

Top Ten Operational How-To's

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1. Understand the Model

- Website:
<https://www.omegahomenetwork.org/>
- Literature: **An Introduction and Overview of Social Model Hospice Care**, Grant, Hilary Shirah MSN, RN, CHPN; Scott, Kelley Kathleen BSN, RN, CHPN. Journal of Hospice & Palliative Nursing: October 2015 - Volume 17 - Issue 5 - p 456–461
- Member Forum:
<https://forum.omegahomenetwork.org/>
- NOT Medical Hospice or Inpatient Hospice



Feature Article

An Introduction and Overview of Social Model Hospice Care

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The purpose of this article is to introduce the social model hospice as an option for families facing the harsh realities of caring for a loved one at the end of life as well as addressing the gap that exists between desired and actual place of death for hospice patients.

Honoring the individual's values, goals, and informed preferences, the social model hospice complements and enhances traditional medical hospice care. This model of care is provided in a community home, utilizing a network of volunteers and paid staff, in combination with traditional medical hospices, addressing the lack of resources and the burden often accompanying the care of the dying. Cantor (*Ann Am Acad Polit Soc Sci*. 1989;503:99-112; *Gerontologist*. 1991;31(3):337-346) introduced the idea of social care with the elderly, but recently, this concept has been expanded to include end-of-life care. Early research has shown that caregiver well-being and bereavement are improved with the utilization of a social model hospice. Grassroots, geographic expansion of this community-based model offers one solution to mitigating the growing caregiver crisis.

placing additional stress on families to provide increasingly complicated care. These families are also juggling other daily activities, such as the care of children and work outside the home. As the aging population continues to grow, the struggle for many families to provide end-of-life (EOL) care for their loved ones within the traditional medical hospice model will intensify.

Within our complex health care system, dying people are often isolated and suffering unnecessarily. Those caring for loved ones at home are often overburdened physically, emotionally, and financially. These dynamics drive a need for a cultural shift in the delivery and quality of care during the final days, and the social model hospice (SMH) offers a viable solution. The SMH is a community home with 24-hour care, accessed when the care needed to die at home exceeds an individual's support network of family and friends. The model enables dying individuals to define their final days while receiving care in a noninstitutional, homelike environment utilizing both volunteers and paid staff. Collaboration between the SMH and the traditional medical model hospice bridges the gap in care that the medical hospice alone cannot fill. Traditional medical hospice programs serve as the case managers providing the full breadth of the Medicare Hospice Benefit (MHB), whereas the SMH provides the environment and hands-on care. For families, the caregiver burden is alleviated, and they are able to reclaim their family member role, participating more fully in the process as a spouse, child, mother, father, family member, or friend. Within this model, individuals and families can redefine the dying process as a family event, rather than a medical one, empowered to define and live out their individual definition of quality living throughout the dying process and begin a healthy grief journey.

Research overwhelmingly indicates that people want to die at home if given a choice.²⁻¹⁰ A systematic review of the literature by Gomes et al⁸ found evidence that up to 87% of patients prefer to die at home. Yet, in 2013, less than 50% of all deaths in the United States occurred while receiving hospice care.^{1,11} In addition, many patients and families are receiving only the traditional medical hospice benefit at the very end of life, often in crisis.¹ Unfortunately, the reality of being at home for EOL care is still out of reach for many. According to the National Hospice and Palliative Care Organization, in 2013 only 66.6% of hospice patients died at

KEY WORDS

caregiver, caregiver crisis, end-of-life care, good death, hospice, social model

The medical model of hospice care is the criterion standard for providing care to dying individuals and their families. The effectiveness of the model, however, is dependent on the family as primary caregivers. This is evolving into an unrealistic expectation for a large proportion of Americans. Over the last several years, the median length of stay for hospice patients has decreased,¹

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Funding was not provided for the development or submission of the manuscript.

H.S.G. and K.K.S. have made substantial contributions to the conception and design of the manuscript. Both have participated in drafting and revising the manuscript for important intellectual content. Final approval of the version to be published was also completed by both H.S.G. and K.K.S.

The authors have no conflicts of interest to disclose.

DOI: 10.1097/NJH.0000000000000186



home,¹ indicating a discrepancy, or gap, in the actual place of death when compared with the desired place of death.

Inpatient hospice units and hospital-based hospice beds are options for crises, but these options, although appropriate for medical crises, are less than ideal for the social crises many patients and their families face at the end of life. The lack of community, financial, environmental, and caregiver resources combined with late or no referral to hospice often leaves institutionalization as the only option for EOL care. The potential for a significant increase in the utilization of hospice over the next decade is tremendous if EOL care incorporates this proposed SMH into the existing continuum of care. Offered in combination with medical model hospices, the SMH bridges the care gap, delivering comprehensive, holistic care in a homelike setting.

HOSPICE CARE WITHIN A MEDICAL MODEL

The framework and delivery of modern hospice care in the United States were driven by the development of the MHB in 1982, which entitles an individual with a life expectancy of less than 6 months access to EOL care.^{2,12–14} Acceptance of the medical hospice model of care over the last 30 years has resulted in enrollment growing from 25 000 to 1.6 million individuals per year in the United States. Of the 1.6 million Americans receiving hospice care in 2013, a large proportion (87.2%) accessed the MHB as a payer source.¹ Medical hospice care utilization, particularly with Medicare beneficiaries, has ballooned in part because of the aging population, which is expected to increase to 72.1 million individuals older than 65 years in 2030.¹⁵

The MHB provides multiple levels and intensities of care based on clinical needs: routine home care, general inpatient care, continuous care, and respite care. Nearly 97% of hospice care is provided at the routine home care level, yet this level of care does not include any coverage or reimbursement for around-the-clock care.¹⁶ Unfortunately, the provision of a home and 24/7 care for a dying individual is not available through the MHB or private health insurance. In a well-managed death with no symptom crises, caregiver absence or exhaustion can be relieved for a maximum of 5 days via the respite care benefit, but no ongoing caregiver relief is available. Individuals, families, or friends must provide this care themselves or pay for it out-of-pocket. Continuous care, through the MHB, provides a brief period of in-home nursing care to manage a symptom crisis, such as pain, but is not indicated for caregiver relief. Finally, for acute or complex symptom management that cannot be managed in other settings, many hospice programs offer general inpatient care in an inpatient facility.¹ This level of care, however, must be provided in a Medicare-certified facility with registered nurses. Hospice houses, owned and operated by medical hospice programs, may provide general

inpatient care, respite care, and routine home care, all under the MHB, but for routine home care, a room and board charge is levied, and a limited number of beds are available.

HOSPICE CARE WITHIN A SOCIAL MODEL

Historically, hospices were funded as charitable organizations and maintained through the efforts of volunteers from the community. They were developed to provide hospitality to the dying in a homelike setting,² where care was focused on the whole person, within the social context of kin and friends. After the development of the MHB, however, core services were delineated for reimbursement purposes and service to the dying evolved from a model of volunteerism to that of paid health care professionals, such as nurses, physicians, and social workers. Hospice in the United States came to be defined by Medicare as a package of services delivered in a person's residence on an intermittent basis.

The Centers for Disease Control and Prevention reports that in 2010 approximately 715 000 people died in hospitals.¹⁷ Despite well-documented, widespread preference for the idea of dying at home, many individuals discover that the reality is extremely challenging. An inability to manage symptoms, physical burdens, stress and exhaustion, limitations of the physical environment, and fear of the unknown can overwhelm the positive expectations of an idealized home death.¹⁸ In addition, many individuals die in institutions not because their physical needs are more intense than those of patients cared for at home, but simply because of a lack of someone to provide the care. Thus, a major factor in an individual's experience of dying, his/her environment, is dictated not by a physical condition, but by the unavailability of a critical resource, caregivers. Institutionalization, in this instance, becomes the solution to a social crisis, not a medical one. This dilemma has initiated a call to action. Over the past 2 decades, the increased complexity of dying at home coupled with a widespread aversion to dying in an institution has driven the development of the SMH.

The SMH serves as a compassionate option for patients and families facing caregiver difficulties. Collaborating with traditional medical hospice care without duplicating services, the SMH provides hands-on caregiving in a free-standing home environment developed to care for those in the last weeks or months of life. Uniquely, these homes are sustained by various community advocacy efforts and may therefore fall outside the current health care regulatory environment.

The SMH differs from the medical model hospice in several key areas, as the SMH addresses the care and support needs rather than clinical needs. The SMH offers a home environment and hands-on care free of charge or on a sliding-scale basis. The medical hospice program admits



the patient to the SMH home and continues to provide the services of routine home care including medications, durable medical equipment, case management, and interdisciplinary team care. The SMH staff primarily serve as a surrogate or extension of the patient's support network to provide the 24/7 bedside care. As a community-based program, the SMH is available to any local medical hospice provider who wishes to refer his/her patients (Table).

Collaborative relationships with local hospice agencies, hospital discharge planners, case managers, and social workers are one of the cornerstones of a successful SMH. Referrals come from these sources, which elucidates the significance of building and maintaining relationships. Hospice agencies continue to see individuals just as if they were in their own private home with the frequency of visits scheduled individually but, on a predictable schedule, based on the needs of the person and family.

EXEMPLAR

One model of an SMH is Clarehouse (CH), in Tulsa, Oklahoma, which has provided care to 2850 individuals with terminal illness over the past 12 years. Clarehouse is a nonprofit, 501(C)3 charitable organization that is funded entirely by donation, meaning that no fees are ever charged for care. Clarehouse is not a Medicare-certified hospice program and does not receive state or government funding. Costs are met solely through donations and include gifts from individuals, community groups, corporations, and foundations; an annual fund-raising event; and in-kind goods and services (Figure). Out of gratitude, CH families "pay it forward," and many participate in ongoing support of the

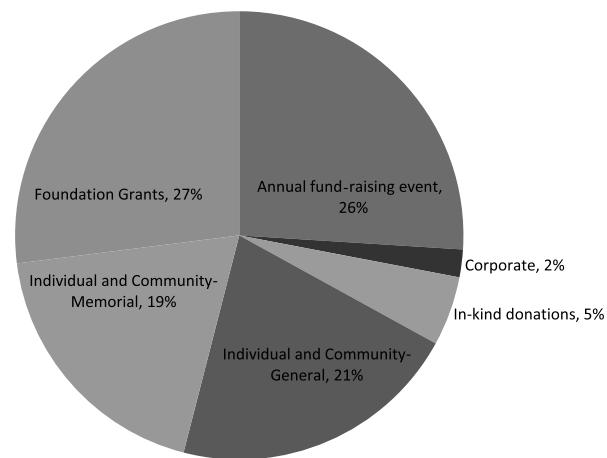


FIGURE. Sources of contributions for care at Clarehouse.

mission. Criteria for admission to CH include a life expectancy of a month or less, a documented do-not-resuscitate status, enrollment in a local hospice program, and a desire for comfort care only. The average length of stay is 8 days but has ranged from just a few minutes to 6 months. Eighty-five percent of CH guests have an annual household income of less than \$50 000, whereas 59% fall in the range of less than \$25 000, highlighting the correlation between lower-income levels and less access to resources, including caregiving options.

