The Growing Care Gap

Why are Supportive Services Needed by Family Caregivers of Persons Living with Dementia?

• Dementia impacts the person as well as the family
• Dementia caregivers experience more stress than those caring for people with disabilities who do not have dementia
  – Typically spend more hours and years in caregiving role
  – Rates of depression are twice as high
Dementia is one of the costliest health conditions

- Financial risks for dementia caregivers are especially high
- An AARP study found that dementia caregivers reported nearly twice the average out-of-pocket costs in 2016 than those caring for someone who doesn’t have dementia ($10,697 vs. $5,758).


High caregiver stress is a predictor of a person’s placement in a nursing home
Less than half of dementia caregivers (44%) said a doctor, nurse or social worker ever asked them about what was needed to care for their relative/close friend.

Only about 1 in 4 (24%) said a health provider had asked what they need to care for themselves.

Types of Community-Based Caregiver Supportive Services

- Assessing Needs, Values and Preferences
- Care Coordination
- Counseling and Support Groups
  - Family Meetings
- Legal and Financial Consultations
- Education and Skills Training
- Transportation Services and Nutrition Programs
- Respite Care
  - In-home, Adult Day Centers
- Employee Assistance Programs
  - FMLA, paid family leave
- Hospice and Palliative Care
10 Common Attributes of Evidence-Based Caregiver Support Programs

1) Adopting the principle of person- and family-centered care

2) Targeting family members/friends most likely to benefit from the program

3) Building a trusting relationship with the person and the family

4) Ensuring appropriate language access and cultural sensitivity

5) Assessing the family caregiver’s unique needs, problems, strengths, and resources, as identified by the family caregiver
10 Common Attributes of Evidence-Based Caregiver Support Programs

6) Providing the family caregiver with a combination of services to address multiple areas of unmet needs

7) Tailoring services to the family caregiver’s specific concerns and needs

8) Utilizing trained staff

9) Offering periodic follow-up support as needs change over time

10) Evaluating caregiver outcomes to improve the program

Adapted from: L. Feinberg, in press, From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia, AARP Public Policy Institute.
• It is time to treat family caregiving with an urgency and make it a national priority.

www.nationalacademies.org/caregiving
• Evidence-based dementia caregiver interventions should be scaled up and made *available, accessible, and affordable* to the families who need them.
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