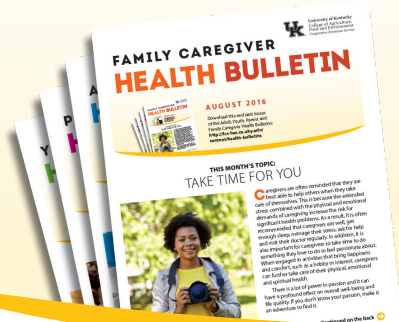


FAMILY CAREGIVER HEALTH BULLETIN



OCTOBER 2019

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THIS MONTH'S TOPIC:
**DEMENTIA CAREGIVERS
AND DISEASE TRAJECTORY**



Alzheimer's disease (AD) is a type of dementia that causes problems with memory, thinking and behavior. Changes in the brain also affect mood, behavior and personality (Alzheimer's Association, 2019). In addition to affecting the person living with the disease, it can also have adverse effects on entire families, especially to those who are not prepared to care (Werner, Mittelman, Goldstein, & Heinik, 2011).

In the United States, approximately 5.8 million individuals live with AD; a number that is expected to rise to 14 million by the year 2050 (Alzheimer's Association, 2019). A person with AD will become increasingly dependent on caregivers, who are often family members with no caregiving training. Caring for

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Alzheimer's progresses slowly across three general stages: mild, moderate, and severe.

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someone with the AD can be emotional and overwhelming, especially as the disease progresses and more care and supervision is required.

On average, a person with AD lives four to eight years after diagnosis, but some people have lived as long as 20 years. The disease progresses slowly across three general stages: mild, moderate, and severe (Alzheimer's Association, 2019). The specific trajectory of the disease is unique to each person diagnosed, but staging the disease helps healthcare professionals and caregivers know what to expect.

- **Mild Stage:** In the early stage of the disease, a person with Alzheimer's may maintain high amounts of independence, but forget trivial things such as where they placed their car keys. Family members may start to notice increasing memory lapses, trouble with recalling words and names, and increasing challenges with planning and organizing (Alzheimer's Association, 2019).
- **Moderate Stage:** In the middle stage, a person with Alzheimer's has increasing trouble remembering and performing routine tasks. They are more likely to wander or feel confused about time and place. They may even forget their own personal history. Some individuals struggle with bladder and bowel control, have trouble sleeping, and/or experience major personality and behavioral changes, such as becoming suspicious, delusional or compulsive (Alzheimer's Association, 2019). The middle stage typically lasts the longest and will require increasing care and supervision.
- **Severe Stage:** In the late stage of AD, symptoms are severe and full-time care is needed with personal care and activities of daily living. A person with late stage AD will have trouble communicating, walking, sitting and even swallowing. Unable to respond to their environment or even control their own movements, they become increasingly vulnerable to infections such as pneumonia (Alzheimer's Association, 2019).

As the disease progresses, family caregivers are the most vulnerable during the middle and

late stage of the disease. They also experience the greatest instability to their lives during the middle and late stages as physical and emotional care demands increase, round-the-clock care is required, high financial costs are paid, and basic communication with their loved one is challenged. During these times, it is important for caregivers to recognize the warning signs of stress and find ways to manage it. Warning signs may include, anxiety or panic attacks, irritability and moodiness, aches and pains, changes in skin or with breathing, problems sleeping, substance abuse and sadness or depression (Keys to Embracing Aging, 2017).

Dementia care survey research study

If you care for a loved one with dementia, live in Kentucky and are at least 18 years old, the University of Kentucky Family and Consumer Sciences (FCS) Extension and the Kent School of Social Work in Louisville invite you to participate in an online survey about dementia care experiences. The purpose of the survey is to learn more about dementia service needs and service delivery preferences for those who provide care to someone with dementia. Your feedback will help inform efforts related to reducing caregiver burden. Participants will be eligible to enter a drawing for a \$50 gift card.

https://louisvillekent.az1.qualtrics.com/jfe/form/SV_3gTJrePrDM9sRB

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HEALTH BULLETIN

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