The creation and development of CH arose from the identified need in the Tulsa community for a quality alternative when dying at home was not an option because of a lack of caregiver resources. Clarehouse bridges the gap in care and funding. For individuals with terminal illness without adequate family resources available to provide the necessary

TABLE Comparison of Social Model Hospice and Traditional Medical Hospice Services

	Medical Model Hospice: Home Services	Social Model Hospice	Medical Model Hospice: Inpatient Facility
Type of care	Medical care, visiting service, team led by doctors and nurses	Personal and residential care, community home setting, team of trained caregivers and volunteers	Medical and care, a medical facility, team led by doctors and nurses
Frequency of visits	Intermittent	24/7	24/7
Costs	Paid for by Medicare/Medicaid and some private insurance companies	Free or sliding-scale fees	Paid for by Medicare/Medicaid and some private insurance companies, may require additional room and board charges
Admission criteria	Life expectancy of ≤ 6 mo as documented by the physician	Enrolled with a hospice agency and has a life expectancy of up to 6 mo without adequate caregiver resources at home	Enrolled with a hospice agency and has an acute medical or social crisis that cannot be managed at home
Levels of Medicare reimbursable care	Routine home care, continuous care	Not applicable	General inpatient care, respite care

Adapted with permission from Caring House, Inc, YourCaringHouse.org.



around-the-clock care in their final days, CH offers an alternative to institutionalization. The objectives of CH focus on diminishing the burden for family caregivers during the final days, as well as the accompanying physical, emotional, financial, and social burdens placed on families. This enables each individual to live out his/her definition of a good death. With community support through donations, the free care provided by CH allows family caregivers to maintain their employment so they will not exhaust limited resources or incur further financial burden.

In keeping with the philosophy of individualized care and dignity in a social setting, individuals admitted to CH are not referred to as “patients,” but rather as “guests.” Guests are admitted to CH in the last days to weeks of life in partnership with a local medical hospice of the guest’s choice. Clarehouse staff and volunteers work in collaboration with the hospice team to ensure dignity and comfort during the dying process while identifying challenges concerning symptom management, coping, grief, and complicated family dynamics. In accordance with Medicare Hospice Conditions of Participation, the medical hospice provides the registered nurse case manager¹⁹ and CH to participates in the plan of care as designed by the case manager and hospice interdisciplinary group. Development of provider agreements with each hospice agency is important in order to establish the scope of case management services provided for individuals admitted to the home. They allow for an understanding of expectations as well as a measure for maintaining the highest standard of care. All disciplines and services from the medical hospice continue at CH as in any place of residence. This effort ensures that individualized, holistic services are provided in an organized and effective fashion encompassing guest and family as the unit of care without duplication of services or confusion of roles.

Care at CH includes presence, personal hygiene, assistance with activities of daily living, meals, medication administration, symptom management, teaching, and around-the-clock support. Through volunteers, additional support is offered such as companionship, vigiling, pet therapy, musical visitors, massage therapy, yoga, reiki, spiritual companions, hair and nail care, and a variety of audio-visual and print resources. Support services are customized to each guest’s needs and desires and depending on the type of service may be available on a continuous, scheduled, or as-requested basis. A volunteer physician is also utilized once a week to evaluate each guest, provide and reinforce teaching for guests and families, facilitate CH team meetings, and collaborate in symptom management with the hospice agency providing case management. Clarehouse offers 10 large, private bedrooms with outdoor access via private decks or patios, sleeping arrangements for a loved one, gathering spaces, meal hospitality, a butterfly habitat, a freshwater aquarium, gardens, an outdoor chapel, and a walking labyrinth.

All care is provided in the context of a team, and the house rule is that everyone does anything that needs to be done. One licensed practical nurse and 1 caregiver make up the 24/7 paid staff, providing a consistent 5:1 ratio for the 10 guests. The caregivers may be certified nursing assistants or home health aides or simply laypeople trained by CH. Nearly 50% of CH staff is specialty certified in hospice and palliative care via the Hospice and Palliative Credentialing Center. The core care team is supplemented by administrative staff consisting of an executive director, administrative director, clinical director, support services director, education director, and development coordinator. Paid staff number approximately 30 in a combination of full-time, part-time, and as-needed status. In addition, more than 200 volunteers provide the support services as well as direct care, cooking, cleaning, laundry, shopping, hospitality, clerical, maintenance, and gardening throughout the day and evening. On an average day, 10 to 15 volunteers serve the guests and families of CH and are an integral component of the team. In 2014, volunteers contributed 8513 hours, a value of \$177 751.²⁰

DISCUSSION

The term “social” has many connotations based on context, but a pervasive commonality among them is the sense of connectedness, the presence of a relationship, or the interaction between living things.²¹ For example, Cantor^{22,23} conceptualized social care as a model of interactive concentric circles where care moves fluidly back and forth based on the needs of the individual. At the innermost level, however, care is usually provided through a system of family and friends. This type of ideology is analogous with the concept of providing hospice care within a social model.

In 2011, the concept of an SMH was introduced in the literature through the exploration of the innovative caregiving community of Sarah House in Santa Barbara, California.²⁴ Sarah House opened in 2005 as an EOL care home, after providing 14 years of care as a community home for people with AIDS. Social model hospice homes, older and younger than Sarah House, exist across the country in Ohio, Oklahoma, Indiana, California, Michigan, New York, and Texas, sharing common values and missions. All are charitable organizations, inspired locally by a vision to provide care to dying individuals, responding to the needs of each community. Although variations in staffing, policies, funding, and licensing may be found within the model, the SMH community shares a commitment to loving kindness, family, and home. Sunday²⁵ discussed the core values of an SMH in terms of “the medicine of the house,” citing relationship of caregivers, homelike atmosphere, and willingness to be present as key factors.

Early research of the SMH has shown a significantly positive effect on caregiver well-being and bereavement



(D. V. Simonet, A. Narayan, unpublished data, 2014). Specifically, the data indicate that CH improves the well-being of those served by creating a space that offers relief from suffering, the lifting of burdens, and care that exceeds expectations. Anecdotally, family service evaluations, mailed 30 days after a death, provide consistently positive feedback regarding care, collaboration, and the home itself.

The extension of hospice care within a social model, as a solution to the caregiver crisis, is in alignment with the key findings and recommendations of the Institute of Medicine's recent consensus report. It encourages the provision of comprehensive medical and social services that are patient centered, family oriented, and accessible around-the-clock, as well as care that is consistent with individuals' goals, values, and informed preferences.²⁶ The report's recommendations stress collaboration by sharing successful strategies and promising practices across organizations. The SMH is a rising response to these recommendations as it complements traditional medical hospice services while filling the caregiver gap with an approach that is grounded in meeting the needs of the whole person and family.

Over the past 10 years, through networking, many SMH homes have become connected, supporting and mentoring each other and reaching out to similar homes as they are identified across the country. These homes have joined to form the Social Hospice Network, an informal system of support for communicating, consulting, and mentoring. The network facilitates a grassroots effort to spread the model and educate communities about living well through dying. Currently, at least 18 other projects are in development across the country, utilizing existing SMH homes for site visits, consulting, and mentoring. The Social Hospice Network Forum, www.socialhospicenetwork.org, offers the sharing of practice, experiences, and ideas between existing and aspiring homes to facilitate growth of the movement. Members post discussions on a variety of topics related to the model, mission and vision, organizational start-up, nonprofit management, clinical practice, volunteer development, and fund-raising. In addition, the annual conference of the Social Hospice Network is in its third year, offering an educational and networking event for homes and projects across the country. Currently, the network is informal and organic, but the rapid growth over the past 2 years indicates the need for the establishment of a formalized structure. Management of the network resides at CH. (For more information, contact Julie Anderson, director of education, at janderson@clarehouse.org.)

CONCLUSION

The SMH offers a solution to the impending caregiver crisis in EOL care and is in alignment with the majority of individuals' idea of a good death. This article is presented as an introduction to the concept of hospice care within a

social model along with the recognition of the need to explore this topic further. Hospice care within a social model is replicable and sustainable in committed communities as shown by the years of service of existing homes and the growth and spread of the concept. Future research is needed to explore the efficacy of the model's ability to diminish the burden of care for families, assess the impact on survivor grief, and to understand the possible relationships between income and utilization of the model, as well as the financial implications within the health care continuum.

Acknowledgment

The authors thank Dr Jennifer Clark, MD, chief quality officer and palliative medicine physician, Hillcrest Medical Center, Tulsa, Oklahoma, for her expertise in the editing process.

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The Social Model Hospice: The Community Answer to the End-of-Life Caregiver Crisis



The Crisis

- 4 of 5 Americans indicate a desire to die at home, only 1 of them actually will.
- Medical Model Hospice services are comprehensive but intermittent.
- End-of-life care is round-the-clock with significant physical, emotional, social and financial demands.
- When dying at home is not possible due to environment or inadequate caregivers, institutionalization becomes a medical solution to a social problem.

The Evidence

With the University of Tulsa, we launched an outcome-based evaluation using surveys of guests, caregivers, and staff to better understand

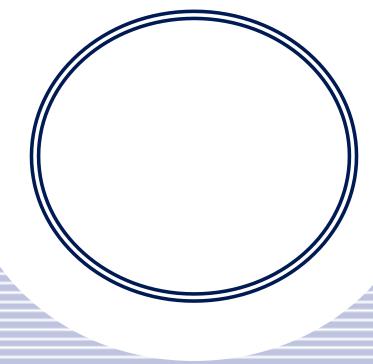
the Clarehouse Experience:

- Relieves the physical suffering of guests
- Allows guests and their caregivers the experience of a “good death”
- Lifts caregiver burden
- Improves caregiver well-being

www.socialhospicenetwork.org

Clarehouse®
Living. Loving. Sharing.

Clarehouse provides a loving home, quality end-of-life care & access to hospice services to people in need.



The Social Model Hospice

Through passionate grassroots efforts, community-supported homes have been established offering a place of warmth and loving care for people who can no longer remain in their own homes during the last months of life.

Social Model Hospice homes...

- ✓ are inclusive and open to all people, according to local regulations
- ✓ are fundamentally grass-roots in nature
- ✓ are independent and freestanding
- ✓ are non-profit organizations
- ✓ are funded by community and family support
- ✓ are not government or third-party funded
- ✓ are staffed by paid caregivers and volunteers who are considered “extended family”
- ✓ are in a collaborative working relationship with a local medical hospice provider
- ✓ are complementary and unique to what already exists in the community
- ✓ are not a hospital, nursing home, medical hospice, or medical facility
- ✓ are simply “home and family” and carry the heart of everything that means.

The Future – Education

- Clinical Rotations in End-of-Life Care
 - Community Outreach & Awareness
- Expansion of the Social Model Hospice

We envision a future where:

People and families across the nation have the expectation of dying well — In comfort, with dignity and supported by expert and compassionate care.

Health Care professionals incorporate end-of-life best practices throughout settings.

A Social Hospice home is available in every community willing and able to support one.



www.clarehouse.org



Omega Homes are part of the movement to improve the end-of-life experience for individuals and families in need.

Adopt Our Model

The Omega Home Network is a national membership organization that promotes the development and expansion of community homes for dying people. Through information sharing, consultation and educational offerings, we provide direct assistance to those developing and operating homes in their communities.

Over the past decade, through passionate grassroots efforts, we have worked to build a network of community homes, varying in size, appearance, and internal policies, that offer places of warmth and loving care for people who can no longer remain in their own homes during the last months of life.

Membership Criteria

- Must have nonprofit status and provide proof of nonprofit 501c3 status for organization or for sponsoring organization, or provide proof of intent to file for nonprofit status within the first year of membership.
- Must serve persons with a terminal illness with an emphasis on individual and family-centered end-of-life care in a home environment.
- 24/7 care is provided by a combination of paid and volunteer staff.
- Must not be a medical hospice provider but collaborates with local medical hospices, who provide medical care/case management

Omega Homes are:

- dedicated to the care of dying individuals and families.
- individualized loving care in a community home setting.
- non-profit, charitable organizations.
- provided by a mix of paid and volunteer caregivers.
- 24/7/365.
- free or sliding-scale.
- provided in collaboration with a medical hospice responsible for case management.
- not covered by Medicare, Medicaid or private insurance.
- grass-roots and community based and supported.
- unique and do not duplicate existing community resources.
- home and family to people in need.



