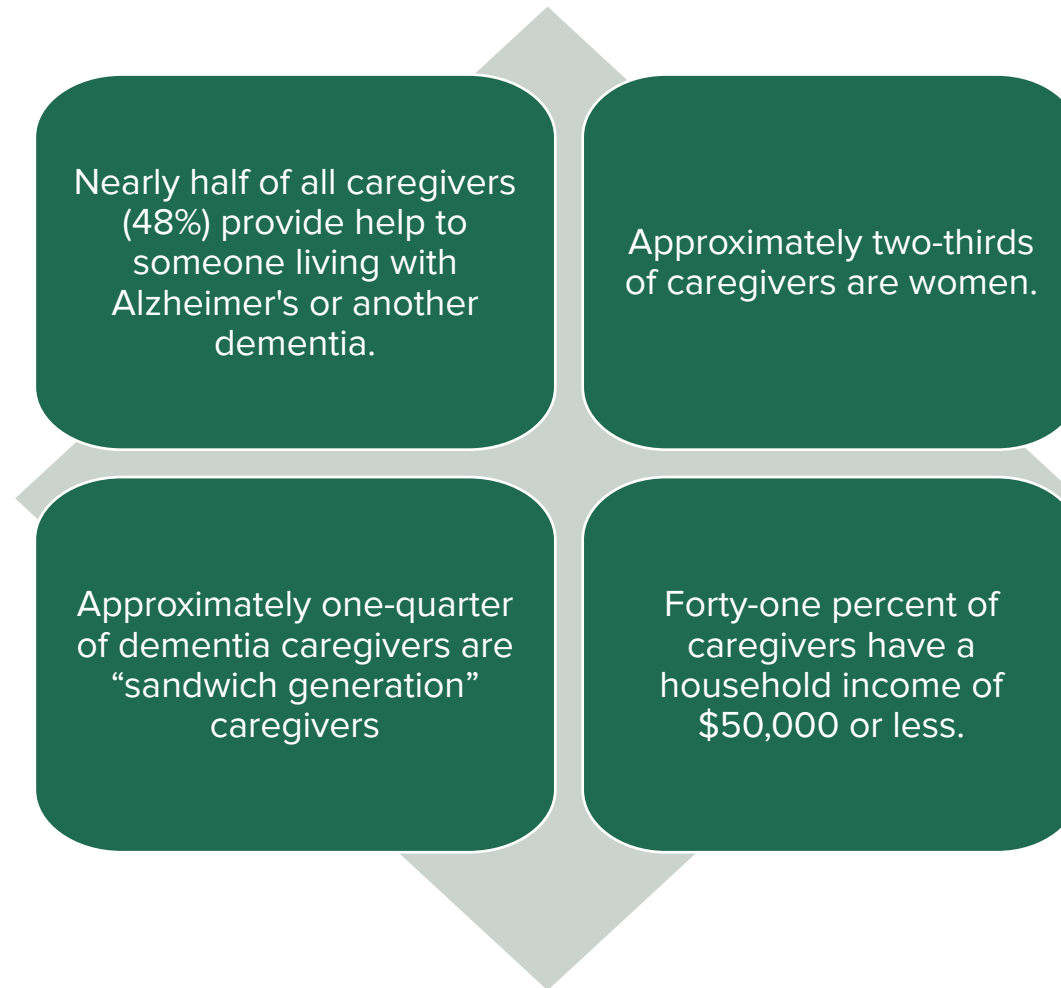
Older Hispanics are about one and one-half times as likely to have Alzheimer's or other dementias as older non-Hispanic Whites.

Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2023;19(4). DOI 10.1002/alz.13016



Dementia affects the whole family

Family members are an important source of support for people living with dementia.



Alzheimer's Association. 2023 Alzheimer's Disease Facts and Figures. *Alzheimers Dement* 2023;19(4). DOI 10.1002/alz.13016

The role of the family dementia caregivers.

- Assist with daily activities (e.g., bathing, grooming, eating, toileting)
- Assist with mobility and transfer
- Schedule and coordinate medical appointments
- Administer and monitor medications
- Manage household chores (e.g., cooking, cleaning, and shopping)
- Provide transportation





Caregiver Well-Being

“Al final del día me siento extenuada”

Family caregivers or a relative living with dementia experience increased stress and poor mental health over time.



**What are some reasons
dementia caregivers may
experience poor mental
health?**

Caregiver mental health is linked to caregiving stress

Functional decline of the individual living with dementia

Physical demands of caregiving

Managing behavioral symptoms of dementia (BSDs)

Feast et al., 2016; Ornstein & Gaugler, 2012



Daily Caregiving Experiences

“Cada día es un reto, y si surge algún imprevisto
es aún más.”

