

## HEALTH JOURNAL

# Home Sick: When the Burden Of Care Falls on the Family

Last fall, I wrote about how important it is for hospital patients to have a friend or family member act as an advocate. A few readers wrote to say that a hospital stay can be a breeze compared to bringing a patient home.

Suddenly, responsibility for monitoring, medicating and meeting other needs shifts to the family. “We’re asking family members to do things that even professionals find difficult—like taking care of complex wounds,” says Diane Mason, editor in chief of the American Journal of Nursing, which devoted an issue to the topic in September.



By Melinda Beck

Patients are being discharged “quicker and sicker” than ever, as insurance companies and Medicare seek to limit costly hospital stays. The number of patients who needed home health care after being discharged grew 53% between 1997 and 2006, according to the U.S. Agency for Healthcare Research and Quality.

Families often get little instruction and little warning. “You get this call where they say, ‘We’re discharging your father in two hours and we hope you have a hospital bed at home,’ or ‘Here’s a list of home-health agencies—go check them out,’” says Bonnie Lawrence at the Family Caregiver Alliance, a nonprofit resource center in San Francisco.

Increasingly, patients who can’t yet manage at home are being transferred to less costly nursing homes temporarily. Those “sub-acute care” facilities are also under pressure to

limit stays, so a patient may have several unsettling transitions in a short period of time.

Experts say families should be proactive in finding out what to expect, particularly if someone will need to leave work or arrange child care to care for a patient. Some tips:

**Be prepared.** In some hospitals, discharge planners begin assessing conditions at home as soon as a patient is admitted. “If that doesn’t happen, inquire yourself,” says Ms. Mason. “Ask when will the patient come home and what will they need and for how long.” If the patient will have difficulty walking, you may need to move furniture and pick up rugs.

**Know your rights.** Discharge decisions are often dictated by insurers or Medicare. But you have the right to appeal if you think the patient isn’t ready. By law, the hospital must tell you how to go about that. Enlist the doctor’s help and act quickly. Hospitals try to avoid readmitting patients.

**Learn as much as you can.** Ask the nurses to demonstrate any tasks you’ll have to take on at home. Be sure to ask what symptoms to watch out for—like pain, fever, shortness of breath—and what to do if they occur. “There should be written instructions for everything. If you can tape record your conversations, even better. You won’t remember everything,” says Ms. Mason.

**Understand home care.** “People assume from old movies that there’s going to be a nurse in a white cap hanging around the bed all day. That’s not going to happen,” says Carol Levine, director of the Families and Health Care Project at the United Hospital Fund, a nonprofit in New York

City. If a doctor orders “skilled care”—from a visiting nurse or physical therapist—it’s generally for just a few hours a week. A home-care agency will assess whether the patient needs “custodial care”—such as help with bathing or dressing. That may or may not be covered by insurance. Either way, home care is usually very limited. Most day-to-day care will



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likely fall to the family.

**Organize the family.** Designate a primary contact so hospital personnel don’t get mixed signals. Plan in advance who’ll help the patient and where. Recognize that old family roles have changed, tension is common and patients may be frightened and loath to be a burden. “Nobody’s comfortable with it—but somebody has to take responsibility and you can’t go through 10 years of therapy to determine who Mom really likes best,” says Ms. Levine.

**Investigate resources.** The United Hospital Fund has a detailed guide to these issues at [www.nextstepincare.org](http://www.nextstepincare.org). The Family Caregiver Alliance lists resources for every state—look for the Family Care Navigator at [www.caregiver.org](http://www.caregiver.org). You can also find a local Area Agency on Aging at [www.eldercare.gov](http://www.eldercare.gov) or dial 211 for local assistance programs.

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