Visit Our Homes

Because we feel so strongly that every community should have an Omega Home, we mentor projects nationally, sharing our stories, our homes and our expertise. Interested individuals are welcomed for site visits to tour our homes, meet staff and see the compassionate care firsthand. Projects begin organically, with local visionaries sharing their passion and building a team within their community. [Contact the Network to get started!](#)

The Forum

The Omega Home Network Forum offers the sharing of practice, experiences and ideas between existing and aspiring homes to facilitate growth of the movement. Members post discussions on a variety of topics related to the model, mission and vision, organizational start-up, non-profit management, clinical practice, volunteer development and fund-raising.

The Conference

The Network hosts an annual conference offering an educational event for homes and projects across the country. The conference focuses on providing information about opening and sustaining an Omega Home. Through information sharing in breakout sessions, we mentor visionaries and support their passion for furthering our mission. [To learn more, visit **omegahomenetwork.org**.](#)

"Without the Omega Home Network and the committed outreach, we do not believe we would be at this point. Your mission to mentor is critical in the further development of the Omega Home movement across our country. For that, we are ever grateful to you."

Bob Ingalls and Annie Pillars, Serenity House, Pullman, Washington

Annual Membership

Full or partial scholarship requests considered

Home Member - Operating non-profit community homes for end-of-life care. Unlimited individual participation.

Associate Member - Incorporated organizations actively working to establish a home and homes that have been open for five years or less. Unlimited individual participation.

Individual Member - Individuals interested in the movement.

Your annual membership provides:

- affiliation with a national membership organization
- educational resources
- peer support
- discounted conference fees
- online forum access
- mentoring
- monthly e-newsletter
- webinars

2. Tell your story

- Passion
- Vision
- Well-articulated mission
- How you are different from medical hospice
- How you will not be duplicating services that already exist
- Know the data

FRANCIS HOUSE

<https://francishouseny.org/our-care/>

"Francis House provides a home and extended family to persons with terminal illnesses so they can die with dignity surrounded by the unconditional love of God."

We will use our lived experience as a resource for others.

Francis House provides a home and a supportive extended family to people with terminal illnesses with a prognosis of six months or less to live. The values of Francis House are to accept each resident unconditionally and ensure that they are treated with dignity, respect and compassion.

Staff and volunteers function as an extended family offering physical, emotional and spiritual support. 24-hour medical supervision is provided by licensed home health care agencies. Each resident has a private bedroom with telephone and cable television. Laundry service is provided with personal laundry done at the house. Visiting hours are open anytime for family and friends.

Our Quality, Individualized Care Includes:

- 24-hour care
- home-cooked meals
- pastoral care if requested
- remembrance therapy
- pet and music therapy
- birthday and holiday celebrations
- bedside vigils

SARAH HOUSE

<http://www.sarahhousesb.org/residential-housing-for-low-income-individuals-on-hospice>

Sarah House Santa Barbara is a beautiful eight-bedroom home for low-income men and women receiving hospice care. We provide a home and loving care to those facing end-of-life. We also provide care to those living with HIV/AIDS, whether they are at the end of their lives or they simply need a home for regaining health.

Our mission is to provide care to those in need regardless of their ability to pay. We offer 24-hour care personally tailored to individual needs. Our services include private bedrooms in a shared living environment; nutritious, home-cooked meals; and assistance in an atmosphere of unconditional kindness and comfort. Additionally, Sarah House Staff offers loving support to family and friends of residents.

Partnering with local hospice providers, we integrate high-quality medical care into our warm home setting. We attempt to satisfy each individual's physical, spiritual, and emotional needs to the best of our ability. Residents, as well as family members, may have confidence that their stay at Sarah House will be marked by genuine compassion and faithful services.

CLAREHOUSE

<https://www.clarehouse.org/about-us/mission/>

Mission Statement: ***Clarehouse provides a loving home, quality end-of-life care and access to hospice services to people in need.***

We are a loving home for terminally ill people, providing living space, practical care and access to hospice services – devoted to the care of dying people and to the support of their loved ones.

Welcome Home is more than a greeting: it's a feeling that permeates the experience of everyone who enters Clarehouse. Before Clarehouse, families in our community had few choices when their loved one needed more care than medical hospice services could provide.

Clarehouse was formed in January of 2001 by a group of committed individuals with a passion for easing the burden of those dying in need. At Clarehouse, we consider ourselves an extension of the family as caregiver and home to dying people. We provide living space and round the clock practical care for terminally ill people, accessing hospice care through existing local hospice programs. Clarehouse provides short-term, end-of-life care to people of all ages. Guests must be enrolled in a local hospice program.

We're an Omega Home

Clarehouse was the first Omega Home in Oklahoma. What's an Omega Home? Among other things, it's a home that's:

- designed for and totally focused on care at the end of life
- staffed by paid caregivers supported by community volunteers
- not a medical facility
- created by the local community for the local community
- an independent nonprofit.

SERENITY HOUSE

<http://friendsofhospice.net/serenity-house-comfort-care-at-end-of-life/>

Omega Homes are part of the movement to improve the end-of-life experience for individuals and families in America. [More about Omega Homes ...](#)

What is a Community Home for the Dying?

Community homes for the dying, sometimes called social model hospice houses, have been around for more than 25 years in our country. They are rooted in the origins of hospice – serving the dying through a

community network of care. These homes are run by not-for-profit community-based collaborative organizations that partner with existing local resources.

These homes, located in our neighborhoods and part of the community we live in, focus on the unique needs of those in the last days of their life, and their families. The desire for deep connection, meaning, and purpose are honored. Families are supported in sitting beside their loved one, sharing their stories, and expressing their hellos and good byes. Staff and volunteers are trained specifically in end-of-life care.

Why A Community Home for the Dying?

Often a person cannot stay in their home at the end of their life. Perhaps the home is not well set up. There is no family caregiver, or they are unable to assist with the care needed. Maybe it's too hard physically or emotionally. Or the family or individual is not comfortable with the idea of dying at home. We want to honor and respect the unique needs of both the individual and the family offering a home that specifically serves those at the end of life.

A New Way to Serve the Dying and Their Families

Friends of Hospice has been augmenting and supporting end-of-life care since 1994. Our services, and support of existing services, have expanded over the years as new needs were identified: [Advance Care Planning](#), [Music & Memory](#), [Threshold Choir of the Palouse](#), [Living Legacy](#), [Massage Therapy](#), and [Grief Support](#) groups. We have in place many services that augment a community home for the dying project.

Now we have a house! Friends of Hospice has purchased a 3 bedroom, 2 bath home at 1125 SE Sandalwood Drive in Pullman, Washington. We are filled with gratitude for the financial contributions over the years that have made this dream a reality.

Our goal is to make Serenity House an integral part of end-of-life care on the Palouse. This home does not replace any services currently offered in the area. Our home will fill a gap in services and we pledge the following for the dear souls who will live with us for a short while:

- **A place of welcome and support** in the last weeks of life, with a gentle, guiding hand for the individual and their family to reach out for reassurance and comfort.
- **Loving support and assistance** with daily needs, meals, and 24-hour wake staff in a warm, inviting home setting by dedicated, caring staff and gifted volunteers who become an extension of the family.
- **The licensed hospice agency** provides all the Medicare hospice benefits and medical treatment, just like they do for any hospice patient, including symptom and pain management.
- **Admission requires the person** to be enrolled in hospice, remain on hospice, and be in the last month of life.

What is a Social Hospice?

The term "hospice" can be traced back to medieval times; used to describe a place of shelter and rest for weary or ill travelers on a long journey. The name was first applied to specialized care for dying people in 1967 by physician Dame Cicely Saunders, who founded the first modern hospice—St. Christopher's Hospice—in a residential suburb of London. In 1982, the United States Congress created the Hospice Medicare Benefit, and subsequent use of the term referred mostly to this highly medicalized model. This model involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support tailored to the patient's and loved ones' needs and wishes. Services are provided in homes or care facilities. The intermittent nature of the hospice team's visits requires a primary caregiver to be present in the home to assist the patient with round the clock needs.

However, dying at home is not always possible for those without a safe environment or adequate caregivers and resources. Many people die in institutions not because their physical needs are more intense than patients cared for at home, but because of a lack of someone to provide the care. Thus, a major factor in a person's experience of dying; his or her environment, is not dictated by a physical condition, but by the unavailability of a critical resource; caregivers. Institutionalization, in this instance, becomes the solution to a social issue, not a medical one.

The Social Hospice model serves as a compassionate option for patients and families facing such difficulties. Collaborating with medical-model hospice care without duplicating services, the Social Hospice provides hands-on caregiving in free-standing home environments developed to care for those in the last weeks of life. The Social Hospice provides a loving home to dying individuals in caregiver crisis as a charity based service. Considered the "next-best-thing to home", the Social Hospice is focused on individualized, cost-effective, compassionate, hands-on care of dying people and their families. Across the nation, communities are asking for changes in end-of-life care and the Social Hospice is arising as a valuable alternative.



Social Model Hospice Presentation Summary

Title

Outside the Box; Creating a Solution for the Caregiver Crisis in Final Days Care

Outline

- A. The Crisis: Our caregiver crisis and implications for end-of-life care
- B. The Vision: The Social Model Hospice as an innovative solution
- C. Exploring the Social Model Hospice
- D. Contrasting Social and Medical Models
- E. Regulations and Funding
- F. Impact on dying individuals and families
- G. Spreading the model

Objectives

1. Define the Social Model Hospice and understand the grassroots history of the movement
2. Articulate the key components of the Social Model Hospice including scope of care, collaborations, home design, staffing and funding.
3. Understand the benefits of the Social Model Hospice in individual dying experiences and family grief processes.

Description

When dying at home is not possible for those without a safe environment or adequate caregivers, institutionalization becomes the solution to a social issue, not a medical one. What about a “next-best-thing to home” option? The Social Model Hospice serves as a compassionate option for people desiring a home death. Combined with traditional medical hospice care, the Social Model Hospice provides caregiving in free-standing home environments developed to care for those in the last weeks of life. Learn about this emerging model as an innovative option to improve individualized care and heighten the expectation of dying well.

This presentation will explore the current caregiver crisis in end-of-life care and understand the assessment, planning and execution of a collaborative solution to this growing healthcare problem.



Published on *Family Caregiver Alliance* (<https://www.caregiver.org>)

Caregiver Statistics: Demographics

Definitions

A **caregiver**—sometimes called an *informal caregiver*—is an unpaid individual (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks. **Formal caregivers** are paid care providers providing care in one's home or in a care setting (day care, residential facility, long-term care facility). For the purposes of the present fact sheet, displayed statistics generally refer to caregivers of adults.

The figures below reflect variations in the definitions and criteria used in each cited source. For example, the age of care recipients or relationship of caregiver to care recipient may differ from study to study.

How Many Caregivers in the U.S.?

- Approximately 43.5 million caregivers have provided unpaid care to an adult or child in the last 12 months. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- About 34.2 million Americans have provided unpaid care to an adult age 50 or older in the last 12 months. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- The majority of caregivers (82%) care for one other adult, while 15% care for 2 adults, and 3% for 3 or more adults. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Approximately 39.8 million caregivers provide care to adults (aged 18+) with a disability or illness or 16.6% of Americans. [Coughlin, J. (2010). Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management.]
- About 15.7 million adult family caregivers care for someone who has Alzheimer's disease or other dementia. [Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.]

Economic Value

- The value of services provided by informal caregivers has steadily increased over the last decade, with an estimated economic value of \$470 billion in 2013, up from \$450 billion in 2009 and \$375 billion in 2007. [AARP Public Policy Institute. (2015). Valuing the Invaluable: 2015 Update.]
- At \$470 billion in 2013, the value of unpaid caregiving exceeded the value of paid home care and total Medicaid spending in the same year, and nearly matched the value of the sales of the world's largest company, Wal-Mart (\$477 billion). [AARP Public Policy Institute. (2015). Valuing the Invaluable: 2015 Update.]
- The economic value of the care provided by unpaid caregivers of those with Alzheimer's disease or other dementias was \$217.7 billion in 2014. [Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.]

