

11**Caregiver stress and possible solutions**

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INTRODUCTION

Providing care for a relative with Alzheimer's disease or another progressive dementia is associated with many hardships. The course of the illness is largely uncontrollable and unpredictable, and eventual death is the only certainty. Patients may live from a few years to over a decade after the onset of dementia. Caregivers often describe their experience as one of living bereavement, as they watch the personality and intellect of their loved one disintegrate. While grieving their loved ones, caregivers also face great challenges maintaining their own quality of life. Caregiving is encompassing, requiring time, energy, and resources that place tremendous strain on an individual.

There are several different theories about peoples' response to the strains of chronic dementia caregiving (1,2). The "wear-and-tear hypothesis" suggests that, over time, caregivers' functioning will steadily decline as a result of prolonged stress. In contrast, the adaptation hypothesis posits that people will adapt to the demands of caregiving over time; their physical and mental health may ultimately stabilize or improve under strenuous circumstances. A third model, the trait hypothesis, suggests that in spite of dementia progression, caregivers may function well because of individual characteristics like personal resources, coping skills, and social supports (1).

Although the adaptation theory has received the most support, a dementia patient's symptoms cannot be defined as "worsening" or increasing; the severity and type of impairments do not proceed in a linear fashion (1). For example, patients may lose the ability to work and manage finances early on, disruptive personality and behavioral problems may appear later, and basic self-care issues are typically problematic later in illness (1). Various illness manifestations affect caregivers differently, with significant personal and social consequences. Thus, caregiver stress, commonly called burden, cannot be tied strictly to the severity of a dementia patient's illness or length of time someone has provided care. Burden is also greatly affected by factors beyond the patient's condition. A person's response to caregiving depends on their ability to manage present symptoms, their support systems, and ways of coping (3–5). The individual's perception of the larger implications and emotional meaning of their loved one's deficits, and conflicts external to their relationship with the patient also play a substantial role in caregiver well-being. By assessing both difficult aspects of caregiving and the protective effects of personal and external resources, we can better understand how caregiver stress evolves.

This chapter addresses a number of issues pertaining to dementia caregivers. First, we discuss caregiver burden, beginning with an overview of key stressful points in dementia. Next, we describe other contributors to burden,

1 including family conflict and social isolation. We explore how variations in family relationships, gender, and race may affect stress and coping. Finally, we focus
2 on the evidence behind caregiver interventions, including respite care. We conclude
3 by looking at the feasibility of individualizing caregiver assessments and
4 interventions, and the role of primary care clinicians in helping caregivers.
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8 **CAREGIVER ISSUES OVER THE COURSE OF ALZHEIMER'S DISEASE**

9 Caregivers face different issues throughout Alzheimer's disease, and these vary
10 over the course of illness. In this section, we provide an outline of common
11 dementia patient symptoms in the early, middle, and late stages of illness, and
12 caregivers' responses. Dementia is a dynamic process, and the caregiver must
13 adapt to many alterations in their day-to-day routine, responsibilities, and emotions
14 throughout illness.

15 Alzheimer's disease may initially appear as short-term memory disturbances or
16 personality changes long before formal diagnosis is made (6). These early symptoms
17 often concern caregivers; in fact, the initial diagnosis may provide some relief.
18 However, an Alzheimer's diagnosis is also stressful, raising
19 many difficult questions for caregivers and patients.

20 As cognitive changes continue, patients may have difficulty dealing with
21 money or performing tasks like shopping, causing frustrating mistakes. Caregivers
22 may also worry about the patient's safety while driving or using household
23 appliances. Patients often want to continue doing activities, which may be
24 potentially harmful, to retain independence. Meanwhile, caregivers often prefer
25 that patients avoid certain tasks to prevent accidents.

26 Differing perspectives related to patient activities are common sources of
27 conflict in early illness, and finding solutions that satisfy both parties can be
28 difficult. In addition to addressing immediate concerns, caregivers and patients
29 need to think about the future. Approaching topics such as the possibility of
30 the patient's eventual nursing home placement and advanced directives may be
31 stressful, but discussions would ideally occur while the patient has only mild
32 mental deficits.

