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Aging and Unhoused: What End-of-Life Care Looks Like

Non-medical community homes provide dignified care to older adults who are homeless and terminally ill

By **Terry Ann Donner** | December 2, 2024 | **End of Life**

Karen Robyn is a 62-year-old homeless woman on disability, living on the east side of Cleveland; she fears dying alone on the streets or in a hospital hooked up to machines she doesn't want to use. Others share her fear.

Clarehouse in Tulsa, Oklahoma, one of a new kind of nonprofit community homes for unhoused people who are dying and have no caregiver support. | Credit: Courtesy Clarehouse

For the 138,098 people aged 55 and older experiencing homelessness and 5 million older adults living below the poverty level, dying alone and unhoused is a real concern.

When someone is homeless and seeks medical care at an emergency room without legal documents that clearly state the person's health care wishes or identify someone authorized to make decisions for them, medical staff may employ the full range of life-sustaining treatments. These can include artificial ventilation, cardiopulmonary resuscitation, intravenous infusions, intubation, medications and transfer to an intensive care unit.

> **"I do not trust those people. They push you around and don't let you have your things or smoke."**

If there is no designated decision-maker, medical personnel may insert a feeding tube and transfer the patient to a nursing home.

Few Unhoused People State Their Wishes

Hospitals provide acute care. When an older homeless person, waiting for an opening in a shelter, remains in a hospital, without curative treatment, Medicare or other insurers don't pay the hospital. This motivates hospitals to make quick discharges to shelters once these patients are stable, even if they are terminally ill.

The Hope-Home study, a long-term research project funded by the National Institute on Aging, found that less than 9% of older people experiencing homelessness complete advance directives.

Robyn, who agreed to talk with me only if I don't use her real name, does not have a durable power of attorney for health care or a living will, and has no one in Ohio to make decisions on her behalf. She has not talked to the social worker at the shelter or hospital about documenting her choice not to be put on machines.

Lack of Trust in the System

Robyn raised her voice, and her eyes narrowed as she said, "I do not trust those people. They push you around and don't let you have your things or smoke." Robyn has her belongings packed neatly in a folding shopping cart, and stays in a bus shelter, the post office lobby or a low-budget hotel for a few days, rather than a shelter.

Like many other homeless people, Robyn has had negative experiences with shelters and the health care system. She is not comfortable with rules or structure and is resigned to the fact that she has no one to help her.

Many homeless shelters only provide a place to sleep at night. Emergency shelters may provide some limited 24-hour housing. With the increasing rate of homelessness in the United States, especially among older adults, who often have chronic or terminal conditions, there is an urgent need to find housing where they can receive around the clock caregiving and hospice services.

To receive hospice care, you must have a stable home environment and a caregiver available 24 hours a day. A tent on the street or a random hotel room are not stable home environments. A few hospices will go into tent communities and other places where homeless people stay, to provide limited care. With outside fires being used for warmth, oxygen often cannot be provided. Pain medications cannot be left in these settings because of the high risk of theft.

A New Alternative to Hospice Care

However, a viable solution has been quietly growing in communities across the country. Small nonprofit community homes provide hope for terminally ill people who do not have a reliable caregiver or a stable living environment. These small homes, usually caring for up to 4 to 10 guests at a time, provide "family" caregivers and a safe place to receive end-of-life care. They are developing outside of the health care system and receive no federal or state funding.

Clarehouse interior, Tulsa, Oklahoma | Credit: Courtesy Clarehouse

Kelley Scott, executive director of the Omega Home Network and Clarehouse in Tulsa, Oklahoma, explains that the network's mission is to "foster the development of nonprofit community homes for people who are dying and have no caregiver support" due to a lack of family, homelessness or family dysfunction. The network has 135 members with 55 homes providing care and another 70 to 80 homes in development.

The Omega Home Network provides its members with a step-by-step plan for creating a nonprofit community home; written policies and procedures to run the home; an annual educational conference; monthly meetings; fundraising information; and other online support.

How Community Homes Work

Scott explains that community homes address the social and caregiving needs of the terminally ill. Most do not charge for their care and are usually not required to be licensed.

> **"Community homes fill a gap for hospice and the health care system."**

These homes contract with local hospices to provide medical care to their terminally ill guests. Each guest must be under the care of one of these hospices to stay in a community home. Reimbursed under Medicare Part A, hospice provides an interdisciplinary team of caregivers, including a nurse, social worker, home health aide and chaplain who come intermittently. Hospice also provides medical equipment and medications that are needed for end-of-life care.

The hospice nurse visits once or twice a week, the home health aide may visit up to five days per week, and the chaplain and social worker come every couple of weeks. The day-to-day assistance with basic activities of daily living like bathing, getting up in a chair, eating, grooming and toileting are provided by community home caregivers.

"Community homes fill a gap for hospice and the health care system," says Scott. Caring for 350 to 400 terminally ill guests per year, paid caregivers at Clarehouse are like family caregivers, helping with meal preparation, laundry, physical care and carrying out instructions from hospice, including the administration of oral or topical medications.

> **Clare House also has 100 volunteers who sit and talk with guests, take them to appointments, bring food and meals, help**

Clare House also has 100 volunteers who sit and talk with guests, take them to appointments, bring food and meals, help with cleaning, gardening and home repairs. Some bring their pets or make crafts with guests. They also provide emotional support to family and friends who visit.

Community Support Is Vital

> **with cleaning, gardening and home repairs.**

In Chattanooga, Tennessee, a social worker named Sherry Campbell founded another member of the Omega Home Network, Welcome Home of Chattanooga, in 2015. It has a four-bedroom home for terminally ill homeless guests, and recently added two cancer respite homes, each with three-bedrooms for homeless guests receiving cancer treatment.

Michelle Goble, the "director of happiness" in charge of daily operations, explains that guests are referred to Welcome Home by hospitals, hospices or health clinics. Some come directly from the community and are immediately connected with a hospice if they are terminally ill.

Welcome Home has a small paid staff and many volunteers. Goble proudly shares that 50% of Welcome Home's funding is from individuals who give $20 to $25 a month. The remainder comes from local fundraising events or grants from philanthropic or family foundations in the area.

How to Prepare

Goble emphasizes that Welcome Home staff and volunteers get as much inspiration and support from the guests as the guests get from them. She says she is always amazed at the number of hours joyfully given by volunteers and the amount of food, money and supplies provided by the local community.

As for Robyn, two community homes exist in the Cleveland-Akron metro area. She needs to document her end-of-life care wishes in a living will, including any desire to be admitted to a community home if she becomes terminally ill. She should then ask any hospital or clinic that cares for her to place a copy of this living will in her medical record.

Terry Ann Donner is a registered nurse, elder law attorney and health reporter who writes about aging with dignity, managing chronic health conditions and obtaining quality care. Her work has appeared in Next Avenue and Healthnews. Find her at RNWriteNow.com, with Donner Health Communications LLC. Read More

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