Understanding the CARE Act: New Guides for Patients and Caregivers

What is the CARE Act? What does it mean to me if I’m a hospital patient or that person’s family caregiver? United Hospital Fund (UHF) has prepared two free guides to help patients and caregivers understand New York State’s Caregiver Advise, Record and Enable (CARE) Act (not to be confused with the federal Affordable Care Act).

Hospital staff often say that discharge planning begins at admission. Family caregivers, however, often feel that planning begins just before discharge—and without their participation. Many caregivers don’t feel prepared to take on new responsibilities and perform new and often challenging medical/nursing tasks. Filling that gap is the goal of the CARE Act, which was developed by AARP to require hospitals to include family caregivers in the discharge planning process and receive instructions about post-discharge care. Over the past two years more than 30 states have enacted versions of the CARE Act. The legislation grew out of the conclusions in the AARP/UHF study Home Alone: Family Caregivers Providing Complex Chronic Care.

The basic elements of the CARE Act are the same in all states, so the guides can be a starting point for caregivers in all the states that have CARE Acts. The guides—a short version and a longer, more detailed document—are free and available on the Next Step in Care website in English, Spanish, Chinese, and Russian. There is a user survey to provide feedback on the guides.

New York State’s CARE Act requires hospitals to:

- Ask the patient if he or she wishes to identify a caregiver—a person who will be able to assist with care at home; document that person’s contact information in the medical record
- Obtain written consent from the patient to share personal medical information
- Inform the caregiver about anticipated discharge date
- Provide instruction to the caregiver about care needs at home
UHF has also created a toolkit that helps hospital staff meet CARE Act requirements for engaging family caregivers and patients as they move from the hospital to home. The CARE Act materials were funded by The Fan Fox and Leslie R. Samuels Foundation, Inc.

**When Caregivers Call for Help, Who Will Answer?**

Carol Levine, director of UHF’s Families and Health Care Project, was named a “2016 Influencer in Aging” by Next Avenue, public media’s only digital publication dedicated to covering issues for older Americans.

Next Avenue asked Ms. Levine, “What is the one thing you would change about aging in America?” Her response: “Meeting the caregiving needs of older adults should be seen not only as a family duty but also as a responsibility shared with health care professionals, community leaders, employers, and public officials. Family caregivers need many sources of help to achieve the best possible health, well-being, and quality of life for both the people they care for and themselves.”

Next Avenue invited all of the 2016 "influencers" to write longer essays about needed changes related to aging in America. Ms. Levine's essay, *No Caregiver Is an Island, Though It May Seem That Way,* which builds on her short statement, appeared on both NextAvenue.com and Forbes.com.

**Long-Term Care Insurance on the Air**

As the population ages, and as long-term care becomes increasingly expensive, should people buy long-term care insurance? That was the starting point of a radio discussion on “Morning Shift,” produced by WBEZ, Chicago Public Media. The program featured Carol Levine and a Chicago-based insurance agent, and the questions ranged beyond insurance to cover some more general aspects of long-term care.

For more commentary on family caregiving and transitions, join the conversation on our page!

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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