

# Carol Levine

## Advocate for the life-changing roles of family caregivers

BY CINDY HODNETT

Even people who are considered well informed about the health care system face difficult decision-making challenges when a medical crisis occurs, but for Carol Levine, the experience was life changing. A health policy and medical ethics specialist who suddenly found herself in a caregiver role after a tragic accident, Levine decided to use her personal experience to help others facing similar circumstances.

“My husband and I were in an automobile accident in January 1990,” Levine explains. “I was not injured, but he suffered a severe brain stem injury, was in a coma for four months and in rehab for months after that. He regained consciousness, but was left quadriplegic and with significant cognitive problems and depression. I cared for him at home for 17 years, until his death in 2007.”

Levine says that she, like many people in a new caregiver situation, was frequently overwhelmed by the demands of her transformed life.

“I learned how life can change so completely and suddenly,” she says. “Everything about the experience was difficult—the emotional upheaval, the financial drain, the lack of support from professionals once the acute phase was over, the isolation, the impact on my health.

“I thought I knew my way around the health system, but when it came to my husband’s care, I couldn’t cope,” Levine continues. “I was told that what I was going through was my problem, but I finally came to the realization that it was a system problem. Our health care system has been so focused on acute care—which was the reason my husband’s life was saved—that it hadn’t

dealt with chronic illness and disability, much less the caregiver’s role in providing and managing care.

“In 1996, I joined the United Hospital Fund (UHF), which is a nonprofit health services research and philanthropy organization, to bring more attention to both those issues.”

Since joining UHF, Levine has been active in research, advocacy and program development that focuses on family caregivers. She also works on Next Step in Care, a program designed to improve patient transitions from one health care setting to another. The program includes 16 guides for family caregivers in English and Spanish, and it covers issues like medication management, discharge planning, caregiver needs assessment and home care and rehabilitation, all topics that affected Levine personally during her husband’s convalescence.

“One of our goals is to change provider practice so that they routinely include family caregivers in transition planning and implementation and inform family caregivers about how to navigate the health care system,” Levine says. “People who are suddenly placed in a caregiver role have to make some quick decisions about treatment, immediate needs, etc. But I urge people to postpone major life decisions until they have time to consider all the options and their consequences. For example, some people immediately think they have to leave their jobs and become full-time caregivers. That may be the right choice, but it shouldn’t be made hastily.”



For more information, go to [www.nextstepincare.org](http://www.nextstepincare.org).





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## FAMILY CAREGIVERS & HEALTH CARE PROFESSIONALS WORKING TOGETHER

Next Step in Care, a project of the United Hospital Fund, seeks to improve collaboration between family caregivers and health care professionals especially during times of care transition, when a patient moves from one health care

setting to another. These are critical times in patient care and family caregivers often assume tremendous responsibility for follow up care, yet are seldom integrated into the transition process. The project's website [www.nextstepincare.org](http://www.nextstepincare.org)

has 16 web-based guides for family caregivers that offer simple, and practical information about transitions and follow up care. Examples include medication management, assessing one's needs as a caregiver, and planning

for discharge. The guides are available in English and Spanish and will be translated to Chinese and Russian in the near future. Additional guides are under development. All materials are downloadable for free.

