

# 'Invisible work' takes toll on unpaid caregivers

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Unpaid family and friends who assist older people with disabilities by coordinating doctor appointments and managing medications are significantly more likely to experience emotional, physical and financial difficulties than caregivers who don't provide this type of support, new research finds.

Johns Hopkins Bloomberg School of Public Health researchers, reporting in the Feb. 15 *JAMA Internal Medicine*, say such [caregivers](#) are also three times more likely to be less productive at work due to distraction and/or fatigue, a phenomenon called "presenteeism," as well as outright absenteeism. Researchers say this shows that there is a significant - and often unrecognized - cost borne by employers.

"A lot of work goes into managing the care of people with complex health needs, and this work is borne not only by [health care](#) providers and patients, but also by their families," says Jennifer L. Wolff, PhD, an associate professor of health policy and management at the Bloomberg School. "Little attention has been directed at understanding the extent of or consequences for this unpaid and invisible workforce that is vital to the care of the chronically ill. Our study aims to do that."

The study finds that in the United States, an estimated 14.7 million unpaid caregivers, most of them family, assist 7.7 million [older adults](#). Of those, 6.5 million caregivers provide substantial help with health care, 4.4 million provide some help and 3.8 million provide no help.

For their study, the researchers examined data from 1,739 family and unpaid caregivers of 1,171 older adults included in the 2011 National Health and Aging Trends Study. They found that caregivers who provide substantial help with health care activities were significantly more likely to live with the older adult they care for than those who did not help with these activities (61.1 percent vs. 37.6 percent), and they were also more likely to report caregiving-related emotional difficulty (34.3 percent vs. 14.6 percent), physical difficulty (21.6 percent vs. 5.7 percent) and financial difficulty (23 percent vs. 6.7 percent). Caregivers who provide substantial help with health care needs also provided care of greater intensity (28.1 hours per week vs. 8.3 hours per week).

Wolff says the caregiver is often the linchpin in the health care of older adults, making sure that treatment plans developed by physicians are being carried out at home, but their role often goes unrecognized in the fragmented American health care system. She says that caregivers need to be included and supported as members of the health care team and given greater access to information about patients' health and treatments, which is often a challenge because of federal patient privacy laws.

Wolff says [health care providers](#) can do a better job of involving caregivers when they accompany patients to medical appointments, recognizing their key roles and more purposefully engaging them.

"The more we know about this invisible workforce, the better we will be able to develop strategies that include unpaid caregivers as part of patients' health care team," she says.

**More information:** "A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities"  
*JAMA Internal Medicine*, 2016. doi:10.1001/jamainternmed.2015.7664

Provided by Johns Hopkins University Bloomberg School of Public Health

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