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New Report Documents Impact on Family Caregivers When Person Receiving Chronic Care Also Has Dementia, Depression, or Other Cognitive or Behavioral Conditions

More Complex Physical Health Needs and Resistance of Care Recipients Result in Greater Stress and Diminished Quality of Life for Caregivers

NEW YORK, NEW YORK August 19, 2014— The United Hospital Fund and AARP Public Policy Institute issued a report today with compelling new evidence that family caregivers who provide complex chronic care to people who also have cognitive and behavioral health conditions face particularly demanding challenges, including high levels of self-reported depression. As a result, a majority of them (61 percent) reported feeling stress “sometimes to always,” between their caregiving responsibilities and trying to meet other work or family obligations.

Adding to the challenge, people with cognitive and behavioral conditions (collectively termed in the report “challenging behaviors”) were generally sicker than other people requiring caregiving. These persons needing care often had chronic physical health diagnoses—including cardiac disease, stroke/hypertension, musculoskeletal problems (such as arthritis or osteoporosis), and diabetes—at higher rates than those without cognitive and behavioral conditions. Further illustrating the complexity, family caregivers of people with challenging behaviors often met with resistance from the person they were trying to help. Caregivers noted that “more cooperation from their family member” would make one key medical/nursing task—managing medications—easier.

Family Caregivers Providing Complex Chronic Care to People with Cognitive and Behavioral Health Conditions, a publication in the “Insight on the Issues” series, summarizes the new findings. They are drawn from additional analysis of data based on a December 2011 national survey of 1,677 family caregivers, 22 percent of whom were caring for someone with one or more challenging behaviors. Earlier findings were published in the groundbreaking Public Policy Institute/United Hospital Fund report *Home Alone: Family Caregivers Providing Complex Chronic Care* and in earlier publications in the “Insight on the Issues” series, including *Employed Family Caregivers Providing Complex Chronic Care* and *Family Caregivers Providing Complex Chronic Care to Their Spouses*.

The report concludes, “All caregivers need training and support; caregivers who are responsible for people with challenging behaviors are among those most in need of assistance.”

“Take a hard look at this profile of today’s overstretched and overstressed caregiver for someone with cognitive or behavioral issues,” said Susan Reinhard, AARP’s Senior Vice President for Public Policy. “This is the face of caregiving’s future unless we improve long-term services and support for family caregivers,” she said, pointing to the **expected surge in the incidence of Alzheimer’s disease** and the **projected drop by more than half** in the ratio of potential caregivers to those likely to need care.

Focused caregiver assessments were one of six recommendations outlined in the report. The others were better integration of behavioral and physical health programs, efforts to set up respite and adult day care programs for family caregivers, training of family caregivers to better understand and respond to challenging behaviors, better training of health care providers to work more effectively with family caregivers, and revisions to most support and training materials for family caregivers to reflect care management of the whole person, rather than just the specific condition.

“Caring for a family member is hard enough when the family member is on the same page,” said co-author Carol Levine, Director of the Families and Health Care Project for United Hospital Fund. “But when that family member has a cognitive impairment, like Alzheimer’s, or a behavioral issue, such as depression—things that can interfere with daily life as well as decision-making—the burden on the caregiver is multiplied. And currently, our health care system often doesn’t provide the kind of support that can make a difference.”

Sarah Samis, former Senior Health Policy Analyst at United Hospital Fund, was the third author of the new publication, along with Susan C. Reinhard and Carol Levine.

There are more than 42 million unpaid family caregivers in the United States.

Family Caregivers Providing Complex Chronic Care to People with Cognitive and Behavioral Health

Conditions was produced with support from the John A. Hartford Foundation. The report is available at <http://www.aarp.org/home-family/caregiving/info-2014/family-caregivers-providing-complex-chronic-care-cognitive-behavioral-AARP-ppi-health.html> or <https://www.uhfnyc.org/publications/881005>.

The earlier report *Home Alone: Family Caregivers Providing Complex Chronic Care* is available, at <http://www.uhfnyc.org/publications/880853> or www.aarp.org/homealone. The earlier “Insight on the Issues” publications are also available:

- *Employed Family Caregivers Providing Complex Chronic Care*, at <http://www.uhfnyc.org/publications/880949> or <http://www.aarp.org/home-family/caregiving/info-11-2013/employed-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.html>
- *Family Caregivers Providing Complex Chronic Care to Their Spouses*, at <http://www.uhfnyc.org/publications/880975> or <http://www.aarp.org/home-family/caregiving/info-04-2014/family-caregivers-providing-complex-chronic-care-to-spouses-AARP-ppi-health.html>.

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About AARP

AARP is a nonprofit, nonpartisan organization, with a membership of more than 37 million, that helps people 50+ have independence, choice and control in ways that are beneficial to them and society as a whole. AARP does not endorse candidates for public office or make contributions to either political campaigns or candidates. We produce AARP The Magazine, the definitive voice for Americans 50+ and the world's largest-circulation magazine; AARP Bulletin, the go-to news source for the 50+ audience; AARP VIVA, a bilingual lifestyle multimedia platform addressing the interests and needs of Hispanic Americans; and national television and radio programming including My Generation and Inside E Street. The AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. AARP has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Learn more at www.aarp.org.

About The United Hospital Fund

The United Hospital Fund is a nonprofit health services research and philanthropic organization whose primary mission is to shape positive change in health care for the people of New York. The Fund's longtime focus on family caregiving includes landmark reports, initiatives targeting health care providers, and a website (www.nextstepincare.org) with free guides to help family caregivers and health care providers work together more effectively. Learn more at www.uhfnyc.org.

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