



Caring for the caregiver in dementia

Caregiver stress is higher for dementia caregiving than other types. By focusing on the family, FPs can help to ease the burden.

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> THE CASE

Sam C* is a 68-year-old man who presented to his family physician in a rural health clinic due to concerns about weight loss. Since his visit 8 months prior, Mr. C unintentionally had lost 20 pounds. Upon questioning, Mr. C also reported feeling irritable and having difficulty with sleep and concentration.

A review of systems did not indicate the presence of infection or other medical conditions. In the 6 years since becoming a patient to the practice, he had reported no chronic health concerns, was taking no medications, and had only been to the clinic for his annual check-up appointments. He completed a Patient Health Questionnaire (PHQ-9) and scored 18, indicating moderately severe depression.

Mr. C had established care with his physician when he moved to the area from out of state so that he could be closer to his parents, who were in their mid-80s at the time. Mr. C's physician also had been the family physician for his parents for the previous 20 years. Three years prior to Mr. C's presentation for weight loss, his mother had received a diagnosis of acute leukemia; she died a year later.

Over the past year, Mr. C had needed to take a more active role in the care of his father, who was now in his early 90s. Mr. C's father, who was previously in excellent health, had begun to develop significant health problems, including degenerative arthritis and progressive vascular dementia. He also had ataxia, leading to poor mobility, and a neurogenic bladder requiring self-catheterization, which required Mr. C's assistance. Mr. C lived next door to his father and provided frequent assistance with activities of daily living. However, his father, who always had been the dominant figure in the family, was determined to maintain his independence and not relinquish control to others.

The strain of caregiving activities, along with managing his father's inflexibility, was causing increasing distress for Mr. C. As he told his family physician, "I just don't know what to do."

○ HOW WOULD YOU PROCEED WITH THIS PATIENT?

** The patient's name has been changed to protect his identity.*

It is estimated that more than 11 million Americans provided more than 18 billion hours in unpaid support for individuals with dementia in 2022, averaging 30 hours of care per caregiver per week.¹ As individuals with dementia progressively decline, they require increased assistance with activities of daily living (ADLs, such as bathing and dress-

TABLE 1

Health outcomes associated with dementia caregiving⁸⁻¹⁴

Physical outcomes	Psychological outcomes
Poorer self-reported health ^a	Depression ¹¹
Increased use of health care	Anxiety ¹²
More prescribed medications ⁸	Burnout ¹³
Hypertension ⁹	Loneliness ¹⁴
Changes in physiologic biomarkers of stress ¹⁰	Decreased quality of life ⁹
Decreased cognitive function ¹⁰	Insomnia and other sleep issues ¹⁰

ing) and instrumental activities of daily living (IADLs, such as paying bills and using transportation). Most of this assistance comes from informal caregiving provided by family members and friends.

Caregiver burden can be defined as “the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member.”² Caregiver stress has been found to be higher for dementia caregiving than other types of caregiving.³ In particular, caring for someone with greater behavioral and psychological symptoms of dementia (BPSDs) has been associated with higher caregiver burden.⁴⁻⁷

Beyond the subjective burden of caregiving, there are other potential negative consequences for dementia caregivers (see **TABLE 1**⁸⁻¹⁴ and **TABLE 2**^{15,16}). In addition, caregiver distress is related to a number of care recipient outcomes, including earlier institutionalization, more hospitalizations, more BPSDs, poorer quality of life, and greater likelihood of experiencing elder abuse.¹⁷

ASSESSMENT, REASSESSMENT ARE KEY TO MEETING NEEDS

Numerous factors can foster caregiver well-being, including feelings of accomplishment and contribution, a strengthening of the relationship with the care recipient, and feeling supported by friends, family, and formal care systems.^{18,19} Family physicians can play an important role by assessing and supporting patients with dementia and their caregivers. Ideally, the individual with dementia and the caregiver will be assessed both together and separately.

A thorough assessment includes gather-

TABLE 2

Health conditions reported by dementia caregivers^{15,16}

Anxiety	44%
Depression	30%-40%
Obesity	32.7%
Cancer	14.3%
Diabetes	12.8%
Coronary heart disease	8.3%
Stroke	5.2%

ing information about the context and quality of the caregiving relationship; caregiver perception of the care recipient’s health and functional status; caregiver values and preferences; caregiver well-being (including mental health assessment); caregiver skills, abilities, and knowledge about caregiving; and positive and negative consequences of caregiving.²⁰ Caregiver needs—including informational, care support, emotional, physical, and social needs—also should be assessed.

Tools are available to facilitate caregiver assessment. For example, the Zarit Burden Interview is a 22-item self-report measure that can be given to the caregiver²¹; shorter versions (4 and 12 items) are also available.²² Another resource available for caregiver assessment guidance is a toolkit developed by the Family Caregiver Alliance.²⁰

Continually assess for changing needs

As the condition of the individual with dementia progresses, it will be important to reassess the caregiver, as stressors and needs will change over the course of the caregiving relationship. Support should be adapted accordingly.

> Caregiver distress is related to care recipient outcomes, such as earlier institutionalization, more hospitalizations, and poorer quality of life.