33 In middle phases of illness, patients have poorer short-term memory
34 and communication abilities, greater personality changes, and impairments in
35 abstract thinking and judgment (6,7). These deficits lead to patient confusion
36 and repetitive questioning, which caregivers commonly describe as very burdensome.
37 Patients may also exhibit anger and agitation, which may be more distressing
38 to caregivers than cognitive changes (8,9). Depression, which is also common
39 in dementia patients, greatly worries caregivers (8). As dementia symptoms
40 become more complex, a cycle of negative emotions may begin in both the
41 caregiver and patient.

42 In addition to contributing to burden, both patient and caregiver depression
43 are risk factors for physical aggression directed toward the caregiver. Indeed,
44 nearly 25% of female caregivers experience some form of aggression from their
45 partner in the middle stages of illness (10). Women should be aware that physical
46 aggression may accompany dementia, so they can feel prepared to assert
47 themselves if needed, preventing harm of themselves or the patient. However,
48 patients may also be victims; as functioning decreases, they are at increased risk
49 for physical or verbal mistreatment (11). Caregivers are more likely to yell at or

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1 insult their loved ones if they are depressed or anxious; these actions that may
2 lead to feelings of guilt, thus increasing burden.

3 By the middle to late stages of dementia, many caregivers decide that using
4 respite care or nursing home placement is the best choice to provide optimal care
5 to their loved one and to preserve their own health. Although it would seem that
6 nursing home placement would ultimately decrease caregiver burden, this does
7 not necessarily occur. For example, a recent multi-site study looked at caregiver
8 mental health immediately and 1 year following dementia patient placement into
9 an extended care facility (12). The researchers found that while caregiver anxiety
10 decreased after placement, depression did not. Anxiety was higher in cohabiting
11 caregivers at baseline; improvement may occur when the individual no longer
12 had to deal with unpredictable behavior issues and the patient's poor health
13 status on a daily basis. In contrast, depression may have persisted after placement
14 because of new financial strains, the loss of companionship, and concerns about
15 the quality of nursing home care.

16 As the patient approaches terminal stages, it is helpful if end-of-life medical
17 care has been discussed. One survey of advanced directives showed that dementia
18 patients were more likely to have a durable power of attorney for health care and
19 living will than other ill elderly patients. By having advanced directives in place,
20 caregivers can be sure that their decisions about life-sustaining measures are
21 aligned with their loved one's wishes (13). Moreover, caregivers who are uncertain
22 about health care decisions have higher rates of depression, and preemptive
23 discussions may reduce future burden (14).

24 Despite the many difficulties of caregiving, the death of the dementia
25 patient does not reliably ease burden. The year following death, depression often
26 declines, but may remain at a significant level for several years (15,16). More
27 burdened caregivers may be particularly susceptible to depression, and may find
28 that their social networks have deteriorated, leaving them without an important
29 coping resource (15,16).

30 If available, the support of family and friends can truly make a differ-
31 ence during grieving; caregivers who have social support show reduced risk
32 for depression (15,16). Throughout illness, positive interactions with family may
33 serve as a source of strength and peace. However, in the presence of conflict,
34 family involvement may also hinder caregiver health (17,18).

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**36 ADDITIONAL CAREGIVER CHALLENGES: CONFLICTS WITH
37 FAMILY AND FRIENDS**

38 Family conflict may begin with the patient's initial diagnosis. Logically, individu-
39 als living with dementia patients, typically spouses, are the first parties to notice
40 memory loss or personality change. Often, these individuals will not share their
41 concerns with others, hoping that these alterations are temporary. However, this
42 silence may be problematic when a dementia diagnosis finally occurs: other fam-
43 ily members may then deny that symptoms are significant even when problems
44 may have been present for years. Differing perceptions of disease severity may
45 cause families to clash over the course of their loved one's illness.

46 Multiple aspects of dementia may induce family controversy, including
47 sharing caregiving and financial responsibilities. Also, it may be challeng-
48 ing for caregivers who are already strained to mediate family disagreements.
49 Families may have difficulty finding practical solutions to problems. Trouble

1 communicating within families may actually increase burden (19,20). Individual
2 or group counseling may help to improve problem solving, collaboration, and
3 conflict resolution, thereby decreasing associated burden (21). Granted, times of
4 stress may not be the most conducive for working toward better communication,
5 but changing negative patterns may significantly lower stress.

