GUIDE

Guiding an Improved Dementia Experience

When Janice realized that Bruce, her husband of 35 years, could no longer find his way home from the grocery store which was a block from their home, she knew they were in trouble. For the next 5 years, Janice was the primary caregiver for her then 84-year-old spouse. The growing demands of short-term memory, increasing incontinence, wandering and aggressive behavior took a toll, often resulting in bouts of depression for Janice and isolation from friends for them both. They did not have a meaningful connection to their children, or other social support and Janice felt alone and vulnerable with her health care providers offering little in the way of collaborative support for her husband's needs and her own declining health. In an unexpected turn of events, Bruce, fell down their front steps in his effort to "go to work" and died from the resulting injuries. Their story is full of sorrow and regret, but it is unfortunately common across our country.

Currently in the United States, 6.7 million Americans are living with Alzheimer's disease or another form of dementia. By 2060, that number is projected to reach nearly 14 million. Dementia not only affects the individual diagnosed but also has a significant impact on their entire family. Adult children, relatives, and friends often step into caregiving roles, which can be emotionally, physically, and financially overwhelming.

According to the Alzheimer's Association, 70% of caregivers report experiencing stress related to their caregiving responsibilities. Many caregivers spend an average of 31 hours per week providing care. With so much time devoted to supporting a loved one, caregivers may struggle to meet their own needs—such as maintaining employment, attending medical appointments, pursuing hobbies, nurturing relationships, and practicing self-care. When a caregiver's needs go unmet, negative health outcomes and burnout can occur, which may unintentionally impact the quality of care provided.

To address these challenges, Medicare has launched GUIDE (Guiding an Improved Dementia Experience), an eight-year pilot program designed to test the impact of providing comprehensive services and support for people living with dementia and their caregivers.

Who Is Eligible?

Individuals enrolled in Original Medicare Part B who are not enrolled in PACE or Hospice and not living in a long-term care facility.

Why Choose GUIDE?

In North Carolina, 15 organizations are offering the GUIDE model—some in partnership with local, trusted community-based organizations (CBO)—to deliver respite services and additional support to eligible patients and caregivers. Centralina Area Agency on Aging is one CBO partnered with Eli Health to conduct care navigation in the Charlotte region.

Key features of GUIDE include:

- No cost to participants: GUIDE services are fully covered by Medicare.
- Annual respite allowance: Each client may use up to $2,563 per year for respite care delivered in the comfort of their home. Respite care provides caregivers with a much-needed break to rest and attend to personal responsibilities.
- Dedicated care navigator: Each client is paired with a trained professional who helps address medical and emotional needs, coordinates community resources, and supports the caregiving experience.
- 24/7 caregiver support line: Access to round-the-clock guidance can help answer urgent questions and may prevent unnecessary emergency room visits.
- Caregiver training and support: GUIDE offers caregiver support groups, education sessions, and skill-building workshops to help caregivers adjust as their loved one's dementia progresses.

WE'RE HERE TO HELP

The need for comprehensive dementia care continues to grow, and Centralina Area Agency on Aging is committed to supporting individuals and caregivers in our region. To learn more about enrollment and Medicare eligibility, visit our website www.centralina.org or contact us directly, 1-800-508-5777.