■ **In the early stage of dementia**, caregivers may need information on disease progression and dementia care planning, ways to navigate the health care system, financial planning, and useful resources. Caregivers also may need emotional support to help them adapt to the role of caregiver, deal with denial, and manage their stress.^{23,24}

■ **With dementia progression**, caregivers may need support related to increased decision-making responsibility, managing challenging behaviors, assisting with ADLs and IADLs, and identifying opportunities to meet personal social and well-being needs. They also may need support to accept the changes they are seeing in the individual with dementia and the shifts they are experiencing in their relationship with him or her.^{23,25}

■ **In late-stage dementia**, caregiver needs tend to shift to determining the need for long-term care placement vs staying at home, end-of-life planning, loneliness, and anticipatory grief.^{23,26} Support with managing changing and accumulating stress typically remains a primary need throughout the progression of dementia.²⁷

■ **Specific populations have distinct needs.** Some caregivers, including members of the LGBTQ+ community and different racial and ethnic groups, as well as caregivers of people with younger-onset dementia, may have additional support needs.²⁸

For example, African American and Latino caregivers tend to have caregiving relationships of longer duration, requiring more time-intensive care, but use fewer formal support services than White caregivers.²⁹ Caregivers from non-White racial and ethnic groups also are more likely to experience discrimination when interacting with health care services on behalf of care recipients.³⁰

Having an awareness of potential specialized needs may help to prevent or address potential care disparities, and cultural humility may help to improve caregiver experiences with primary care physicians.

RESOURCES TO SUPPORT CAREGIVERS

Family physicians are well situated to provide informational and emotional support for

both patients with dementia and their informal care providers.³¹ Given the variability of caregiver concerns, multicomponent interventions addressing informational, self-care, social support, and financial needs often are needed.³¹ Supportive counseling and psychoeducation can help dementia caregivers with stress management, self-care, coping, and skills training—supporting the development of self-efficacy.^{32,33}

■ **Outside resources.** Although significant caregiver support can be provided directly by the physician, caregivers should be connected with outside resources, including support groups, counselors, psychotherapists, financial and legal support, and formal care services.³⁴

■ **Psychosocial and complementary interventions.** Various psychosocial interventions (eg, psychoeducation, cognitive behavioral therapy, support groups) have been found to be beneficial in alleviating caregiver symptoms of depression, anxiety, and stress and improving well-being, perceived burden, and quality of life. However, systematic reviews have found variability in the degree of helpfulness of these interventions.^{35,36}

Some caregivers and care recipients may benefit from complementary and integrative medicine referrals. Mind-body therapies such as mindfulness, yoga, and Tai Chi have shown some beneficial effects.³⁷

■ **Online resources.** Caregivers also can be directed to online resources from organizations such as the Alzheimer's Association (www.alz.org), the National Institutes of Health (www.alzheimers.gov), and the Family Caregiver Alliance (www.caregiver.org).

In rural settings, such as the one in which this case took place, online resources may decrease some barriers to supporting caregivers.³⁸ Internet-based interventions also have been found to have some benefit for dementia caregivers.^{31,39}

However, some rural locations continue to have limited reliable Internet services.⁴⁰ In affected areas, a strong relationship with a primary care physician may be even more important to the well-being of caregivers, since other support services may be less accessible.⁴¹

■ **Impacts of the pandemic.** Although our case took place prior to the COVID-19 pan-



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demic, it is important to acknowledge ways the pandemic has impacted informal dementia caregiving.

Caregiver stress, depression, and anxiety increased during the pandemic, and the need for greater home confinement and social distancing amplified the negative impact of social isolation, including loneliness, on caregivers.^{42,43} Caregivers often needed to increase their caregiving responsibilities and had more difficulty with care coordination due to limited access to in-person resources.⁴³ The pandemic led to increased reliance on technology and telehealth in the support of dementia caregivers.⁴³

➤ THE CASE

The physician prescribed mirtazapine for Mr. C, titrating the dose as needed to address depressive symptoms and promote weight gain. The physician connected Mr. C's father with home health services, including physical therapy for fall risk reduction. Mr. C also hired part-time support to provide additional assistance with ADLs and IADLs, allowing Mr. C to have time to attend to his own needs. Though provided with information about a local caregiver support group, Mr. C chose not to attend. The physician also assisted the family with advanced directives.

A particular challenge that occurred during care for the family was addressing Mr. C's father's driving capacity, considering his strong need for independence. To address this concern, a family meeting was held with Mr. C, his father, and his siblings from out of town. Although Mr. C's father was not willing to relinquish his driver's license during that meeting, he agreed to complete a functional driving assessment.

The physician continued to meet with Mr. C and his father together, as well as with Mr. C individually, to provide supportive counseling as needed. As the father's dementia progressed and it became more difficult to complete office appointments, the physician transitioned to home visits to provide care until the father's death.

After the death of Mr. C's father, the physician continued to serve as Mr. C's primary care provider.

KEEPING THE "FAMILY" IN FAMILY MEDICINE

Through longitudinal assessment, needs identification, and provision of relevant information, emotional support, and resources, family physicians can provide care that can improve the quality of life and well-being and help alleviate burden experienced by dementia caregivers. Family physicians also are positioned to provide treatments that can address the negative physical and psychological health outcomes associated with informal dementia caregiving. By building relationships with multiple family members across generations, family physicians can understand the context of caregiving dynamics and work together with individuals with dementia and their caregivers throughout disease progression, providing consistent support to the family unit. **JFP**

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