6 Friendships may be less likely to raise conflict and often provide another
7 important source of support for caregivers (4). However, as the patient's cognitive
8 and functional abilities decline, many caregivers lose contact with friends, con-
9 tributing to social isolation (16,22). While discussing taking care of her husband,
10 one woman said "The hardest part was losing all of our friends. He couldn't
11 play cards anymore, didn't enjoy dinner conversation anymore eventually they
12 stopped calling." Caregivers often report that friends are generally kind and for-
13 giving of patient behaviors when provided with clear explanation in advance.
14 However, combined with potential difficulties in orientation, walking, and conti-
15 nence, behavioral outbursts may contribute to fewer social outings and isolation.

16 Support groups are one place caregivers may feel comfortable outside their
17 homes. Many groups allow dementia patients to attend, eliminating the care-
18 giver's need for respite care. Thus, support groups are a good way for caregivers
19 to decrease social isolation, in addition to gaining knowledge and receiving emo-
20 tional support.

21 22 23 **THE ROLE OF RELATIONSHIPS, GENDER, AND ETHNICITY** 24 **IN CAREGIVER STRESS**

25 Dementia patients are most often cared for by their spouses or children. Although
26 burden is a relevant issue for all caregivers, spousal care is more prevalent, and
27 married caregivers seem to be studied more in the literature. Certain elements of
28 caregiving particularly affect spouses, who cope with losses in their intimate rela-
29 tionship while managing the challenges of cohabitation and providing daily care.

30 Spousal caregivers often take over domestic responsibilities, such as cook-
31 ing, shopping, and managing finances, that were previously assumed by their
32 partner. As changes in household functioning occur, strain may result. Addi-
33 tionally, spouses may be stressed while adapting to differences in the emotional
34 workings of their relationship. For example, the caregiver might need to adjust
35 their expressions of logic, emotion, or affection to maintain balance within the
36 marriage. Even if relationship changes are desired, adjustments may be stressful.
37 Some spouses have even commented that having a partner with Alzheimer's "is
38 like living with someone new."

39 Spouses may also be negatively affected as dementia upsets their partner's
40 sleep patterns. Dementia patients' sleep cycles are commonly abnormal, resulting
41 in odd hours of rest and wakefulness (6,23). Incontinence and yelling may also
42 disrupt the patient's sleep, and in turn, their spouse's. Whether spouses share a
43 bed or sleep separately, these disturbances can decrease the quantity and quality
44 of caregivers' rest, affecting their mood, energy, and health.

45 Adult children caring for their parents may not always experience the
46 strains of cohabitation, but are stressed in other ways. Filial caregivers, while
47 caring for their own children, may feel guilt that they are not doing enough for
48 their parents (22). In addition to being torn by family responsibilities, sons and
49 daughters may also continue working while managing caregiving.

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1 Due to competing obligations, employment can become increasingly dif-
2 ficult, and many caregivers report voluntarily cutting back work hours (24).
3 Employees may also be late or absent, and work tensions may contribute to bur-
4 den (25). Despite difficulties balancing work and caregiving, many people say
5 that their employers have been quite flexible and understanding. Still, lost work
6 time may lead to financial strain, contributing to burden.

7 Regardless of their relationship to the care recipient, women are more com-
8 monly caregivers, and they typically spend more hours providing care than men
9 (26,27). Across cultures, women report the most burden and are at greater risk
10 for depression and anxiety as the patient's health worsens (26–29). The physical
11 health of women also declines while caregiving, whereas men pay more attention
12 to their own health and are less likely to have health decrements.

13 In holding themselves to internal and societal expectations, women may
14 feel that they should be able to independently provide support to an ill relative.
15 Consequently, they may experience feelings of guilt in taking time for themselves
16 or asking for help (30). In their roles as wives, mothers, and daughters, women
17 may take sole responsibility for caregiving; if family members do not offer assist-
18 ance, women may not ask for it, even under great stress. One spousal caregiver
19 described caregiving for her husband as a nuptial and maternal duty saying "He's
20 not the kids' responsibility. I don't want him to be a burden to them."

21 Although husbands or wives may take on the role of household money man-
22 ager, greater attention has recently been given to helping elderly women manage
23 finances (31). Elderly women may experience both gender and age discrimination
24 in handling business matters, which may have been previously reduced by their
25 spouse's involvement (30,31). For both women and men who lack experience,
26 instruction in financial management may help to prevent stress by decreasing
27 actual difficulties and anxiety related to potential problems.