Gender

- 65% of care recipients are female, with an average age of 69.4. The younger the care recipient, the more likely the recipient is to be male. 45% of recipients aged 18-45 are male, while 33% of recipients aged 50 or higher are male. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]

- Upwards of 75% of all caregivers are female, and may spend as much as 50% more time providing care than males. [Institute on Aging. (2016). Read How IOA Views Aging in America.]
- Male caregivers are less likely to provide personal care, but 24% helped a loved one get dressed compared to 28% of female caregivers. 16% of male caregivers help with bathing versus 30% of females. 40% of male caregivers use paid assistance for a loved one's personal care. About 14.5 million caregivers are males out of the 43.4% who care for an older family member. [National Alliance for Caregiving and AARP. (2009). Caregiving in the U.S.]

Gender and Care Tasks

- Males may be sharing in caregiving tasks more than in the past, but females still shoulder the major burden of care. For example, while some studies show a relatively equitable distribution of caregiving between males and females, female caregivers spend more time providing care than males do (21.9 vs. 17.4 hours per week). [National Alliance for Caregiving and AARP. (2009). Caregiving in the U.S.]
- Higher-hour caregivers (21 hours or more weekly) are nearly 4 times more likely to be caring for a spouse/partner. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Among spousal caregivers aged 75+, both sexes provide equal amounts of care. [McCann, J. J., Hebert, L. E., Beckett, L. A., Morris, M. C., Scherr, P. A., & Evans, D. A. (2000). Comparison of Informal Caregiving by Black and White Older Adults in a Community Population.]
- Other studies indicate that 36% of female caregivers handle the most difficult caregiving tasks (i.e., bathing, toileting, and dressing) when compared with 24% for their male counterparts, who are more likely to help with finances, arrangement of care, and other less burdensome tasks. [National Alliance for Caregiving and AARP. (2009). Caregiving in the U.S.]

Caregiving in the Lesbian, Gay, Bisexual, and Transgender (LGBT) Communities

- 9% of caregivers self-identify as LGBT. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- There are at least 3 million LGBT persons aged 55+ in the U.S. This number is expected to double in the next two decades. [Espinoza, R. (2014). Out and Visible: The Experiences and Attitudes of Lesbian, Gay, Bisexual and Transgender Older Adults, Ages 45-75.]
- Male caregivers report providing more hours of care than female caregivers. The average weekly hours of care provided by females from both the LGBT and general population samples is similar—26 vs. 28 hours—but LGBT males provide far more hours of care than males from the comparison sample (41 hours vs. 29). This reflects that about 14% of gay males indicate that they are full-time caregivers, spending over 150 hours per week in this capacity, compared to 3% of lesbian and 2% of bisexual respondents. [MetLife. (2010). Still Out, Still Aging: Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers.]
- LGBT individuals are more likely to be very concerned about having enough money (51% vs. 36%), experiencing loneliness in old age (32% vs. 19%), declining physical health (43% vs. 33%), not being able to take care of themselves (43% vs. 34%) or not having anybody to take care of them (30% vs. 16%) compared to non-LGBT. [Fredriksen-Goldsen, K. I., Kim, H. J., Emlet, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., Goldsen, J., & Petry, H. (2011). The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults.]
- 20% of older LGBT individuals and 44% of older transgender individuals feel their relationship with their healthcare provider would be adversely affected if their health provider knew their sexual orientation/gender. [Fredriksen-Goldsen, K. I., Kim, H.-J., Emlet, C. A., Muraco, A., Erosheva, E. A., Hoy-Ellis, C. P., Goldsen, J., & Petry, H. (2011). The Aging and Health Report: Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults.]
- LGBT older adults are twice as likely to age as a single person, twice as likely to reside alone, and three to four times less likely to have children. [MetLife. (2010). Still Out, Still Aging: The MetLife Study of Lesbian, Gay, Bisexual, and Transgender Baby Boomers.]

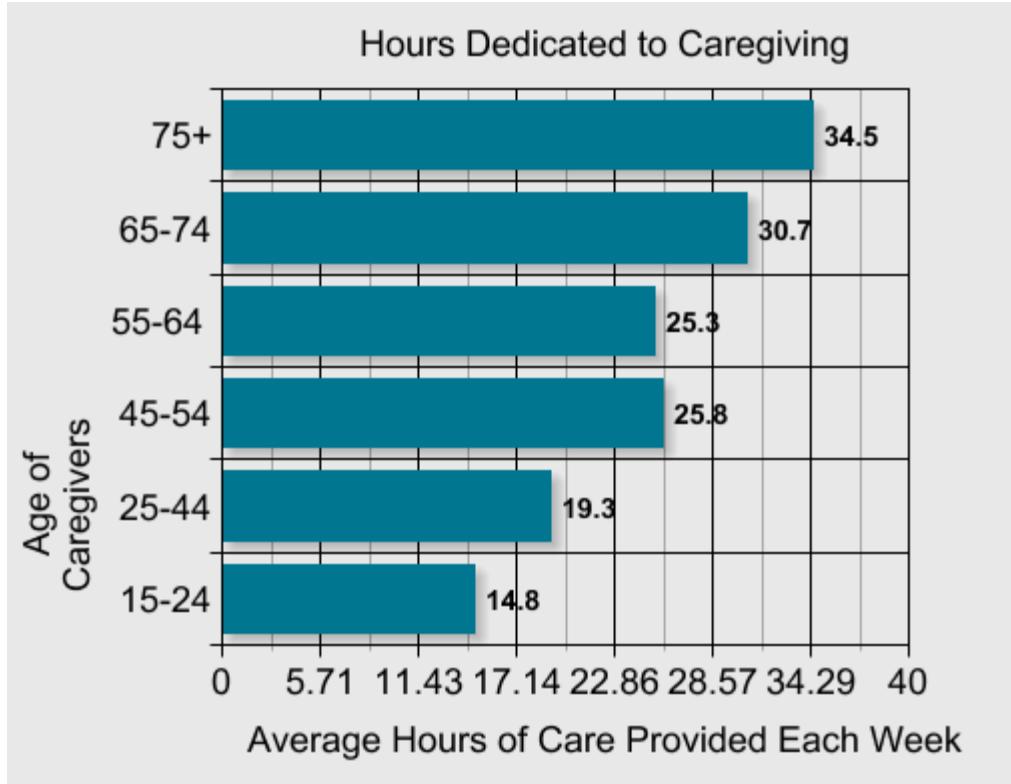
Caregiving Tasks

- On average, caregivers spend:
 - 13 days each month on tasks such as shopping, food preparation, housekeeping, laundry, transportation, and giving medication;
 - 6 days per month on feeding, dressing, grooming, walking, bathing, and assistance toileting;
 - 13 hours per month researching care services or information on disease, coordinating physician visits or managing financial matters. [Gallup-Healthways. (2011). Gallup-Healthways Well-Being Index.]
- Of family caregivers who provide complex chronic care:
 - 46% perform medical and nursing tasks;
 - More than 96% provide help with activities of daily living (ADLs) such as personal hygiene, dressing and undressing, getting in and out of bed, or instrumental activities of daily living (IADLs) such as taking prescribed medications, shopping for groceries, transportation, or using technology, or both. [AARP and United Health Hospital Fund. (2012). Home Alone: Family Caregivers Providing Complex Chronic Care.]
- On average, caregivers perform 1.7 of 6 ADLs, most commonly getting in and out of beds and chairs (43%). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- On average, caregivers perform 4.2 of 7 IADLs, most commonly transportation (78%), grocery or other shopping (76%), and housework (72%). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- 57% of caregivers report that they do not have a choice about performing clinical tasks, and that this lack of choice is self-imposed.
 - 43% feel that these tasks are their personal responsibility because no one else can do it or because insurance will not pay for a professional caregiver.
 - 12% report that they are pressured to perform these tasks by the care receiver.
 - 8% report that they are pressured to perform these tasks by another family member. [AARP and United Health Hospital Fund. (2012). Home Alone: Family Caregivers Providing Complex Chronic Care.]
- Caregivers report holding significant decision-making authority regarding the following:
 - Monitoring of the care recipient's condition and adjusting care (66%);
 - Communicating with healthcare professionals on behalf of the care recipient (63%);
 - Acting as an advocate for the care recipient with care providers, community services, or government agencies (50%). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]

Age

- Distribution of caregiver age:
 - Average age: 49.2 years old
 - 48% of caregivers are 18-49 years old
 - 34% of caregivers are 65+ years old [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Distribution of care recipient age:
 - Average age: 69.4 years old
 - 14% of care recipients are 18-49 years old
 - 47% of care recipients are 75+ years old [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- The number of hours dedicated to caregiving increases with the age of the caregiver.
 - Higher-hour caregivers are, on average, 51.8 years of age.
 - Lower-hour caregivers average 48 years of age.

Number of Hours Dedicated to Caregiving by Age of Family Caregiver



[The Partnership for Solutions. (2004). Chronic Conditions: Making the Case for Ongoing Care.]

- Older caregivers are more likely to care for a spouse or partner. The average age of spousal caregivers is 62.3. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Many caregivers of older adults are themselves growing older. The average caregiver of a recipient 65 years of age or older is 63 years old. Of these caregivers, one third report being in fair to poor health. [Administration on Aging. (2005). NFCSP: Complete Resource Guide.]

Time Spent Caregiving

- 4 in 10 (40%) caregivers are in high-burden situations, 18% medium burden, and 41% low burden based on the Level of Care Index (1997). Burden of care increases with hours of care provided. 92% of providers providing 21 or more hours per week are high burden versus 16% of lower hour providers. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Primary family caregivers of people with dementia report spending an average of 9 hours per day providing help to their relatives. [Fisher, G. G., Franks, M. M., Plassman, B. L., Brown, S. L., Potter, G. G., Llewellyn, D., et al. (2011). Caring for Individuals with Dementia and Cognitive Impairment, not Dementia: Findings from the Aging, Demographics, and Memory Study.]

Hours per Week

- Family caregivers spend an average of 24.4 hours per week providing care. Nearly 1 in 4 caregivers spends 41 hours or more per week providing care. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Family caregivers who reside with those they provide care for spend 40.5 hours per week caring for this person.
 - Those caring for a spouse/partner spend 44.6 hours per week performing caregiving tasks.

- Those caring for a child under age 18 spend 29.7 hours per week performing caregiving tasks. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Older caregivers who are 75+ years old provide 34 hours in an average week on caregiving. Middle aged caregivers report spending 21.7 hours per week on caregiving tasks. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Family and other unpaid caregivers of people with Alzheimer's disease and other dementias provide an estimated 21.9 hours of care per week. [Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.]

Months and Years Providing Care

- The average duration of a caregiver's role is 4 years.
 - Only 30% of caregivers provide care for less than a year.
 - 24% of caregivers provide care for more than 5 years.
 - 15% of caregivers provide care for 10 or more years. Higher-hour caregivers are twice as likely to have been in their caregiving role for 10 years or more. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Regardless of employment status, unpaid caregivers report that positive activities in their respective daily lives are reduced by 27.2% as a result of their caregiving responsibilities. This effect is three times greater in their personal lives than in their professional lives. [Coughlin, J. (2010). Estimating the Impact of Caregiving and Employment on Well-Being: Outcomes & Insights in Health Management.]
- Measured by duration of care, Alzheimer's and dementia caregivers provide care on average 1-4 years more than caregivers caring for someone with an illness other than Alzheimer's disease. They are also more likely to be providing care for five years or longer. [Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.]

