



A United Hospital Fund Campaign

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## Family Caregivers Talk about Medication Management, Wound Care, and Video Instruction

In a series of six discussion groups conducted by United Hospital Fund's (UHF's) Families and Health Care Project, in collaboration with AARP Public Policy Institute (PPI), family caregivers reported feeling unprepared by health care providers for the complex medical/ nursing tasks they were expected to perform at home. The participants also offered valuable guidance on how video instruction could be improved to help them perform their caregiving tasks with less anxiety and stress.

The discussion groups were held in New York City, and participants included young as well as older caregivers, and both men and women. One of the six groups was conducted in Spanish, and a second in Chinese. Common themes in all the groups included lack of information from hospitals and community health care providers, failure to address emotional issues related to doing challenging tasks, and poor care coordination.

A new report, "It All Falls on Me": Family Caregiver Perspectives on Medication Management, Wound Care, and Video Instruction, summarizes key themes from the discussions, with quotes from caregivers. It also suggests a list of "do's and don'ts" for video instruction. The new report was co-authored by Carol Levine, director of UHF's Families and Health Care Project, and Susan C. Reinhard, RN, Ph.D., Senior Vice President, AARP PPI.

A series of caregiver instruction videos, produced by AARP PPI and which UHF helped develop, is also available on UHF's Next Step in Care website. Family Caregiver's Video Guide to Managing Medications includes "Guide to Giving Injections"; "Beyond Pills: Eye Drops, Patches, and Suppositories"; and "Overcoming Challenges: Medication and Dementia."

This deep dive into caregiver perspectives is an outgrowth of a joint 2012 UHF/AARP Public Policy Institute report, <u>Home Alone: Family Caregivers</u> <u>Providing Complex Chronic Care</u>. That report found that 46 percent of family

caregivers across the country were performing medical and nursing tasks such as managing medications, providing wound care, and operating equipment for a family member with multiple chronic conditions. These caregivers felt they were not adequately prepared by the health care system to perform these tasks.

## **Health Care Professionals: Watch Your Language!**

Patients and family caregivers are often at a disadvantage in discussions with health care providers. It's not just the technical terms about diseases and treatments that are unfamiliar; often it's the bureaucratic language of health care policy and insurance coverage that is mystifying. In an overview for a series of articles on language in the September issue of *Aging Today*, Carol Levine describes the difference between jargon and slang and offers some advice about <a href="Demystifying the Language of Health Care and Social Services">Demystifying the Language of Health Care and Social Services</a>. "There's no easy way to ensure that communication results in understanding," she says. "But at a minimum, professionals can explain all the terms they use, acknowledge that there are special meanings attached to some of them, and treat all questions as valid."

The Next Step in Care website, <a href="www.nextstepincare.org">www.nextstepincare.org</a>, was created by the United Hospital Fund, an independent, nonprofit organization working to build a more effective health care system for every New Yorker. All materials on the Next Step in Care website are copyrighted. They are free and can be downloaded and distributed, but may not be altered or condensed without permission. To make suggestions or comment about the website, send an e-mail to <a href="mailto:nextstepincare@uhfnyc.org">nextstepincare@uhfnyc.org</a>. If you do not want to receive further emails related to Next Step in Care or from United Hospital Fund on any subject, please click on the corresponding link below.

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United Hospital Fund 1411 Broadway, 12th Floor, New York, NY 10018

Phone: 212.494.0700 | Fax: 212.494.0800 | Email: info@uhfnyc.org

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