Daily Depression and Anxiety



- 85% of caregivers reported depressive-symptoms on at least one day.
- 94% of caregivers reported anxiety related-symptoms on at least one day.
- Depression and anxiety symptom was reported on 58% and 69% of the days.
 - That's 12-14 days out of 21 days!

Puga et al., 2023



Daily Stress

- Caregivers were **more likely** to experience depression and anxiety symptoms on days stressful behavioral symptoms of dementia occurred.
- Stress related to **restlessness** and **mood disturbances** was associated with a **higher** likelihood of caregivers experiencing depression and anxiety symptoms.

Puga et al., 2023



Daily Social Support

- Receiving **tangible support** was associated with a **lower** likelihood of experiencing **depressive symptoms**.
- Receiving **emotional support** was associated with a **higher** likelihood of experiencing **anxiety-related symptoms**.

Puga et al., 2023



Daily Coping

- **Social connection** and **pleasant non-care activities** were associated with a **lower** likelihood of experiencing depressive symptoms.
- **Social connection** and **exercise** were associated with a **lower** likelihood of experiencing anxiety-related symptoms.

Puga et al., 2023



Caring for the Caregiver

“Noto que estoy durmiendo más durante el día.,
comiendo menos y [estoy] cansada.”

Warning Signs



Feeling exhausted, overwhelmed, or anxious



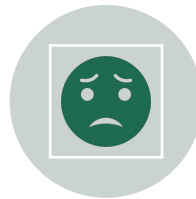
Becoming easily angered or impatient



Feeling lonely or disconnected from others



Having trouble sleeping or not getting enough sleep



Feeling sad or hopeless, or losing interest in activities you used to enjoy



Having frequent headaches, pain, or other physical problems



Not having enough time to exercise or prepare healthy food for yourself



Skipping showers or other personal care tasks such as brushing your teeth

Self-Care

The ability to care for oneself through awareness, self-control, and self-reliance in order to achieve, maintain, or promote optimal health and well-being.

Martínez N, Connelly CD, Pérez A, & Calero P. (2021).

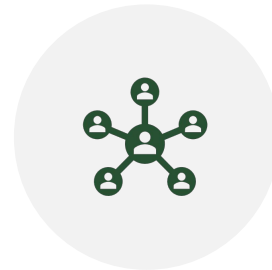
Key Self Care Areas



PHYSICAL: ACTIVITIES TO
SUPPORT YOUR PHYSICAL
HEALTH



PSYCHOLOGICAL/EMOTIONAL:
ACTIVITIES TO HELP MANAGE
STRESS AND SUPPORT YOUR
MOOD



SOCIAL: ACTIVITIES TO
NURTURE RELATIONSHIPS AND
SOCIAL CONNECTION



SPIRITUAL: ACTIVITIES TO
NURTURE SPIRITUALITY

Activity: Self-Care Reflection

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Physical Self Care

Rate how well, or how frequently, you believe that you engage in each activity

1 = I rarely do this, or I don't do this well

2 = I sometimes do this, or I'm average at doing this

3 = I do this often, or I do this very well)

- Attending wellness appointments
- Resting when unwell
- Drinking enough water
- Getting sufficient sleep
- Eating regular meals
- Enjoying group exercises (e.g., gym classes)
- Exercising out of doors
- Maintaining good hygiene
- Eating a healthy diet
- General physical self-care

Psychological/Emotional Self-Care

Rate how well, or how frequently, you believe that you engage in each activity

- 1 = I rarely do this, or I don't do this well
- 2 = I sometimes do this, or I'm average at doing this
- 3 = I do this often, or I do this very well)

- 'Unplugging' from technology
- Expressing emotions and feelings
- Appreciating own talents, accomplishments, and strengths
- Taking days off/rest days from responsibilities
- Enjoying hobbies
- Learning about or exploring new things
- Practicing self-nurturing activities
- Laughing about things
- Taking a holiday, escape, or mini-break
- General emotional self-care

Social Self-Care

Rate how well, or how frequently, you believe that you engage in each activity

1 = I rarely do this, or I don't do this well

2 = I sometimes do this, or I'm average at doing this

3 = I do this often, or I do this very well)

- Making time for friends or family
- Staying in contact with distant connections
- Engaging in mentally stimulating discussions
- Asking for help when you require it
- Doing fun activities with others/enjoyable group activities
- Spending quiet private time with partner or close friend
- Making new friends/talking to new people
- Overall social self-care

Spiritual Self-Care

Rate how well, or how frequently, you believe that you engage in each activity

1 = I rarely do this, or I don't do this well

2 = I sometimes do this, or I'm average at doing this

3 = I do this often, or I do this very well)

- Enjoying outdoor/nature time
- Volunteering for charity/community
- Religious practice
- Practicing gratitude
- Meditating
- Allocating quiet time for reflection
- Applying personal strengths, talents, or values
- Appreciating beauty (e.g. music, art, literature)
- General spiritual self-care

**What are some
practical things
caregivers can do for
self-care?**



Taking Care of Yourself

- Ask for help when you need it.
- Get exercise as often as you can.
- Eat nutritious foods.
- Join a caregiver's support group online or in person.
- Take breaks each day.
- Prioritize sleep.
- Keep up with your own health
- Spend time with friends and keep up with hobbies.
- Try practicing meditation.
- Consider seeking help from mental health professionals to help you cope with stress and anxiety.
- Be kind to yourself.