28 Racial differences may also affect how individuals handle caregiving stress.
29 African American caregivers may feel more positively about caregiving, and
30 may have different ways of coping. For example, they report more reliance on
31 religion, including prayer and attending formal services, and may place greater
32 importance on religion in general (32). Additionally, African American caregivers
33 are less distressed by memory and behavior problems (33).

34 Latino caregivers place a similar emphasis on religion and may be more
35 likely to use spiritual coping (34,35). Religious values may influence Latino care-
36 givers' acceptance of the role, viewing challenges as fate from God to enhance
37 spiritual growth (35). Latinos also view caregiving more positively than Cau-
38 casians. It has been suggested that differences in satisfaction may arise from the
39 cultural emphasis on family and the benefits of caregiving to the larger fam-
40 ily unit. Cultural values may translate into a greater acceptance of caregiving
41 from the beginning; Mexican-Americans take on the caregiver role earlier than
42 Caucasians, even when their relatives are less impaired (35).

43 Like Latinos, African Americans may also more readily accept caregiving,
44 due to the expectation that children will take care of their parents in old age,
45 as well as a greater traditional respect for elders in black culture. In contrast,
46 caregiving may be seen as a process that is unexpected and interruptive of plans
47 for retirement in white culture; feelings of loss that accompany caregiving may
48 extend to personal goals that an individual may have had for later life (36). The
49 aforementioned differences highlight only a few of many cultural variations that

1 may exist in caregiver beliefs, stress, and coping. It is increasingly important
2 for clinicians and researchers to acknowledge cultural differences to effectively
3 intervene in problems facing people of all backgrounds.

4 As we have shown, burden is affected not only by behaviors of the dementia
5 patient, but characteristics of the caregiver and the context of their life. Stress
6 affects the individual, their relationships with their family and friends, work
7 abilities, and the patient's health. If these are not reasons enough to be concerned
8 with stress, we turn to another consequence of caregiving: the negative effects of
9 burden on the caregiver's physical health.

10

11 **HEALTH OUTCOMES OF CAREGIVING: STRESS, IMMUNE** 12 **DYSFUNCTION, AND INFLAMMATION**

13 How significant is the caregiver's response to stress? To illustrate this point with
14 the most dramatic example, one prospective longitudinal study found that, over
15 a 4-year period, the relative risk for all-cause mortality among strained caregivers
16 was 63% higher than non-caregiving controls (37). The causes of increased mortal-
17 ity are many, but research on stress and the immune system provides important
18 insights about the interplay between stress and health, and the dangers of chronic
19 stress for older adults.

20 The immunological decrements associated with the stress of caregiving are
21 of particular concern because older individuals already have age-related reduc-
22 tions in cellular immune function with important health consequences. Older
23 adults are generally more susceptible to infectious diseases such as influenza
24 and pneumonia which are major causes of death in this age group (38). Fur-
25 thermore, caregivers appear to be at even greater risk for these illnesses. For
26 example, dementia caregivers exhibit significant deficits relative to well-matched
27 non-caregivers in their immune responses to an influenza virus vaccine (39,40).
28 Caregivers also may have poorer immune responses to pneumococcal vaccines
29 than age-matched non-caregivers (41). Adults who show poorer responses to
30 vaccines also experience higher rates of clinical illness, and these vaccine data
31 suggest that caregivers have increased vulnerability to influenza and pneumonia
32 infections, as well as other infectious agents (38).

33 The immune system also has a central role in wound healing, and
34 caregiving-related distress provokes substantial delays in wound healing (42).
35 Clinically, differences in wound healing leave caregivers susceptible to prolonged
36 pain and recovery post-surgery or injury and higher rates of infection. Repeated,
37 chronic, or slow-resolving infections or wounds enhance secretion of proinflam-
38 matory cytokines, important chemical mediators in the immune system.

39 Some of the key evidence about caregiver physical health risks comes from
40 studies on proinflammatory cytokines, and their secondary effects on stress hor-
41 mones and immune response. Cytokines modulate the body's immune response
42 by attracting immune cells to sites of infection or injury, and priming them to
43 become activated to respond (43). Interleukin-6 (IL-6) is one cytokine of partic-
44 ular relevance. Epidemiological studies of individuals 65 years or older have
45 found that the highest quartile of serum IL-6, values greater than 3.19 pg/mL,
46 was associated with twofold greater risk of death compared to the lowest quartile
47 (44,45).