Race and Ethnicity

- Individual adult caregivers in the U.S. identify their race/ethnicity as the following:
 - White: 62%
 - African-American: 13%
 - Hispanic (non-White, non-African-American): 17%
 - Asian-American: 6% [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Hispanic (non-White, non-African-American) caregivers have the highest reported prevalence of caregiving at 21%. Caregiver prevalence among other racial/ethnic groups are as follows:
 - African-American: 20.3%
 - Asian-American: 19.7%
 - White: 16.9% [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- White caregivers are on average older (52.5 years old) than their counterparts among other races/ethnicities. The average age of caregivers among other racial/ethnic groups are as follows:
 - Asian-American: 46.6 years old
 - African-American: 44.2 years old
 - Hispanic (non-White, non-African-American): 42.7 years old [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Hispanic (non-White, non-African-American) and African-American caregivers experience higher burdens from caregiving and spend more time caregiving on average than their White or Asian-American peers. The percentage of high burden caregivers caregiving time by racial/ethnic groups are as follows:
 - African-American: 57%, 30 hours per week
 - Hispanic (non-White, non-African-American): 45%, 30 hours per week

- White: 33%, 20 hours per week
- Asian-American: 30%, 16 hours per week [Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.]
- More than half of African-American caregivers find themselves "sandwiched" between caring for an older person and a younger person under age 18, or caring for more than one older person. African-American caregivers are also more likely to reside with the care recipient and spend an average of 20.6 hours per week providing care. In addition, 66 percent of African-American caregivers are employed full or part-time. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- The needs of care recipients vary by race/ethnicity. African-American caregivers (41%) are more likely to provide help with more than three ADLs than white caregivers (28%) or Asian-Americans (23%). [Alzheimer's Association. (2015). 2015 Alzheimer's Disease Facts and Figures.]

Relationships between Caregivers and Care Recipients

- A vast majority of caregivers (85%) care for a relative or other loved one:
 - 42% care for a parent (31% for a mother, 11% for a father);
 - 15% care for a friend, neighbor or another non-relative;
 - 14 % care for a child;
 - 7% care for a parent-in-law;
 - 7% care for a grandparent or grandparent-in-law. [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Parent care continues to be the primary caregiving situation for mid-life caregivers with 70% of the caregivers between the ages of 50 and 64. [Wagner, D. & Takagi, E. (2010). Health Affairs: Informal Caregiving by and for Older Adults.]
- Most care recipients reside in their own home (48%), and one in three (35%) reside in their caregiver's home. 3 in 10 care recipients who are not in assisted-living or skilled nursing facilities reside alone (31%).

Caregivers: With Whom do They Reside?		
	2004	2009
Reside alone	47%	43%
Reside with a spouse/partner	26%	27%
Reside with grown children	11%	13%
Reside with someone else	1%	1%

[National Alliance for Caregiving and AARP. (2009 & 2015). Caregiving in the U.S.]

Elder Abuse

- The Department of Health defines abuse as, "a violation of an individual's human and civil rights by another person or persons." Abuse can take many forms, including physical, psychological, sexual, or financial abuse, discrimination, or neglect.
 - Under this definition, as many as 25% of elder care recipients report significant levels of abuse. [Cooper, C., Selwood, A., & Livingston, G. (2008). The Prevalence of Elder Abuse and Neglect: A Systematic Review.]

- Approximately 1 in 10 Americans aged 60+ have experienced some form of elder abuse. Some estimates range as high as 5 million elders who are abused each year. [National Council on Aging. (2016). Elder Abuse Facts.]
- Only 7% of elder abuse cases are ever reported to authorities. [National Research Council. (2003). Elder Mistreatment: Abuse, Neglect and Exploitation in an Aging America.]
- For every 1 case of elder abuse known to programs and agencies there are 24 unknown cases. [Lifespan of Greater Rochester, Inc., Weill Cornell Medical Center of Cornell University & New York City Department for the Aging. (2011). Under the Radar: New York State Elder Abuse Prevalence Study.]
- Elder abuse, even modest abuse, increases risk of death by 300% compared to elders who have not been abused. [Dong, X., Simon, M. A., Beck, T., Farran, C., McCann, J., Mendes de Leon, C., et al. (2011). Elder Abuse and Mortality: The Role of Psychological and Social Wellbeing.]
- The direct medical costs associated with violent injuries to older adults are estimated to add over \$5.3 billion to the nation's annual health expenditures, and the annual financial loss by victims of elder financial exploitation were estimated to be \$2.9 billion in 2009, a 12% increase from 2008. [Administration on Aging: National Center on Elder Abuse. (2016). Statistics/Data: Impact of Elder Abuse].

Geographic Distance Between Caregiver and Care Recipient

- The vast majority of caregivers (75%) reside within 20 minutes of their care recipient. 13% of caregivers reside between 20 minutes and an hour away from their care recipient.
 - The proportion of caregivers reporting they reside fewer than 20 minutes from the home of their care recipient has increased steadily over the past 10 years (44% in 2004, 51% in 2009, and 75% in 2015). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- As the age of the caregiver increases, their distance from their recipient decreases. 84% of caregivers aged 75+ reside within 20 minutes of their care recipient, compared to their caregiving peers in other age brackets:
 - 76% of caregivers aged 65-74
 - 72% of caregivers aged 50-64
 - 74% of caregivers aged 18-49 [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- 48% of care recipients reside in their own home.
 - Higher-hour care recipients are less likely to reside at home (28%) than lower-hour recipients (57%).
 - Inversely, higher-hour care recipients are more likely to reside in their caregiver's home (62%) than lower-hour recipients (22%). [National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.]
- Approximately 5-7 million caregivers in the U.S. (about 15% of all caregivers) are long-distance caregivers. This number is projected to double by 2020. [National Council on Aging. (2006). Nearly 7 Million Long-Distance Caregivers Make Work and Personal Sacrifices.]
- Long-distance caregivers have the highest annual expenses (about \$8,728) compared to co-resident caregivers (about \$5,885) or those who care for a loved one nearby (about \$4,570). [AARP Public Policy Institute. (2008). Valuing the Invaluable: The Economic Value of Family Caregiving.]
- Long-distance caregivers reside an average of 450 miles (724 km) from their care recipients (or approximately 7 hours travel time).
 - More males (58%) than females (42%) are long-distance caregivers. [National Alliance for Caregiving and the MetLife Mature Market Institute. (2004). Miles Away: The MetLife Study of Long-Distance Caregiving.]
- Long-distance caregivers are more likely to report emotional distress (47%) than caregivers either residing with their care recipient (43%) or residing less than one hour away (28%). [National Alliance for Caregiving and AARP. (2004). Caregiving in the U.S.]

- Caregivers who do not reside with their care receiver reside the following distances from those for whom they care:

Distance	Percentage of Caregivers
10 miles or fewer	66%
11-25 miles	13%
26+ miles	21%

[Gallup-Healthways. (2011). Gallup-Healthways Well-Being Survey: Caregiving Costs U.S. Economy \$25.2 Billion in Lost Productivity.]

Caregiving in Rural Areas

- More than half of the 65 million Americans living in rural areas are over the age of 50. Elders in rural areas (about a quarter of all elders) are more likely to reside alone, near or at the poverty level, and suffer from a chronic condition or physical disability. They require an average of 46 miles of travel to get to the nearest health professional. [U.S. Department of Health and Human Services Rural Task Force. (2002). HHS Rural Task Force Report.]
- 3-6 million Americans are distance caregivers who provide care for a family member that resides an average of 450 miles away. [National Alliance for Caregiving & AARP. (2005). Caregiving in the U.S.]
- About 51% of caregivers in rural areas use community-based services. [Buckwalter, K. C., & Davis, L. L. (2009). Elder Caregiving in Rural Communities.]

Older Adults with Developmental Disabilities

- There are an estimated 641,000 adults aged 60+ with cognitive and other disabilities (e.g., cerebral palsy, autism, epilepsy, traumatic brain injury).
 - This number is projected to double to 1,242,794 by 2030, coinciding with the aging population of baby boomers born between 1946 and 1964. [Heller, T. (2011). Strength for Caring: Older Adults with Developmental Disabilities and Their Aging Family Caregivers.]
- Families are still the primary caregivers for adults with developmental disabilities and are themselves aging. About 76% of individuals with developmental disabilities reside at home.
 - In 25% of these homes, the family caregiver is over 60 years of age.
 - The average age of the care recipient with a developmental disability is age 38. [Heller, T. (2011). Strength for Caring: Older Adults with Developmental Disabilities and Their Aging Family Caregivers.]

Veterans

- There are a total of 5.5 million caregivers caring for former or current military personnel in the U.S. (1.1 million post 9/11). [Ramchand, R., Tanielian, T., Fisher, M., Vaughan, C., Trail, T., Batka, C., Voorhies, P., Robbins, M., Robinson, E., & Ghosh-Dastidar, B. (2014). Key Facts and Statistics from the RAND Military Caregivers Study.]
- 9 in 10 (96%) caregivers of veterans are female and 70% provide care to their spouse or partner. 30% of veterans' caregivers care for a duration of 10 years or more as compared to 15% of caregivers nationally. 88% report increased stress or anxiety as a result of caregiving, and 77% state sleep deprivation as an issue. [National Alliance for Caregiving and United Health Foundation. (2010). Caregivers of Veterans: Serving on the Home Front.]

- Military caregivers after 9/11 are more likely to be employed (63% vs. 47%), less likely to have a support network (47% vs. 71%), younger (37% under 30 years old vs. 11%), more likely to be caring for a recipient with a behavioral health condition (64% vs. 36%) or a VA disability rating (58% vs. 30%). [Ramchand, R., Tanielian, T., Fisher, M., Vaughan, C., Trail, T., Batka, C., Voorhies, P., Robbins, M., Robinson, E., & Ghosh-Dastidar, B. (2014). Key Facts and Statistics from the RAND Military Caregivers Study.]
 - Veteran care recipients (post 9/11) are more likely to have no health insurance (32% vs. 23%) or regular source of health care (28% vs. 14%), have a mobility limiting disability (80% vs. 66%) or mental health/substance abuse condition (64% vs. 33%), and meet criteria for probable depression (38% vs. 20%) compared to civilians. [Ramchand, R., Tanielian, T., Fisher, M., Vaughan, C., Trail, T., Batka, C., Voorhies, P., Robbins, M., Robinson, E., & Ghosh-Dastidar, B. (2014). Key Facts and Statistics from the RAND Military Caregivers Study.]
 - Veterans suffer more frequently from Traumatic Brain Injury (29%), Post-traumatic Stress Disorder, Diabetes (28%), and paralysis or Spinal Cord Injury (20%). [National Alliance for Caregiving and United Health Foundation. (2010). Caregivers of Veterans: Serving on the Home Front.]
-

Family Caregiver Alliance

National Center on Caregiving

(415) 434-3388 | (800) 445-8106

Website: www.caregiver.org

Email: info@caregiver.org

FCA CareJourney: www.caregiver.org/carejourney

Family Care Navigator: www.caregiver.org/family-care-navigator

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's, and other debilitating disorders that strike adults.

The present fact sheet was prepared by Family Caregiver Alliance. © 2016 Family Caregiver Alliance.
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Date:

Wednesday, April 17, 2019

Source URL: <https://www.caregiver.org/caregiver-statistics-demographics>



Friends of Hospice

Dedicated to the quality of life

A NEW WAY TO SERVE THE DYING AND THEIR FAMILIES

As a community partner serving those at end of life, we want to share an idea with you, and seek your input as one of those community leaders in the care of the dying.

