

FAST FACTS AND CONCEPTS #419
CAREGIVER BURDEN

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Background: Patients with serious illness often require help with activities of daily living, basic medical care, social needs, and patient advocacy. Most of that support comes from family, partners, or friends as “caregivers.” Despite their will and reserve, caregivers commonly experience *burdens* which clinicians often overlook. This *Fast Fact* highlights the clinician’s responsibility to recognize *caregiver burden* and reviews evidence-based interventions to mitigate it.

Defining Caregiver Burden: While no standard definition exists, a useful framework is to consider “*the extent to which caregiving has had an adverse effect on the emotional, social, financial, physical, and spiritual functioning of the caregiver*” (1). This emphasizes both the multidimensional toll of caregiving, and the highly individualized experience (2). Each caregiver may have a different capacity for caregiving as well as threshold for feeling “burdened.” Common stressors include but are not limited to:

- Practical assistance: transportation to appointments, meal preparation, laundry, home care.
- Physical care: bathing, toileting, mouth care, hair care, transfer in/out of bed, nail care.
- Medical care: wound care, medication management and administration, prognostic uncertainty.
- Social care: companionship, encouragement, addressing unresolved issues with the patient, communication with other friends and family.
- Advocacy: helping to guide best medical care with clinicians and insurers.
- Financial distress: direct result of costs of care, lost work, insurance and/or opportunity.

Epidemiology and impact: Unpaid caregivers provide the vast majority of home care in the United States (3). Many are female who work in addition to caring for the person with serious illness (3). Caregiving is often a full-time occupation – an average estimate of 8 hours of caregiving per day over 14 months (4); 66 hours per week during the patient’s last year of life (5). Too often, caregivers are poorly prepared for the demanding, yet vital role. Distress can come in many forms including fears and misconceptions about medication administration and guilt if the patient suffers an adverse event in the home. This psychological burden can get passed on to the patient, increasing their risk of anxiety (6). Only one third of all caregivers report being asked by a healthcare provider what they need to care for the patient; even fewer are asked what they need to care for themselves (3). Caregiving has been linked to diminished quality of life, financial distress, and even mortality (7-9). Their depression risk may be even greater than patients with serious illness (10,11).

Risk factors for caregiver burden include female sex, low educational attainment, residing with the care recipient, history of depression, social isolation, financial distress, higher number of hours spent caregiving, and lack of choice in being a caregiver (11,12). Caregivers may also be at risk when care needs are continuous and indefinite, and particularly during care transitions (13). The need for medically skilled tasks such as changing catheter bags, providing wound care, or overseeing complex medication management may also place caregivers at risk for burden as well (11).

The Caregiver as Partner and Patient: The quality of caregiving — and thus the caregiver’s health and well-being — are critical to maintain the patient’s health and to enable the recipient to remain at home (14). Beyond just attending to the needs of the seriously ill patient, clinicians should explore the caregiver’s sense of well-being, their confidence to provide care, and their need for additional support. This is especially important during care transitions (e.g., recent discharge from the hospital, transition to hospice care). The Family Caregiver Alliance has developed a helpful toolkit for caregiving (www.caregiver.org). Suggested language to initiate conversations with a caregiver include:

- “*To provide the very best patient care, we need to include your needs in the care. Can you tell me how you are doing with these responsibilities?*”
- “*Many caregivers don’t want to burden others. Are there times when you need help but are reluctant to ask?*”
- “*Caregiving is a very hard job. There are community resources available by volunteer or paid help. Has anyone discussed potential community resources with you?*”

Recommendations: Research has identified several interventions that reduce caregiver burden and are associated with improvements in mood, coping, and self-efficacy. These include caregiving skills training, psychosocial educational, cognitive behavioral therapy, and cognitive reframing (16-19). These benefits can get passed on to the patient via improved physical and mental health (16). Other practical suggestions:

- Account for the needs of patients *and* caregivers when discussing treatment options.
- When appropriate, engage in advance care planning with both the patient and caregiver present.
- Utilize telehealth and mail-order pharmacies to limit travel, cost, and inconvenience (20).
- Counsel patients and caregivers on expected changes and prognosis of their underlying condition since many caregivers have limited experience on what is normal or expected.
- Utilize the “teach back” method when providing caregiver information: “*Can you explain that back to me so I can be sure I did a good job explaining it?*”
- Involve licensed social workers to access non-medical home care services (e.g., housekeeping, cooking, physical assistance) as well as medical services such as home health care, adult day-care programs, transportation, and meal delivery.
- Caregiver support groups (in-person or online), best if matched to condition of the patient (21).
- Involve chaplaincy as appropriate for spiritual care.

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