Seniors who want to be left alone at home double their risk of being readmitted, study says

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The 84-year-old man who had suffered a mini-stroke was insistent as he spoke to a social worker about being discharged from the hospital: He didn't want anyone coming into his home, and he didn't think he needed any help.

So the social worker canceled an order for home health care services. And the patient went back to his apartment without plans for follow-up care in place.

When his daughter, Lisa Winstel, found out what had happened she was furious. She'd spent a lot of time trying to convince her father that a few weeks
of help at home was a good idea. And she'd asked the social worker to be in touch if there were any problems.

Similar scenarios occur surprisingly often: As many as 28 percent of patients offered home health care when they're being discharged from a hospital -- mostly older adults -- say "no" to those services, according to a new report.

Understanding why this happens and what can be done about it is important -- part of getting smarter about getting older.

Refusing home health care after a hospitalization puts patients at risk of a difficult, incomplete or slower-than-anticipated recovery. Without these services, older adults' odds of being readmitted to the hospital within 30 or 60 days double, according to one study.

Why, then, do seniors, resist getting this assistance?

"There are a lot of misperceptions about what home health care is," said Carol Levine, director of the United Hospital Fund's Families and Health Care Project, a sponsor of the new report.

Under Medicare, home health care services are available to older adults who are homebound and need intermittent skilled care from a nurse, a physical therapist or a speech therapist, among other medical providers.

Typically, these services last four to six weeks after a hospitalization, with a nurse visiting several times a week. Some patients receive them for much longer.

Many seniors and caregivers confuse home health care with "home care" delivered by aides who help people shower or get dressed or who cook, clean and serve as a companion. The two types of services are not the same: Home health care is delivered by medical professionals; home care is not. Nor is home care covered by Medicare, for the most part.

This was the mistake Winstel's father made. He thought he was being offered an aide who would come to his apartment every day for several hours. "I don't want a babysitter," he complained to Winstel, chief operating officer of the Caregiver Action Network.
Like many other seniors, this older man was proud of living on his own and didn't want to become dependent on anyone.

"Older adults are quite concerned about their independence, and they worry that this might be the first step in someone trying to take that away," said Dr. Leslie Kernisan, a San Francisco geriatrician and creator of the website Better Health While Aging.

Other reasons for refusals: Seniors see their homes as sanctums, and they don't want strangers invading their privacy. They think they've been getting along just fine and have unrealistic expectations of what recovering from a hospitalization will entail.

Or there are circumstances at home -- perhaps hoarding, perhaps physical neglect -- that an older adult doesn't want someone to see. Or the patient's cognition is compromised and he doesn't understand his needs or limitations. Or cost is a concern.

Robert Rosati, vice president of research and quality at Visiting Nurse Association Health Group, New Jersey's largest private home health care provider, said about 6 percent of seniors who've agreed to receive home health care from his organization after a hospitalization end up refusing services.

Often, a breakdown in communication is responsible. Patients haven't been told, in clear and concrete terms, which services would be provided, by whom, for how long, how much it would cost and what the expected benefit would be. So, they don't understand what they're getting into, prompting resistance, Rosati said.

Kathy Bowles, director of the Center for Home Care Policy & Research at the Visiting Nurse Service of New York, suggests a plain-language, positive way to convey this information. For example: "A nurse will check your medications and make sure they're all in order. She'll assess if you need physical therapy to help you regain your strength. And she'll teach you and family members how to care for you once home care is over."

"A lot of resistance arises from pride," said Bowles, also a professor of nursing excellence at the University of Pennsylvania. "The conversation has to change
from 'Look, we think you really need help,' to 'We want to help you take care of yourself.'

Emphasizing that a physician has recommended home health care can also be helpful. "In my experience, if a doctor says 'I'd like a nurse to come see you and check that you're feeling better,' people are fairly responsive," Kernisan said.

Instead of arguing with an older adult who says "I don't want any assistance," try to follow up by asking "Tell me more. What are you concerned about?" Kernisan suggested. "People really want to feel listened to and validated, not lectured to."

This isn't to suggest that persuading an older adult to accept unwanted help is easy. It's not.

Last year, Winstel's father had a medical device implanted in his spine to relieve pain from spinal stenosis -- an outpatient procedure. Once again, he declined postoperative help.

Two days later, Winstel got a phone call from her dad, who had collapsed and couldn't get up from the floor. Winstel said she'd call 911. "No, I don't want someone coming in and finding me like this," her father insisted. "You have to come."

Later, at the hospital, doctors diagnosed an adverse reaction to medication and a surgical site infection on her father's back. "He lives alone. He can't reach back there. He wasn't caring for the wound properly," Winstel explained.

Extensive, heated conversations followed, during which her father insisted he was never going to change. "For him, living independently carries risks, and he's willing to accept those risks," Winstel said.

She hopes the new report on seniors refusing home health care will jump-start a conversation about how to bring caregivers into the process and how recommendations should be conveyed. "As the daughter of someone who has refused care, understanding that this is something lots of people go through makes me feel a little less crazy," Winstel said.