SOCIAL MODEL HOSPICE HOUSE

Friends of Hospice is considering establishing a Social Model Hospice House in Whitman County. Social model hospice houses have been around for more than 20 years and are rooted in the origins of hospice – serving the dying through a community network of care. These homes are run by not-for-profit community-based collaborative organizations that partner with existing local resources. Services are typically provided on a sliding-fee basis. Homes vary in size from 2 bedrooms to 10 bedrooms. They are located across the country including California, Iowa, Ohio, Oklahoma, New York, Texas, and Virginia. Recently Marcie Gilliland and Annie Pillers participated in the 4th Annual Social Hospice Network Conference in Lansing, Michigan, attending sessions on strategic thinking in project development, admission policies and procedures, staffing the best care, volunteer management, and mission-based fundraising. They toured several homes and met with founders, board members, and staff operating homes for years, as well as those just starting homes.

Friends of Hospice has been augmenting and supporting end-of-life care in Whitman County for more than 22 years. In that time our services, and support of existing services, expanded as new needs were identified – advance care planning, Music and Memory, Threshold Choir, Living Legacy, and drop-in and ongoing grief support groups. We have in place the many services that augment a hospice house, but not the hospice house itself. Now is the time to explore that idea too.

AN ALTERNATIVE NEEDED

Often people cannot stay in their home at the end of their life. Perhaps the home is not well set up. Perhaps there is no family caregiver or they are unable to assist with the care needed. Maybe it's too hard physically or emotionally. Perhaps the family or individual is not comfortable with the idea of dying at home. We want to honor and respect the unique needs of both the individual and the family by offering a home that specifically serves those at end of life.

Social Model Hospice House Defined

- A home for the dying where care is provided by a dedicated, caring staff and volunteers that become an extension of the family. It's a safe place to live with meals, loving support, 24-hour wake staff, assistance with activities of daily living, and nurse delegated medication management.
- Admission requires the person be enrolled in hospice, remain on hospice, and be in the last months of life.
- The licensed hospice agency provides all the Medicare hospice benefits and medical care, just like they do for any hospice patient.
- The home is a licensed Adult Family Home through the Washington Department of Health.
- Members of the team include registered nurses, certified nursing assistants, social workers, caregivers, and administrators. Volunteers serve side-by-side staff to provide loving care and companionship.

Moving Forward From Here

- Explore the feasibility of opening and operating a social model hospice house – location, number of bedrooms, operations, regulatory standards, finance, administration, etc.
- Seek input and collaboration from our existing community partners like you.
- Deepen and expand existing partnerships.
- Develop new partnerships.
- Form a broad-based network of professionals and community members on an advisory basis to help the board shape and develop a hospice house that best serves the unique needs here.
- Raise awareness and educate the community-at-large about end-of-life care and a community social model hospice house.
- Develop a strong and sustainable development program for financial support of the house by fostering a culture of philanthropy.

Thank you for being part of this caring community network that is leading the cultural shift how we view death and dying, and how we serve those at end of life.

Community Needs Survey Regarding Caregiver and Housing Deficits For Terminally Ill People in the Tulsa Area

Purpose and Method

Clarehouse, a non-profit organization in Tulsa, recently conducted a survey to document the need for caregiver and housing resources for dying people. The study consisted of direct questioning by telephone of hospice providers in the Tulsa area over a two day period, April 15th and 16th, 2003.

Summary

The survey revealed a significant number of dying people (47 per month or 564 per year) who leave their homes due to unmet needs for caregivers and living arrangements. The need for a non-institutional option to home for terminally ill people in hospice care was evaluated, and according to hospice providers, an estimated 408 people per year would utilize such a service. Hospice programs showed an overwhelming willingness to make referrals to an agency providing a home and caregivers specifically for hospice patients. Finally, roughly half of patients identified as needing this service would require financial assistance.

*For more information regarding method and results,
please contact Clarehouse at (918) 269-4688.*

The following four questions were asked and are followed by the responses obtained.

- Per month, how many patients in your program leave their own homes because of unmet caregiver needs or inadequate living arrangements?

17 agencies contacted

15 responses to question

**Answers ranged from 0 to 10,
with a total of 47 patients**

- In your opinion, how many of that number would choose a small, non-institutional home for terminally ill people if that option existed?

17 agencies contacted

14 responses to question

**Answers ranged from 0 to 10,
with a total of 34 patients**

- Assuming the quality of care was acceptable to you, would your program be willing to refer patients to a non-affiliated, non-profit organization that would provide such a home and caregivers?

17 agencies contacted

15 responses to question

14 – yes

- Of these patients identified, can you estimate what percentage of them would require sliding scale assistance for room and board fees?

17 agencies contacted

13 responses to question

**Answers ranged from 15 to
100% with an average of 55%**

3. Get the right people on the bus

- Founders/Board Members who “get it”
- Use caution with industry experts
- Founders are responsible for enculturating others
- Stay focused and narrowly defined in the beginning

Leaders of great companies ask: First Who, Then What?

<https://www.kinesisinc.com/first-who-then-what/>

BY WENDY MAYNARD • APRIL 21, 2015

If your company's at a standstill, you may be asking the wrong question.

In his book, [Good to Great](#), Jim Collins creates a lasting and memorable metaphor by comparing a business to a bus and the leader as a bus driver. He emphasizes that it is crucial to continuously ask “First Who, Then What?”

You are a bus driver. The bus, your company, is at a standstill, and it's your job to get it going. You have to decide where you're going, how you're going to get there, and who's going with you.

Most people assume that great bus drivers (read: business leaders) immediately start the journey by announcing to the people on the bus where they're going—by setting a new direction or by articulating a fresh corporate vision.

In fact, leaders of companies that go from good to great start not with “where” but with “who.” They start by getting the right people on the bus, the wrong people off the bus, and the right people in the right seats. And they stick with that discipline—first the people, then the direction—no matter how dire the circumstances.

He has also developed a linear process for implementation of the “First Who, Then What?” concept. Here are his steps:

1) Get the right people on the bus.

Leaders must be rigorous in the selection process for [getting new people on the bus](#). Invest substantial time in evaluating each candidate and make systematic use of at least three evaluation devices (e.g., interviews, references, background, testing, etc.).

When in doubt, do not bring the person on the bus. Let a seat go unfilled—taking on extra work as needed—until you have found the right person. Ensure your company does an exceptional job of retaining the right people on the bus to perpetuate your good hiring decisions for a very long time.

2) Get the right people in the right seats.

Have 100% of the key seats on the bus filled with the right people. This doesn't mean 100% of ALL seats have the right people, but 100% of the key seats. If you think there might be a “wrong who,” first give the person the benefit of the doubt that perhaps he or she is in the wrong seat.

Whenever possible, give a person the chance to prove himself or herself in a different seat, before drawing the conclusion that he or she is a wrong person on the bus.

3) Get the wrong people off the bus.

Once you know you need to make a people change be rigorous in the decision, but not ruthless in the implementation. Instead, help people exit with dignity and grace so that, later, the vast majority of people who have left your bus have positive feelings about your organization. Autopsy hiring mistakes, applying the lessons systematically to future hiring decisions.

4) Put who before what.

When confronted with any problem or opportunity, shift the decision from a “what” question (“what should we do?”) into a “who” decision (“who would be the right person to take responsibility for this?”). Spend a significant portion of time on people decisions: get the right people on the bus, get the right people in the right seats, get the wrong people off the bus, develop people into bigger seats, plan for succession, etc. Develop a disciplined, systematic process for getting the right people on the bus. With each passing year, ensure the percentage of people decisions that turn out good versus bad continues to rise.

Once you fill your bus with the right people in the right seats, it becomes less a question of where you’re headed—and instead, how far you can go.

Dividing Duties Between Board and Staff

A nonprofit organization is hierarchical in structure by fiat. Every nonprofit has a board of directors that is the ultimate responsible body for the organization. In the beginning of the nonprofit's existence it is common for the board members to wear different hats and function also in the staff capacity. As soon as it is feasible, most boards designate or hire their first chief executive who then manages the daily affairs. The chief executive reports to the board and other staff hired later on report to the chief executive. The structure defines accountability but everyone working together for the same objective is what makes these partnerships succeed.

Primary roles of board

When defining the role of the board, it is important to remember that the role refers to the group, not to the individual board members. The board functions as a team. Individual board members inherently have no authority – no individual rights – over the organization but must assume accountability for their own actions. The governing body together has three main foci:

Direction – The board guards the mission of the organization and, through guidelines, steers it in the right direction.

Oversight – The board monitors the activities, the health, and the ethical behavior in the organization.

Resources – The board ensures that the organization is well-equipped to fulfill its mission – adequate finances, capable staff, and esteemed reputation.

Primary role of staff

When the board hires the first chief executive, it delegates the daily management to that person. Maintaining a regular contact with the board and particularly the chair, the chief executive keeps the board informed about the issues and activities that are part of the life in the organization. In fact, the board would have great difficulties making well-rounded decisions without constant input from the chief staff person. The rest of the staff – in due time – will help the chief executive more efficiently implement the directives the board has set.

Working together

It is not always easy or even possible to draw a clear line between governance and management. The board's duties are colored by its monitoring role. The chief executive, on the other hand, alone is responsible for making things happen with the help of the rest of the staff. However, both sides need each other's support – and availability, when requested – without veering off to micro-management or 'über-control.' Constructive partnership is built on knowing when to act alone, when to help – or ask for help, and trusting the partner to do the same.

Specific responsibilities

Oversight

Board: Health and success of the organization

- Drafts and/or approves broad policies to guide and protect the organization, board, and staff
- Monitors that all legal requirements get proper attention
- Hires the chief executive and delegates to him or her the daily operations
- Expects regular and objective reports from staff

Chief executive: Programs and administration

- Oversees daily operations
- Hires staff and delegates operational responsibilities to them
- Shares good and bad news with the board

Dividing Duties Between Board and Staff

Planning and evaluation

Board: Strategic framework for the organization

- Adopts an overall strategic mindset by focusing on the big issues that matter most
- Actively participates in strategic sessions and retreats
- Annually evaluates the performance of the chief executive and determines appropriate compensation
- Evaluates its own performance regularly - at least every three to four years
- Via staff reports assesses the organization's achievement of its goals

Chief executive: Strategic and operational plans

- Ensures that strategic planning happens with the board's appropriate involvement
- Leads operational planning and approves the plans for the staff
- Ensures a process for staff performance exists, approves staff compensation, and evaluates his or her own performance

Finances

Board: Fiduciary duty over the organization

- Makes sure adequate financial expertise is secured on the board
- Sets overall fiscal policies and ensures appropriate internal controls
- Approves the annual budget and monitors carefully the financial reports
- Hires an auditor and reviews the audit in an executive session with the auditor

Chief executive: Financial management

- With the help of the financial staff, prepares the annual budget and provides the board with regular financial statements
- With staff, handles the daily financial operations and monitors cash flow
- Defines financial policies and procedures for all daily money transactions

Fundraising

Board: Fundraising policies

- Drafts gift-acceptance policies and personal giving guidelines for board members
- Actively participates in the overall fundraising efforts as directed by development staff
- During capital campaigns takes a lead in securing the campaign's success

Chief executive: Fundraising plan

- Drafts (with development staff) a development plan, oversees its implementation, and involves the board in fundraising
- Acts as the main representative of the organization and (when there is no development director) communicator with major funders

Board recruitment and development

Board:

- Through the governance committee ensures that the board's composition reflects the organization's needs: actively cultivates new recruits
- Drafts board specific policies and ensures the bylaws are applicable
- Incorporates governance training, including orientation, into regular board schedule

Chief executive:

- Assigns staff to support the board in committees and in meeting, orientation, and retreat preparation
- Identifies potential new board members

4. Figure out your state licensing

- State Department of Health
- State Department of Social Services
- Specifically describe the services and the model
- Use what's available
- Avoid legislative changes until you have operational experience

Government Regulation of Omega Homes

Omega Home Network Conference 2019

The regulation of Omega Homes is state-specific and is part of the exploratory process in visioning a home. Homes in our Network range from highly regulated to unlicensed and unregulated. Many states exempt small homes (2 or 3 bedrooms) from any licensing and this can be a simple route to pilot a new project. Attempting to create new legislation prior to having any operating experience is discouraged by Network mentors as we have seen this backfire on new projects. Operating experience is crucial as new legislation should be drafted to support actual care being provided and enhance the Omega Home model of care. We encourage you to speak with existing homes in your state, if any, to coordinate any approach to state agencies.

