

PERSONALITY AND BEHAVIORAL CHANGES

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FAMILY CAREGIVING

- In 2020, there was an estimated 42 million family caregivers of older adults in the U.S. (AARP, 2020)
- Caregiving can be positive: rewarding, fulfilling, lead to a sense of purpose (Pinquart and Sorensen, 2003)
- Caregiving can be challenging: stressful, burdensome, and exhausting (Roth et al., 2015; Zarit, 2012)

FAMILY CAREGIVING

- Lack of knowledge about dementia can cause caregivers to overestimate what their family member is able to do
- May lead to greater anger, frustration, and stress
- Especially for dementia caregivers



WHY IS CAREGIVING STRESSFUL?

- Behavioral and psychological symptoms of dementia (BPSD)
- 90-97% of persons living with dementia experience at least one
 - Repetitive questions or stories
 - Hiding things (paranoia)
 - Apathy or inactivity
 - Emotional outbursts or agitation
 - Depression and anxiety

BEHAVIORS AND SYMPTOMS

- Wandering
- Hallucinations – hearing or seeing something or someone not there
- Delusions – false beliefs that the person thinks are real
- Aberrant motor behavior (fidgeting, pacing)
- Sleep disturbances

CAUSES OF SYMPTOMS

- Pain or discomfort
- Sudden change in environment, routine, or person
- Too much noise or too many people
- Being pushed by others to do something – for example, bathing or remembering events/people
- Fatigue
- Depression, sadness
- Medications

Sundowning

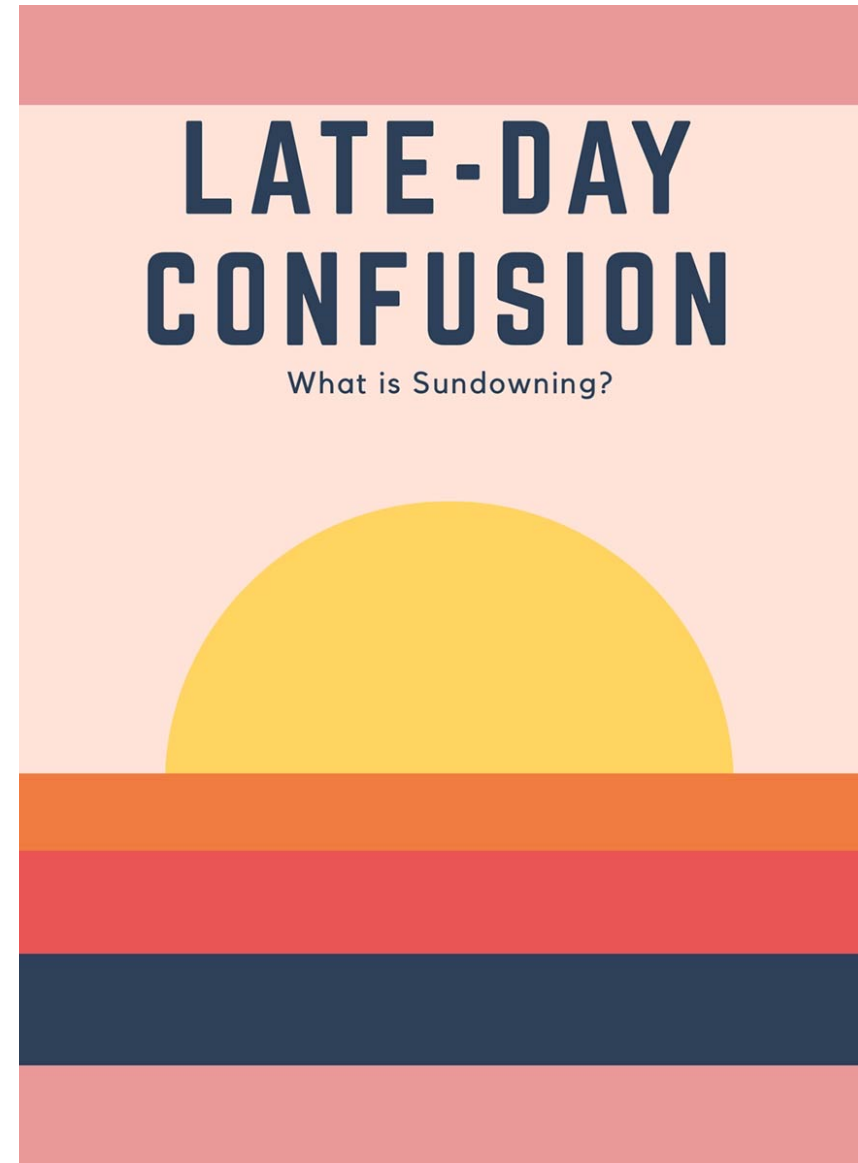
What is it?

A state of confusion occurring in the late afternoon and lasting into the night.

Sundowning can cause different behaviors, such as confusion, anxiety, agitation, aggression, pacing, wandering, or other behaviors.