48 The production of proinflammatory cytokines is stimulated by both depres-
49 sion and stress (46–50). Some of the strongest data have come from studies of

1 caregivers. One longitudinal community study assessed IL-6 production over
2 six years in 119 spousal dementia caregivers and 106 non-caregivers who were
3 matched for chronic health problems, medications, and health behaviors (51).
4 Caregivers' average rate of increase in IL-6 was about four times as large as that
5 of non-caregivers. Moreover, the mean annual changes in IL-6 among former
6 caregivers did not differ from that of current caregivers even several years after
7 the death of the impaired spouse. In this study, the data suggested that spousal
8 caregivers would have reached the upper quartile for IL-6 levels around age 75;
9 this level would not be reached by average non-caregiving controls until after
10 age 90 (51).

11 The risks associated with increased IL-6 and proinflammatory cytokines
12 have been highlighted in recent medical literature. The link to cardiovascular
13 disease, the leading cause of death, has attracted the greatest attention; the asso-
14 ciation with IL-6 is related in part to the central role that this cytokine plays in
15 promoting the production of C-reactive protein (CRP), an important risk factor
16 for myocardial infarction (52–54).

17 In addition to cardiovascular disease, inflammation has been linked to a
18 spectrum of other major health problems associated with aging, including osteo-
19 porosis, arthritis, type 2 diabetes, certain lymphoproliferative diseases or cancers
20 (including multiple myeloma, non-Hodgkin's lymphoma, and chronic lympho-
21 cytic leukemia), Alzheimer's disease, and periodontal disease (55). More globally,
22 chronic inflammation has been suggested as one key biological mechanism that
23 may fuel declines in physical function leading to frailty, disability, and, ultimately,
24 death (56–57).

25 For clinicians, these data highlight the importance of assessing both psy-
26 chosocial and biomedical risk factors in caregivers. Scientifically, the data provide
27 insight about the interplay between stress and health, and the dangers of chronic
28 stress for the elderly.

29

30 **POSITIVE ASPECTS OF CAREGIVING**

31 Although it is important to understand the significance of burden, the positive
32 aspects of caregiving must not be overlooked. Amidst the challenges, many indi-
33 viduals find enhanced spirituality, self-efficacy, and personal growth through
34 caring for a loved one. Companionship and a sense of purpose are parts of care-
35 giving that many individuals appreciate (58). The majority of caregivers report
36 that they feel needed and good about themselves, and have a greater appreciation
37 of life since they have been caring for their loved one (59). Many people say that
38 caregiving has strengthened their relationships with others, and has improved
39 their attitude toward life (59).

40 People who find positive elements in their experience are less depressed
41 and burdened than those who do not (58). Also, individuals who focus on gains,
42 rather than losses, rate their quality of life higher than those who do not (60). The
43 caregiver's outlook may change throughout the patient's illness, and positive
44 perceptions may be a useful indicator of mental health in addition to negative
45 measures, such as depression and burden (58).

46

47 **CAREGIVER INTERVENTIONS**

48 The many factors contributing to burden make it difficult to identify specific
49 interventions, even after decades of caregiver research. Typically, educating

1 caregivers on disease course, managing dementia behaviors, and addressing legal
2 and financial issues does not appear to reduce burden alone (61,62). Combining
3 educational interventions with another type of support may be more helpful (63).
4 Unfortunately, the evidence thus far is that individual counseling and caregiver
5 support groups often show only short-term effectiveness. Thus, caregivers may
6 find psychosocial interventions useful in crisis; however, they have shown lit-
7 tle success in the long-term reduction of burden and depression. Respite care,
8 assistance provided by formal, paid personnel, or unpaid family and friends, has
9 been researched more extensively than other non-pharmacologic interventions;
10 however, the results have been mixed.

11 Some studies show that respite care decreases burden, while others do
12 not (64–67). Differences may be due to difficulties accessing care, or increases in
13 caregiver guilt associated with the use of respite care. Many caregivers also use
14 respite time for work, which may contribute to stress during non-caregiving time
15 (64). Despite gaps in evidence as to its efficacy in decreasing caregiver burden,
16 respite care remains a cornerstone of caregiver support.