The following are examples of various regulating bodies and license categories by states where Omega Homes operate:

California Department of Social Services

- Residential Care Facilities for the Elderly
- Residential Care Facilities for the Terminally Ill

Iowa Department of Inspections and Appeals

- Registered Boarding Home

Texas Health and Human Services Commission

- Special Care Facility
- Unlicensed – Personal Care Home

New York

- Unlicensed – Onondaga County Department of Social Services as a Community Care Shelter for the Terminally Ill
- Comfort Care Homes

Michigan Department of Licensing and Regulatory Affairs

- Adult Foster Care

Oklahoma State Department of Health

- The state does not regulate facilities that do not charge for services.

Review of Charity Status for Clarehouse

Why doesn't Clarehouse charge for services?

At the time of start-up of our services, we explored a sliding scale fee structure. Licensing our facility was a part of this research, and we found that the State of Oklahoma did not have a licensing category that fit our mission and vision of care for the terminally ill. The State could only offer us a Long-Term Care Facility licensing opportunity, and we felt those regulations would be prohibitive for us to provide the environment and care we envisioned in our small home.

At that time, no other license for our specific care environment could be offered by the State, and, ***without a license, a facility cannot charge for services.*** Our Board of Directors came to the decision to initiate our care on a charity basis, based on these legal restrictions as well as the heart of our mission of mercy and compassion.

Since then, the State of Oklahoma has adopted legislation that regulates a new licensing category; a Residential Hospice Home. This home must be owned and operated by a licensed Hospice provider and may offer acute (or inpatient) and custodial levels of care. The home can only serve patients of the individual hospice, and have no more than 12 beds. Extensive physical plant regulations are included.

This new category is not an option for Clarehouse at this time, as we are not a hospice provider. Providing hospice services was never the intent of Clarehouse, as one of our primary philosophies is to avoid duplication of services that exist in the community, and Tulsa already has over 40 hospice providers. Licensing in this way would also eliminate a vital piece of the success of Clarehouse, and that is to be accessible to all as a community based home.

A subcommittee of the Clarehouse Board of Directors continues to evaluate this position and research any options through changing times and needs to ensure the viability of this vital service we provide to our community.

TITLE 63 O.S. §§ 1-1900 et seq. NURSING HOME CARE ACT
§63-1-1903. Licensure Requirement - Applicability of Act
F. The Nursing Home Care Act shall not apply to a facility which is not charging or receiving periodic compensation for services rendered, and not receiving any county, state, or federal assistance.

2/2/06, 7/5/16

5. Establish your criteria for admission

- Comfort Care
- Non-skilled
- Not Medicare regulated
- Clear boundaries with medical hospice
- Length of stay niche

Caring House Admission Criteria

Caring House is a loving home for the last stage. We welcome men and women who are in the last weeks or days of their lives.

We accept residents without regard to race, ethnicity, national origin, religious beliefs, sexual orientation, age, and gender as long as they meet the criteria set forth below.

No person will be admitted without his/her consent and agreement, or that of his/her responsible person(s).

To be admitted, a resident must:

- Have one or more designated family members, friends or other responsible persons who are ready, willing and able to make **care decisions and handle financial matters** for the resident (power of attorney or court order preferred, but not required)
- Be **free of active TB** as shown by a negative TB test or clear chest x-ray (within the last 6 months)
- Not have **behavioral issues** that may cause a danger to themselves or others as well as would not be disruptive to others in the home.
- Not require 24-hour skilled nursing but have **needs that can be met in a non-medical residence** and not exceed Caring House's staff capability
- If on **hospice**,
 - Have agreed on no further aggressive care and hospitalizations for their condition
 - Have in place a Do Not Resuscitate order

See page 2 for specific **medical conditions**.

As a Residential Care Facility for the Elderly, our bedrooms are to be occupied by persons **age** 60 and older; under the regulations, however, Caring House is allowed from time to time to admit a resident under that age if the resident's needs are compatible with our other residents.

All potential residents will be considered by the Caring House admissions team as part of an **admissions pool**, rather than a waiting list, which will be continually evaluated. When more than one family is wanting admission and there is only 1 bedroom available, the team looks for the family with the greater need.

Medical conditions (reflecting California regulations and safety needs):

- **Allowed:** Colostomy; gastrostomy tube (G-tube, either not being used or used for medications only); HIV; Ileostomy; Nephrostomy tube; Pleurex tubes; Infusion pumps; Stage III pressure ulcer requiring simple wound care; or Suprapubic catheter; all OK **provided that before** admission to Caring House the person have been admitted to hospice and the wound care or the care, use and maintenance of the device specifically addressed in the hospice care plan.
- Ask us: Tracheostomy.
- Not allowed: Any active infection (ex: TB, staph, MRSA, VRE, C-diff, AIDS); Any wound requiring complex care or any stage IV pressure ulcers; IVs; Requiring fingers sticks and/or insulin injections

To discuss a potential resident call our admissions team at (310) 796-6625 ext. 2.

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310-796-6625 | License Number: 198602078

You can find this document at yourcaringhouse.org/criteria

Criteria for Admission to Clarehouse

- The guest has a life expectancy of one month or less. This prognosis is subject to medical review by Clarehouse RN and Medical Director.
- The guest does not require care in a hospital or skilled nursing facility and his/her needs can be met in a non-medical setting and do not exceed Clarehouse staff capability.
Clarehouse cannot provide care for a guest requiring IV medication, IM medication, SQ medication, a feeding tube, or fingerstick blood sugar checks or insulin injections.
- The guest is enrolled in a local hospice program.
- The guest or health care power of attorney has established a “**Do Not Resuscitate**” Status.
- The guest’s and/or caregiver’s behavior does not present a danger to self or others and would not be disruptive to others at Clarehouse.
- The guest does not have known, active TB.
- Clarehouse staff and the hospice provider serving the guest recommend the admission and agree upon the plan of care at Clarehouse and plans for discharge and/or continuing care.
- The guest and caregiver agree on the purpose of admission and on the plan of care, including the projected length of stay as a guest at Clarehouse.
- There is a plan for continued care for the guest who is discharged from Clarehouse.
- The guest and caregiver understand that there is no charge for care at Clarehouse.

When there is a question of available space, a decision regarding order of admission will be based on order of application. Clarehouse staff reserves the right to deny admission to guests with active, infectious disease that may place other guests or staff at risk.

To make a referral please call 893-6150 or fax 893-6152



<http://www.theabrahamhouse.org/admission-criteria/>

Admission Criteria

Abraham House admission is not based on income level or ability to pay. Although current program and service costs are \$394 per day per guest, we never bill guests or families for services provided, nor do we collect insurance reimbursements. It is hoped that guests and family members will provide Abraham House with reasonable financial compensation dependent upon their individual ability to pay. We also respectfully request that you keep Abraham House in mind for donations and/or obituary mention.

Criteria for Admission:

Abraham House admissions are facilitated through Hospice & Palliative Care, Inc. who provide the medical care plan and case management for our guests. Therefore, all potential Abraham House guests must also be patients of Hospice. (Note that Abraham House and Hospice & Palliative Care, Inc. are separate non-profit organizations who team together to provide the highest quality care.) Hospice can be contacted at (315) 735-6484 for additional information.

>Candidates for Abraham House are individuals with a terminal diagnosis and a prognosis of three months or less who are in need of round-the-clock loving care and desire a home-like environment. In general, the stay at Abraham House is limited to 3 months.

>Referrals are welcomed from any source including family members, hospitals, physicians, and home care agencies.

>We pre-evaluate all potential admissions and accept guests on a case by case basis.

>Admission to Abraham House is prioritized based on need and not necessarily on a first come-first serve basis. Preference is given to those who are determined to have the highest level of need.

>Our goal is to provide appropriate pain and symptom management so our guests' can have a peaceful and comfortable quality of life throughout even their final days.

>We will accept guests with oxygen, catheters, colostomies, feeding tubes, IV pumps, and tracheotomies provided that they are deemed appropriate by all other standards so we can confidently provide the level of care required.

>We do not accept guests who receive intramuscular or subcutaneous injections (including insulin) as Abraham House caregivers are not authorized to perform injections. If arrangements are made for

necessary injections to be administered by someone other than Abraham House staff, admission exceptions may be considered.

>We will not admit guests whose weight is higher than we can safely maneuver. Due to the fact that we may have one caregiver on duty, we need to be sure we can provide the safest and most comfortable care possible. A general guideline we use is 200 lbs. Level of guest mobility and height must also be considered.

>We only accept guests who smoke under the following conditions:

- = guests may smoke only when there are 2 caregivers available so that they may be accompanied at all times
- = smoking is allowed outside on the back deck only

= all tobacco products, lighters, and matches are to be kept in locked custody of Abraham House staff at all times

>While 24-hour care is provided through our trained surrogate caregivers, we may ask family members to sit with guests if they become agitated.

>A Do Not Resuscitate (DNR) order needs to be in place as staff and volunteers at Abraham House are not authorized to perform CPR or call 911.

We understand that this is a difficult time. Abraham House was established to make the situation a little easier by providing the loving care that terminally ill individuals need and deserve. It is a privilege to care for someone during this time in their life. Thank you for your faith and trust.

For further information, please call Abraham House at (315) 733-8210.

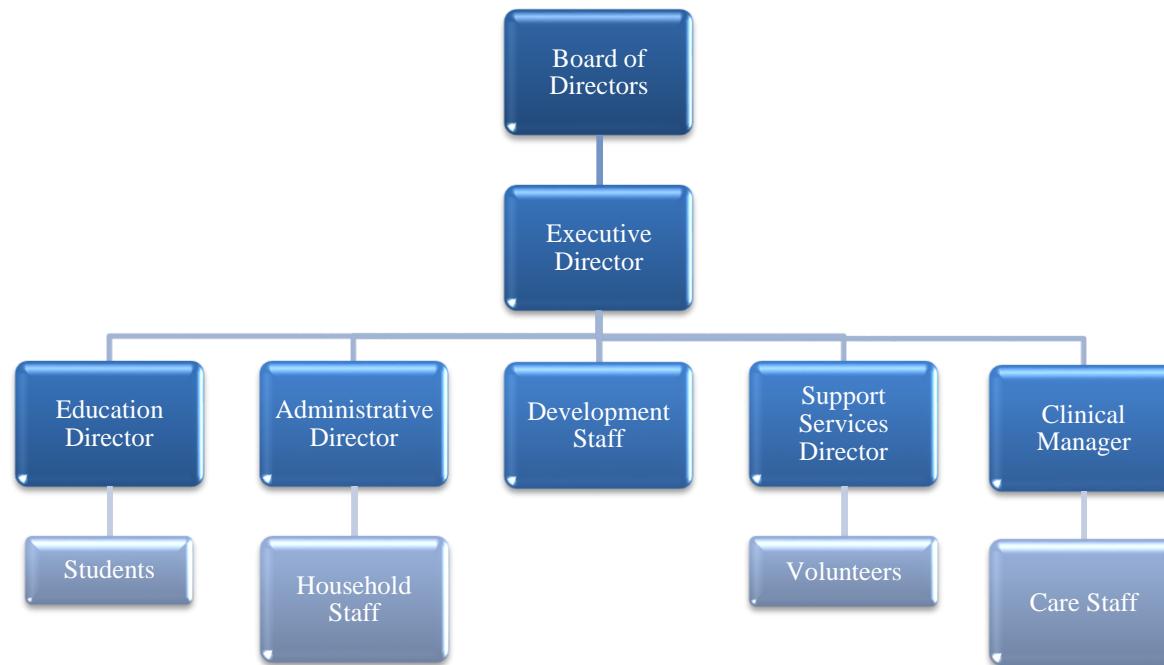
6. Start with a Pilot

- Pre-raise \$ for a trial
- Consider renting space or buy small home
- Learn as you go and develop:
 - ✓ Service reputation
 - ✓ Operational know-how
 - ✓ Donor relationships
 - ✓ Core staff

7. Design your staffing

- Ratio
- Levels of Training
- Volunteer Support
- House Management
- Organizational Management
- Start-up Recruitment and Hiring

Clarehouse Organization Chart



Updated 6.11.19

Clarehouse Caregiver Orientation

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ADMINISTRATIVE SERVICES

Welcome Desk Host/Hostess: Welcome Desk Volunteers are needed to: Greet, check-in, and assist visitors and hospice workers, at our Welcome Desk. Provide hospitality to our guests and families. Conduct tours and distribute brochures. Occasionally answer the phone and record and distribute messages.

