

## PROFESSION

### Caregiving takes toll on 42 million Americans

Relatives give \$450 billion in unpaid care to their loved ones, which often leads to stress and depression. There are ways physicians can help.

By KEVIN B. O'REILLY, *amednews* staff. *Posted Aug. 8, 2011.*

The number of Americans who act as caregivers for infirm loved ones continues to grow, as do the emotional, financial and medical burdens these family caregivers carry as a result. But experts said the health care system -- physicians, nurses, hospitals and manufacturers of medical equipment used at home -- can help make family caregivers' unpaid work a little easier to bear.

The newest figures, released in July by AARP, show that about 42.1 million Americans in 2009 regularly helped an adult loved one with tasks such as cooking, bathing, paying bills, visiting physicians and managing medications. That number, which equals about one in seven Americans, rose 24% from 2007.

"Being a caregiver is becoming a fact of life -- we call it the new normal," said Susan C. Reinhard, PhD, co-author of the AARP report. "If we were to try to hire people to do all the things that all the family caregivers do, it would equal \$450 billion a year."

That figure also represents an increase from 2007, when AARP tallied the unpaid caregiving tab at \$375 billion. The typical caregiver, the report says, is a 49-year-old woman with a job who also has worked 20 hours a week for five years giving unpaid care to her mother. The caregiving commitment often means lost income, lower productivity, higher stress, depression and worse physical health, studies have found.

#### "They feel invisible"

The most important step physicians and their office staff can take to help family caregivers is simply to acknowledge their role, said Reinhard, a retired nurse who is senior vice president of the AARP Public Policy Institute.

"We have done focus groups here at AARP, and the findings are crystal clear. Family caregivers will say that they feel invisible and that health professionals tend to only talk to them directly when they want something from them," Reinhard said.

"They want the insurance card. They want to know when you're going to pick up your mother from the hospital. They want you to fill this prescription. Rarely, they say, does a health professional -- a physician, a nurse, a physical therapist -- ask, 'Do you know how to do this task? Do you know how to give these medicines, or operate this medical equipment?' And then, secondly, they rarely ask caregivers, 'How are you doing? What do you need?'"

Caregivers should be viewed as an integral part of the health care team, aiding with transitions from hospital to home, medical decision-making and more, Reinhard said.

Lee A. Lindquist, MD, a geriatrician at Northwestern Memorial Hospital in Chicago, said she frequently asks her patients' caregivers about their own health.

"You're treating more than just the patient," she said. "You're treating the caregiver. Because if the caregiver isn't doing well or is at their wit's end, they're not going to be able to care for the loved one."

Physicians can help caregivers by being supportive and empathetic when they accompany their loved one to the exam room, Dr. Lindquist said.

"[Caregivers] think it's a failure if they say, 'I'm getting stressed out,'" she said. "And a lot of people feel guilty if they take out personal time for themselves or if they are not doing everything perfectly."

Another way to help caregivers is by taking the time to teach them how to care for their loved ones' health needs, said Daniel Haimowitz, MD, a geriatrician in Levittown, Pa.

"You want to do the same things with the caregivers that you do with patients," he said. "You'll be educating them, verifying what they know, teaching them what to look for, what to expect, about medication use, side effects and preventive care in the elderly."

#### Being ill-equipped

A growing source of stress for caregivers, and one with potential adverse consequences for the family members they are helping, is the medical equipment increasingly used in the home. That is one of the findings of a July report by the National Research Council, one of the National Academies.

The kind of technology employed in home health care ranges from the relatively simple, such as a blood pressure monitor that sends information electronically to the doctor's office, to complex equipment such as ventricular-assist devices.

"These devices have not necessarily been designed, labeled or provided with adequate instructional information that would effectively communicate what the needs or the limits of the technology are -- how you can safely use it, how you can maintain it ... if you aren't formally trained," said David H. Wegman, MD, chair of the National Research Council committee that published the report.

"Health Care Comes Home: The Human Factors" recommends that professional and advocacy organizations develop standards to ensure that paid caregivers know how to use medical equipment in the home. The report also says training materials should be made available to help unpaid family caregivers use and maintain medical devices correctly.

The committee also recommended that the Food and Drug Administration ask manufacturers for proof that they have followed guidelines on making their devices easier to use.

---

**ADDITIONAL INFORMATION:**

**WEBLINK**

"Valuing the Invaluable: 2011 Update -- The Growing Contributions and Costs of Family Caregiving," AARP, July ([www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html](http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html))

American Medical Association on the health risks of caregiving, including links to the caregiver health self-assessment questionnaire ([www.ama-assn.org/go/caregiverhealth](http://www.ama-assn.org/go/caregiverhealth))

AARP caregiving resource center ([www.aarp.org/relationships/caregiving](http://www.aarp.org/relationships/caregiving))

"Health Care Comes Home: The Human Factors," National Research Council, July ([www.nap.edu/catalog.php?record\\_id=13149](http://www.nap.edu/catalog.php?record_id=13149))

"Family Caregivers, Patients and Physicians: Ethical Guidance to Optimize Relationships," American College of Physicians Ethics, Professionalism and Human Rights Committee position paper, 2009 ([www.acponline.org/running\\_practice/ethics/issues/policy/caregivers.pdf](http://www.acponline.org/running_practice/ethics/issues/policy/caregivers.pdf))

---

Copyright 2011 American Medical Association. All rights reserved.

**RELATED CONTENT**

- » **End-of-life care: How you can help stressed surrogates** June 13
- » **Reaching through the fog: A rising tide of Alzheimer's disease** Dec. 20, 2010
- » **Caring for the caregiver: AMA resource shows how doctors can take active role** Editorial Nov. 24, 2003
- » **The invisible caregiver: How can doctors care for them, too?** Sept. 17, 2001