17 Adult day centers are the largest growing segment of respite care, ideally
18 providing meaningful activities and social interaction for dementia patients, and
19 a break for caregivers (68). Some care centers also provide meals and transporta-
20 tion. In spite of these benefits, respite care is often underutilized due to costs,
21 convenience, and the dementia patient's response to the care environment. When
22 asked why they do not use respite services, 48% of caregivers cite inconvenience
23 associated with hours and location, and program styles not matching their needs
24 (69). Health care and social service professionals can look to area Alzheimer's
25 associations, senior organizations, long-term care facilities, and adult day care
26 programs to make appropriate recommendations to their clients.

27 Adult day care costs currently averaged around \$46 per day in 2004 (68).
28 Possibly due to the cost, day care is utilized over three times more frequently by
29 households with an income over \$50,000 per year (68). Even though government
30 programs may subsidize the costs of day care for low-income families, barriers
31 still remain. Racial disparities exist as with many community resources in that a
32 smaller proportion of minorities use respite care than non-minorities (70).

33 Approximately one-third of caregivers do not use respite care because of
34 the dementia patient's negative response (69). Early stage Alzheimer's patients
35 often become depressed or irritated after day care as they are surrounded by
36 others whom they recognize as more ill than themselves. Late stage patients often
37 become agitated in any new environment, which can cause additional home stress
38 after a session at day care. Caregivers who do not use formal respite care may
39 not need it if they receive unpaid assistance from family and friends; however, if
40 people believe they have a greater duty to independently provide care, they are
41 also less likely to use respite care (70). Therefore, caregivers should be assisted in
42 finding programs that suit their needs, and encouraged to use respite care if they
43 think it would be helpful.

44 Home health is the most preferred form of respite care and may be more
45 highly utilized if available. Caregivers report greater trust with the safety and
46 quality of home health care compared with nursing home care (71). Caregivers
47 are also more likely to use respite time for patient self-care if it occurs in the home.
48 Still, conflicting research exists regarding the effects of home health on burden.
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1 For example, caregiver depression and subjective burden did not decrease over a
2 3-month period of home health assistance (72). Nevertheless, the authors suggest
3 that care provision by personnel who could also provide patient education, such
4 as nurses or social workers, may be more likely to reduce depression and burden
5 (72). Although many caregivers prefer home health, respite care outside the home
6 may be more beneficial. One excellent study showed that caregivers' feelings of
7 depression, anger, and strain decreased significantly following use of adult day
8 care for 3 months (67).

9 Research designed to isolate one type of intervention may not necessarily
10 capture circumstances that are true to life. For instance, most support groups are
11 both emotionally supportive and educational, and many people may participate
12 in these while they utilize respite care. These realistic situations are not always
13 reflected in study design. Also, researchers do not typically screen caregivers for
14 specific problems before testing the usefulness of particular interventions (73).
15 Therefore, problem-specific interventions may have better results if applied to
16 people with related needs.

17 Reviewers of caregiving literature say that multi-component interventions,
18 which include education, social support, respite, and psychotherapy, most effec-
19 tively reduce negative outcomes of caregiving (61,62,73). Multi-component inter-
20 ventions decrease depression and burden while improving knowledge and over-
21 all well-being.

23 ADDRESSING CAREGIVER NEEDS IN PRIMARY CARE

24 The implementation of multi-component, individualized caregiver interventions
25 provides a challenge: who has the time, money, and knowledge needed to work
26 with caregivers in this way? Specialized groups like the Alzheimer's Association
27 do an excellent job providing services to those with whom they come in contact.
28 However, research illustrates differences in the utilization of caregiver resources
29 related to gender, race, socioeconomic status, and geographic location. Although
30 many health care providers make referrals to these resources, many caregivers
31 do not or cannot access them.

32 The majority of caregivers report that, aside from family, physicians are
33 their primary source of support (74). Routine contact with health professionals
34 may alone improve caregiver health, by increasing social support and reducing
35 isolation (75). Specialists may provide expert advice in dementia management,
36 but family practice clinicians, including physicians, physician's assistants (PAs),
37 and nurse practitioners (NPs), may see caregivers and dementia patients more
38 frequently. Indeed, primary care providers (PCPs) may serve as the main profes-
39 sional support for some caregivers, particularly to families with limited access to
40 health care and social services (76).