Five Sense Exercise

Spend one minute for each of the following below:

- Notice five things you can see.
- Notice four things you can feel.
- Notice three things you can hear.
- Notice two things you can smell.
- Notice one thing you can taste.

Mindful Breathing Exercise

Set a timer for five minutes and do some deep breathing using these steps:

- Just focus on your breathing.
- Listen to the sound it makes in your head.
- Feel the breath enter through your nose or mouth, move through your body and fill your lungs.
- Each time another thought tries to take over your focus, let it come and go.

Belly Breathing

Belly breathing is easy to do and very relaxing. Try this basic exercise anytime you need to relax or relieve stress.

1. Sit or lie flat in a comfortable position.
2. Put one hand on your belly just below your ribs and the other hand on your chest.
3. Take a slow deep breath in through your nose, and let your belly push your hand out, your chest should not move.
4. Breathe out through pursed lips as if you were whistling, feel the hand on your belly go in and use it to push all the air out.
5. Do this breathing 3 to 10 times; take your time with each breath.
6. Notice how you feel at the end of the exercise

Mindful Movement

Set reminders throughout the day to focus your attention on your body. Some helpful hints to take inventory of are:

- How does your neck feel?
- Are you holding tension in your jaw?
- Notice how your arms hang from your shoulders.
- How is your posture?
- Where are your feet?

**What are some things
you can do with your
relative living with
dementia?**

Shared Activities

- Get outside (e.g., take a walk, water plants, sit on the porch)
- Engage the senses (e.g., play with playdough, look at photos, listen to music)
- Do something personal (e.g., brush your relative's hair, assist with grooming)
- Be creative (e.g., paint or draw)

Helpful Reminders for Shared Activities

- Keep the person's skills and abilities in mind.
- Pay special attention to what the person enjoys.
- Consider if the person begins activities without direction.
- Be aware of physical problems.
- Focus on enjoyment, not achievement.
- Encourage involvement in daily life.
- Consider time of day. Adjust activities to disease stages.
- Keep in mind the progressive nature of dementia

<https://www.alz.org/help-support/caregiving/daily-care/activities>

Building towards self-compassion

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Representation in Research

“Fue un día tranquilo.”



Some Populations Are Disproportionately Impacted by Dementia.

- Dementia among the Latino population is 1.5 times higher than non-Hispanic whites.
- Latino adults also develop dementia at a younger age and experience more severe symptoms than other ethnic/racial groups.
- Higher rates of chronic disease, including diabetes, heart disease, and hypertension, have also been observed among Latino individuals living with dementia.

Cultural Factors and Resilience

- The role of cultural factors:
 - Cultural values (family, religion, respect, fatalism, gender roles)
 - Acculturation
 - Racism/discrimination
 - Stigma
- Cultural factors have also been shown to impact resilience and predict poor mental health outcomes among culturally and ethnically diverse populations.



Attention Hispanic Community!



We want to talk to you!



Do you take care of an older adult from your family with memory loss or dementia?

CONTACT

Lorelí Alvarez
(205)-996-0339
starlab@uab.edu

Who can be enrolled?

Hispanic & Latino/a adults, that take care of a family member with memory loss or dementia

- What to expect from your involvement:
- We will contact you three times in one year.
 - Complete surveys from your phone or computer.
 - After completing all the surveys you will receive a token of appreciation of up to \$271.
 - You can receive the surveys in English or Spanish
 - No social security or medical insurance needed.

To register click [HERE](#)

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¡Atención Comunidad Latina!



¡Queremos hablar contigo!



¿Cuidas de un adulto mayor en tu familia que está perdiendo la memoria?

¡LLAMA HOY!

Lorelí Álvarez
(205)-996-0339
starlab@uab.edu

¿Quién puede inscribirse?

Hispanos/as o Latinos/as que cuiden de un familiar con problemas de memoria o demencia

- ¿Qué esperar después de inscribirte?
- Te contactaremos tres veces en un año.
 - Completar encuestas desde tu celular o computadora.
 - Después de completar todas las encuestas, recibirás como muestra de agradecimiento hasta \$271.
 - Puedes recibir las encuestas en español o inglés.
 - No necesitas número de seguridad social ni seguro médico.

Para registrarse click [AQUÍ](#)

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What does this mean for families impacted by dementia?



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Thank you!

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