



The Bumpy Ride From Hospital to Home

By [Jane Gross](#)

The [United Hospital Fund](#) of New York has launched a Web site offering a variety of materials intended to smooth transitions for patients moving home or from one facility to another.

One of the worst days in [Carol Levine's](#) 17-year caregiving experience came in 1990, when her late husband, Howard, was transferred from an acute care hospital to a rehabilitation center five months after a car accident that had left him a quadriplegic with traumatic brain injury.

In the hospital, medical professionals had done everything, rebuffing her help. They'd seemed glad when she had left at the end of visiting hours, she recalled in a recent interview. Yet in the rehab facility, where her husband would spend a year, Ms. Levine

was expected to participate in his therapy, feed him when his tracheotomy tube was removed, calm him when he became agitated or violent — and do his laundry.

It wasn't that Ms. Levine resented the hard work and time commitment, she said, but rather that nobody in the hospital had prepared her for what would happen in rehab, just as the rehab staff would not prepare her for what lay ahead once she took her husband home. Until Howard Levine's death last year, aides cared for him 12 hours a day. The rest of the time, Ms. Levine handled these duties on her own. It was a daunting experience that I suspect few of us would survive without resorting to a nursing home. What galled her the most, though, was being ignored or disrespected by professionals and left to fend for herself.

As a result, transitions from one care setting to another have informed Ms. Levine's writing, research and [advocacy](#) as director of the families and health care project at the United Hospital Fund of New York. Now that preoccupation has culminated in an ambitious campaign called [Next Step in Care](#), which launched on Tuesday with a Web site designed to help health care professionals and family caregivers learn to handle these hand-offs, as they are known in the trade, in a way that is safer for the patient and less frightening for the caregiver.

The Next Step in Care project is, at heart, an acknowledgment that 80 percent of the long-term and chronic care in the United States is provided by family members and friends. This informal workforce — a critical part of the nation's health care delivery system — is generally unpaid, untrained and unrecognized. Much of the stress experienced by caregivers, Ms. Levine argues, "comes from a lack of confidence, feeling they're not doing a good job and that the professionals aren't helping them." The result: nursing home placements, medication errors and repeated hospitalizations that could have been avoided.

The site provides guides and checklists for professionals and family caregivers specific to each transition — from hospital to rehabilitation, for instance, or from rehabilitation to home. The materials for families are available for free in both English and Spanish. Additional guides are planned for the transition from short-term rehab to a permanent nursing home placement, and from active medical treatment to hospice care.

The content was developed by Ms. Levine and her staff with feedback from doctors, nurses, social workers, caregivers, academics and a health literacy expert. She describes the offerings as "task-oriented" and "not likely to solve your emotional problems or give you a warm fuzzy feeling."

That is true. Still, I have yet to find a Web site for caregivers with more useful information, clearly presented and targeted to one area of need. These guides have been tested in four hospitals, four rehab units and two home-care agencies in New York City. In all, 300 staff members were advised as to how to present these instructions, and 700 binders were distributed to family caregivers explaining the transitions from one setting to another.

After the initial tests, the staff members were debriefed and the families surveyed on what worked and what didn't. The written material was widely praised, Ms. Levine said, and the experience of testing it gave her "a better sense of the pressures the professionals were under."

The responsibility for patient transitions falls to nurses, social workers, discharge planners and physicians, each handling a different part of the process, sometimes with virtually no advance notice if an insurer refuses further coverage. Many staffers agreed that better coordination was sorely needed but felt that integrating this kind of instruction into the routines of discharge would be a challenge.

For Ms. Levine's program to succeed, health facilities will need to coordinate the responsibility, perhaps assigning it to one person with the skills to identify a caregiver's strengths and limitations, someone who devises a realistic plan based on what a caregiver can and cannot do. Time will tell if that happens. For now, I suspect many caregivers will find the new Web site extraordinarily useful.