41 A greater awareness of caregiver needs will help clinicians serve this pop-
42 ulation. Caregivers summarize their concerns as both emotional and practical
43 (76,77). They report needing help with dealing with change, managing compet-
44 ing responsibilities and stressors, and experiencing emotional responses to care
45 provision. As stated previously, an individual's perspective on illness and their
46 role can affect their mental health. In addition to providing emotional support and
47 screening for depression and anxiety, PCPs should encourage caregivers to seek
48 help from friends and family, and counseling or spiritual support if appropriate.

49

1 Local resources often include 24-hour helplines for caregivers or the elderly; care-
2 givers should be aware of these and also be encouraged to seek help if they ever
3 feel like hurting the patient or themselves.

4 Caregivers additionally seek advice about providing care, and finding and
5 using resources, concerns which PCPs should be prepared to address (76,77).
6 As patients' functioning decreases, a wider range of skills may be needed to
7 provide care and caregivers will likely need guidance. In addition to discussing
8 management of activities of daily living/instrumental activities of daily living
9 during appointments, PCPs should also consider referral to outside agencies for
10 assistance, including home nursing care, and physical and occupational therapy
11 (78). Eventually, respite care and adult day facilities, and long-term care or hospice
12 may be necessary (78,79).

13 By asking caregivers specifically about their own concerns with caregiving,
14 and screening for common problems such as depression, anxiety, sleep distur-
15 bance, and fatigue, clinicians can begin to assess caregiver issues. After iden-
16 tifying a particular problem, understanding the effects of patient behaviors on
17 a caregiver's condition may be important in finding effective treatment for the
18 caregiver. For example, caregiver sleep disturbance is one common problem that
19 may have multiple causes, including incontinence or patient-related issues. In this
20 case, triggers and management of patient-related behaviors should be addressed.
21 However, caregiver sleep may be additionally affected by psychological factors
22 like depression or anxiety, or poor sleep hygiene.

23 True solutions to caregiver problems may involve interventions for both
24 patient and caregiver, and clinicians must provide treatment that caregivers will
25 actually follow. For instance, many caregivers refuse to take sleeping pills for fear
26 that they will not hear the dementia patient in need, so adherence to sedating
27 medications may be low. Although less-sedating alternatives may be available,
28 some patients may strongly prefer non-pharmacologic interventions.

29 Many clinicians may not be able to schedule time to talk extensively with
30 patients and caregivers. However, longer appointments may be cost effective
31 due to the potential resultant decreases in medication and health care utilization
32 (80). For example, the results of one study showed that caregivers with detailed
33 verbal and written instructions related to sleep hygiene and regular exercise had
34 significantly higher compliance than those with written information only (80).
35 The group with more instruction also showed greater declines in depression,
36 anxiety, and health care utilization.

37 One large multi-site study compared interventions to be implemented dur-
38 ing a primary care office visit (63). One included only dementia-focused education
39 and another included the same patient education with an additional stress man-
40 agement component. The stress management portion of the intervention included
41 discussions of coping with negative thoughts and feelings, dealing with grief and
42 improving communication, and teaching anger management and relaxation tech-
43 niques. The combined educational and stress management intervention lasted
44 60 minutes per session. The inclusion of stress management assistance resulted
45 in significantly lower depression 6 and 18 months later. While these sessions were
46 "brief" with respect to some, they were not reflective of a typical 15-minute office
47 visit in primary care today. Although components of these examples of primary
48 care interventions may be useful in certain clinical settings, greater attention is
49 needed toward the feasibility of these interventions. By designing and testing

1 interventions that are widely useable, we will be better able to treat caregiver
2 stress on a clinical level.

3 Multi-component interventions, described as ideal by research, are imple-
4 mented by large groups like the Alzheimer's Association. Because these coordi-
5 nated services are unavailable to many caregivers, clinicians should strive to
6 holistically manage caregiver needs by mirroring comprehensive evidence-based
7 interventions to the best of their ability. While health care, mental health, and
8 social service providers cannot remove the causes of burden, they can certainly
9 help the caregiver to manage stressors by working together to improve the quality
10 of life of both the caregiver and the dementia patient.

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