

How to spend your final months at home, sweet home

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There's no mystery about what older adults want when they become seriously ill near the end of their lives.

They want to be cared for at home. For as long as possible.

It's easy to understand why. Home represents familiarity, safety and identity - the place where we belong.

Yet [health systems](#) aren't rewarded financially for making "time at home" a priority like they are for reducing the number of patients readmitted to hospitals.

Researchers from the Dartmouth Institute for Health Policy and Harvard Medical School argued that should change recently in the *New England Journal of Medicine*.

Health systems should focus on "outcomes that matter to patients," they wrote, citing a new national analysis of [terminally ill patients](#).

Where these patients - most of them older adults - spent their last 180 days varied significantly across the country. People had the most time at home in Mason City (145.82 days) and Waterloo, Iowa (144.61 days), and the least time at home in Idaho Falls, Idaho (118.83), and Shreveport, La. (119.15 days).

Multiple factors contributed, including the availability of medical and

social services and seniors' financial and caregiving resources.

Do a few more weeks spent at home matter? Yes, if what patients truly value is taken seriously, the researchers asserted.

They describe a patient who had been in the hospital six weeks and finally returned home accompanied by a family member. "Just to see familiar photos on the wall made us feel we could breathe again," that family member said.

What's needed to make care at home possible during the last six months of life? We asked several experts:

Reallocating resources. "We have to reallocate resources within the healthcare system to the home setting," said Dr. Diane Meier, a geriatrician and director of the Center to Advance Palliative Care in New York City.

This is already happening, to some extent. Medicare is testing the feasibility of bringing comprehensive medical services directly to frail, ill seniors through its Independence at Home demonstration project, now in 14 locations.

And house call programs that send physicians into seniors' homes are beginning to expand across the country. To find a program near you, check www.aahcm.org/?Locate-A-Provider, sponsored by the American Academy of Home Care Medicine.

Clarifying priorities. If staying at home at the end of life is a priority, this has to be communicated - clearly and frequently - to your family, caregivers, and physicians, said Dr. Thomas Lee, co-author of the *New England Journal of Medicine* study and chief medical officer at Press Ganey, a firm that tracks patients' experiences with care.

Tradeoffs have to be part of this discussion.

Lee gives the example of his 89-year-old mother, who lives by herself in a condominium in Boston's Beacon Hill neighborhood. Though she's fallen several times, she's refused to consider moving to assisted living or having a paid caregiver come in to help.

Being safe isn't his mother's foremost goal; independence is, Lee said. And that means accepting the risk that she could fall again or hurt herself.

Every time he sees a frail elderly patient, Dr. Thomas Cornwell asks "do you want to go to the hospital if you get sicker or do you want to stay at home?"

"If a crisis occurs, let's say an exacerbation of congestive heart failure, and your values haven't been discussed, you'll generally end up in a hospital and, at least temporarily, in a nursing home," said Cornwell, who has made over 32,000 house calls and is affiliated with Northwestern Medicine in metropolitan Chicago.

Making medical decisions. Take advantage of services designed for people with serious illnesses who need help at home.

One is home-based palliative care, which addresses worrisome symptoms such as pain or nausea that otherwise could send a vulnerable older adult to a hospital. In this model, a doctor, nurse and social worker join together to address a patient's needs after a comprehensive assessment.

Home-based palliative care is still relatively new and not widely available. To learn more about programs in your area, go to www.getpalliativecare.org. Contact a few and ask if they offer these

services or know of another organization that does.

Hospice care is similar in its approach, but only for people expected to live six months or less. The vast majority receive care in their homes. Unfortunately, most adults wait to sign up for hospice services until the last several weeks of life, missing out on potentially valuable assistance.

Getting needed help. Meier worries that an emphasis on home-based care for people with terminal illness could translate into more work for family caregivers who shoulder the burden of this care, not more support.

Currently, caregivers patch together services as best they can. Medicare doesn't pay for aides who help frail, ill seniors bathe, dress, toilet, take their medications, keep their house clean, and prepare breakfast, lunch or dinner. Low-income seniors can qualify for help from Medicaid, but the amount of assistance available is limited and varies by state.

There's no easy solution to this "how can I get the help I'll need?" dilemma. Be realistic about the cost of care (about \$10 per hour, on average, with wide geographic variation) and the resources you have available. Also, be realistic about other elements of caring for someone at home, including the skills that will be required and whether the environment can support this challenge.

"Are the bedroom, the bathroom, and the kitchen on the same floor?," asked Cornwell. "If not, you're going to have a problem."

Building community. "You're going to need support" from family, friends or other social contacts if you're trying to manage a serious illness at home, said Laura Connors, executive director of Beacon Hill Village in Boston.

Her organization sends volunteers into seniors' homes to help in various ways on an as-needed basis. Older adults pay an annual fee to participate in the community's social events and qualify for discounted [home](#) care services.

As with children, it "takes a community" to care for vulnerable [older adults](#), Connors said, and you need to know "who's going to be there for you."

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