Factors that may aggravate it:

- Spending a day in an unfamiliar place
- Low lighting
- Disruption of the body's "internal clock"
- Difficulty separating reality from dreams
- Being hungry or thirsty
- Presence of an infection such as a urinary tract infection
- Being bored or in pain



COMMUNICATION CHALLENGES

- People with dementia may have a difficult time communicating
 - Understanding what words mean or what you are trying to convey
 - Problems finding the right words to say or losing their train of thought
 - Blocking out background noises or distractions
 - Frustration if communication isn't working

BEHAVIOR IS COMMUNICATION

- Loved ones may not be able to verbalize their problems
- They may pace nervously or talk to themselves
- Behaviors communicate an unmet need
- Look into the feeling/emotion **BEHIND** the behavior
 - Pain
 - Fear
 - Hunger
 - Boredom



STEPS FOR TARGETING BEHAVIOR/PROBLEM

- What is the behavior/issue?
 - Is it a problem?
- When does the behavior/issue occur?
- Assess previous attempts to deal with the issue
- Set a goal for the issue
- Troubleshoot
- Review the issue and plan

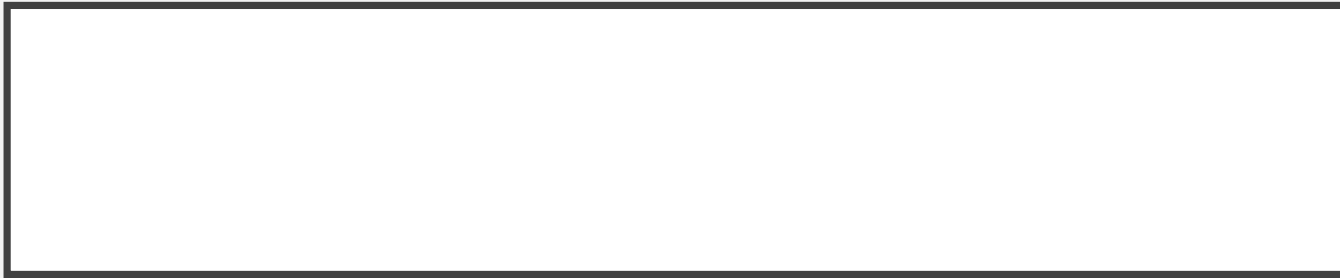
AN EXAMPLE

- What is the behavior/issue?
 - Repetitive questioning/stories
 - Is it a problem? NO!
- What is the behavior/issue?
 - Not eating
 - Is it a problem? YES!
- Assess previous attempts to deal with the issue and trouble shoot
 - Remove distractions (or have them!); tv trial and error
 - Have the setting be consistent (plate, cup, etc.)

OTHER ISSUES

- Losing or misplacing items
 - Have one place that you store the item and consistently remind family member
 - Hold on to the item yourself
 - Have back-ups (glasses, keys, etc.)
- Difficult getting family member to bathe
 - Have clothes set out for them; shampoo and soap all ready
 - Turn on the water and make sure temperature is warm
 - Environment is soothing and calm
 - Make sure YOU have lots of time and don't rush through it

- Importance of social and environmental adaptations rather than medications
- What can YOU do?
 - Simplify your words and sentences
 - Communicate clearly and calmly
 - Don't argue (e.g., in case of paranoia or delusions)
 - Use visual cues for orientation (e.g., brush your hair)
 - Re-direct
- Education and training for caregivers is needed, and available!



- <https://www.youtube.com/watch?v=PQ7VcyEgVzw>
- UCLA Dementia Caregiver Training Videos on YouTube



HELPING CAREGIVERS

- What increases quality of life for caregivers?
 - Caregivers with support (places, people)
 - Quality time on education (learning)
 - Psychological and social support

THINGS TO REMIND YOURSELF

- Loved one has a neurological disease that is causing this behavior
- Issues/personality changes are not by choice
- Behavior is communication!
- Arguing, anger, or stress can exacerbate the situation
- Always re-evaluate the situation and determine how else you might handle it

THINGS TO REMIND YOURSELF

- You are doing the **BEST** you can!



Dyadic Study on Empathy in Caregiving

The Social Relationships, Health, and Altruism Research (SHARE) lab is collaborating with the UC Davis Alzheimer's Disease Center (ADC) to understand how persons living with early-stage Alzheimer's disease (AD) interact with their spousal caregivers. We are conducting a dyadic study and aim to offer essential knowledge to promote the quality of caregiving and well-being outcomes of both persons with AD and caregivers.

Become a part of improving the lives of couples coping with AD by participating in our study!

WHO CAN PARTICIPATE?

Spousal caregivers, and their spouse/partner who:

- Age 60 and older
- Has received a diagnosis of Alzheimer's Disease
- Experience mild to moderate cognitive impairment
- Live in the community

WHAT DOES THIS STUDY INVOLVE?

- Concurrent 60- to 90-minute in person interviews with persons with AD and caregivers at home or on campus
- A 5- to 10-minute follow-up call in 6 months
- Two optional parts including (a) collection of small bits of hair, and (b) an additional in person interview for about 60 minutes.



If you have any questions about the study or to see whether you are eligible to participate, please contact our research team via email at sharelab@ucdavis.edu or by phone at (530) 771-6317.

If you have questions or concerns about this study, you may also contact Principal Investigator Dr. Meng Huo, via email at mmhuo@ucdavis.edu

Compensation is available. Each couple will receive up to \$190 for participating.

THANK YOU!

- Questions?