Clerical Assistant: Assist with data entry, filing, record-keeping, mailings, and other clerical projects. Maintain scrapbooks and memorial albums. Assist with creation of brochures, power point presentations, invitations, and other publications.

Special Events Assistant: Assist with the planning and coordination of holiday events, fund-raisers, volunteer events, memorial services. Schedule and assist with campus use by community groups. Represent Clarehouse at community events (Ambassador Program, health fairs, etc.)

Concierge: *Hospitality, Care, Household and Support Services in one beautiful package!*

Concierge provides high-level hospitality to guests and visitors, helping with various tasks like accessing food & kitchen services, informing or even recommending support resources for guests and families, offering tours to new families/visitors.

CARE SERVICES

Caregiver – Licensed Professional: Assume shift responsibility for guest care in accordance with hospice plan of care & Clarehouse Standards of Care. Administer and account for medications. Provide comfort care and symptom management. Document care on guest chart. Assure continuity of guest care.

Volunteer Care Assistant (VCA): Assist staff caregiver with guest personal care needs. Assist staff caregiver with interventions according to hospice plan of care. Maintain guests' bedrooms/bathrooms. Observe and comply with Clarehouse Standards of Care.

HOUSEHOLD SERVICES

Gardener: Maintain lawn, gardens, annual and perennial beds. Maintain patios, decks, outdoor areas, water features, and exterior buildings.

Handyperson: Perform routine building maintenance and repairs. Transport heavy items. Perform basic construction and installations.

Household Assistant: Prepare and serve meals (Tulsa County Health Department Food Handlers permit required). Perform housekeeping duties and routine cleaning. Ensure a pleasant, healthy, and safe living environment for families and visitors. Shop and run errands. Stock and inventory food and household supplies. Facilitate use of community agencies for food and supply donations. Organize and maintain books and resources. (If using personal vehicle for the benefit of Clarehouse, automobile insurance must be on file.)

Questions? Contact Cynthia Outlaw, Support Services Director, coutlaw@clarehouse.org

Home. Sharing. Peace. Dignity. Love. Warmth. Joy.

7617 South Mingo Road Tulsa OK 74133 (o) 918.893.6150 (f) 918.893.6152 www.clarehouse.org

SUPPORT SERVICES

Friendly Visitor: Provide emotional and spiritual support and hospitality to guests, family and visitor. Read aloud and participate in supportive activities with guests and families. Support during guest active dying phase (11th Hour Vigil). Provide pet therapy visits.

Musician: Provide music (voice or instrumental) to guests and families. Organize and maintain music library.

Spa Services Assistant: Provide massage and aromatherapy. Provide nail care. Perform hair care and styling. Offer ancillary care as approved by the Support Services Director.

"Warm Heart, Hot Meal"

In keeping with Clarehouse's mission of mercy and compassion in a loving home environment, Meal Provider's goal is to provide a nourishing home-cooked meal to guests and their loved ones several times a week. It is a great joy to see the appreciation of the guests and their families as they enjoy a peaceful and refueling meal, together, without having to leave Clarehouse. Volunteers on duty are always happy to help with serving and clean up.

Meal Provider may:

- prepare meals at individual homes and deliver to Clarehouse.
OR
- come to Clarehouse and use kitchen and pantry contents or Meal Provider's contents.*

The number of guests who are able to eat, as well as the number of family members in the House varies. Meal Provider is typically asked to prepare 10-15 servings for breakfast or dinner, and, at least, 25 lunch servings to include our hospice employees, volunteers and staff. Remember:

- flexible scheduling allows volunteer Meal Providers to choose monthly or more frequent meals.
- varied menus keep the meals appealing.
- leftovers are kept/refrigerated to reheat/serve throughout the day and night.

Volunteer Cook Day*: Meal Providers can also schedule cooking days in Clarehouse's kitchen. Two to three volunteer Cooks might partner to prepare a few casseroles to freeze. These can, then, be heated on open-schedule days. Volunteer Cooks may donate ingredients, identify ingredients in advance for Clarehouse's shopping list, or submit receipts for reimbursement up to \$25.

*Tulsa County Health Department Food Handler's Permit required: <http://www.tulsa-health.org/volunteer-online-training>

Questions? Contact Cynthia Outlaw, Support Services Director, coutlaw@clarehouse.org

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8. Get open

- Leap of faith
- Starts with one, then another, then another
- Set the standard of care
- Don't try to do everything at once
- Embrace and share the Pay-It-Forward philosophy
- Be learning machines

I never look at the masses as my responsibility.

I look at the individual.

I can only love one person at a time.

I can only feed one person at a time.

Just one, one, one.

So you begin.

I begin.

I picked up one person - maybe if I hadn't picked up that one person,

I wouldn't have picked up 42,000.

The whole work is a drop in the ocean.

But if I didn't put that drop in, the ocean would be one drop less.

Same thing for you, same thing for your family, same thing for your business.

Wherever you go, just begin.

One, one, one.

- Teresa of Calcutta

Clarehouse Mission Statement

Clarehouse provides a loving home, quality end-of-life care and access to hospice services to people in need.

Core Beliefs

- We believe that dying people deserve the very best we have to offer.
- We believe that no one should suffer pain or other symptoms when comfort is possible.
- We believe that no one should have to die alone or lonely.
- We believe that a loving, homey environment enables death to be a part of personal, family story rather than a medical event.
- We believe that surroundings, aromas, cleanliness and kindness always matter.
- We believe that family and friends deserve our care as much as the person dying.
- We believe that enabling family to be present as a daughter, son, husband, wife, sibling or friend and not the care giver is just what some people need to cope, grieve and say goodbye.
- We believe that dignity and comfort are more important than tasks and schedules.
- We believe that music, birds, candles and touch make a difference, even to those who can't respond.
- We believe in partnering with hospice organizations and other service providers to avoid duplication of services already available in the community.
- We believe our care is important because it is the right thing to do.

Clarehouse

EMPLOYEE HANDBOOK

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Financial Procedures and Policies Manual

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9. Know yourself

- Collect and use your data
 - ✓ Referral trends
 - ✓ Demographics
 - ✓ Service evaluations
 - ✓ Donation sources
 - ✓ Costs

AutoSave Off

9.1 Sample Inquiry Log - Compatibility Mode - Excel

Britni Smith

File Home Insert Page Layout Formulas Data Review View Help Acrobat Tell me what you want to do

Cut Arial 8 A A Wrap Text General AutoSum A Z Sort & Find & Filter

Copy Merge & Center Conditional Format as Cell Insert Delete Format Fill Clear Sort & Find & Filter

Format Painter Alignment Number Styles Cells Editing

J14

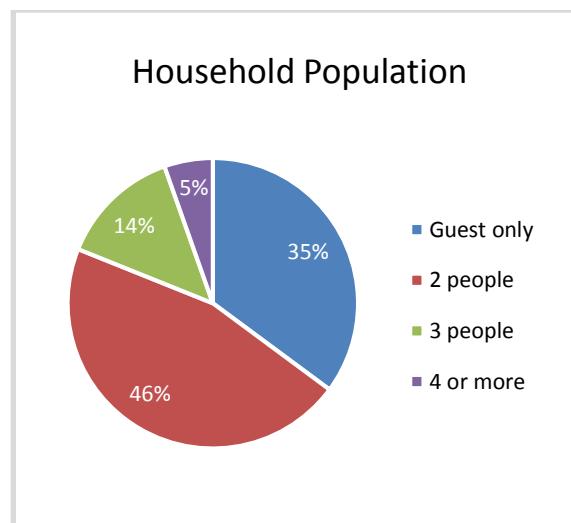
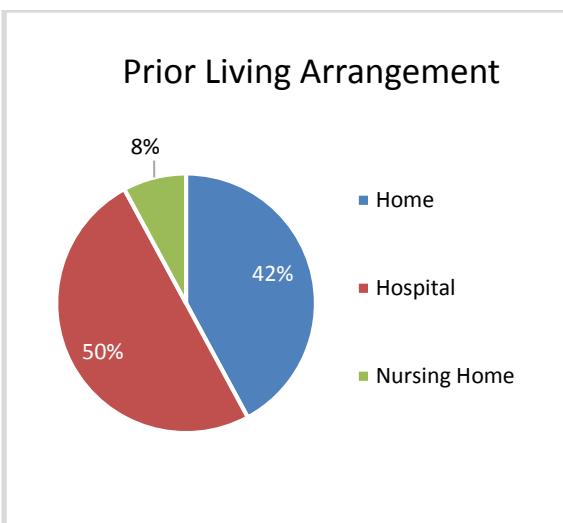
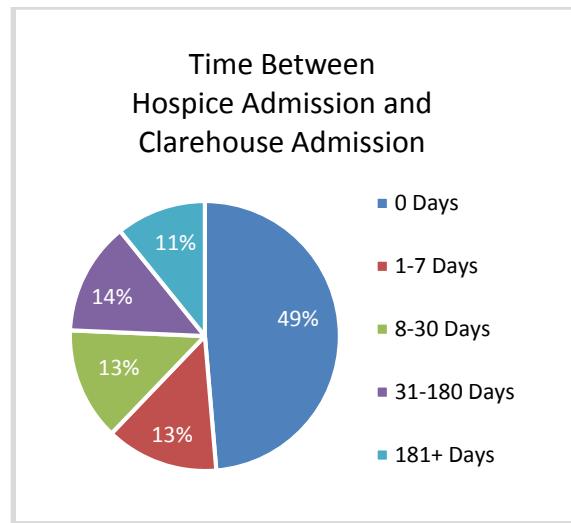
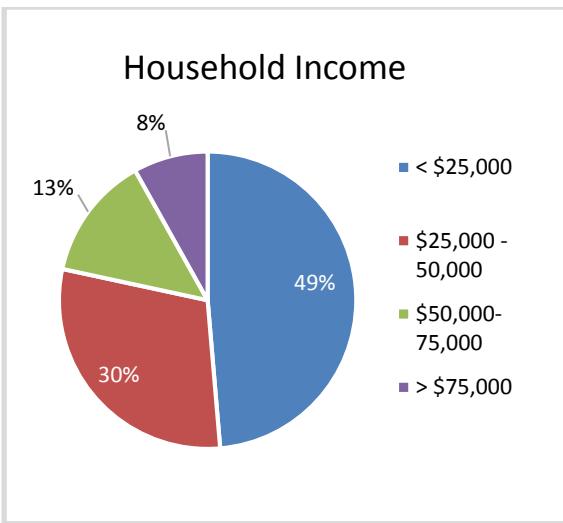
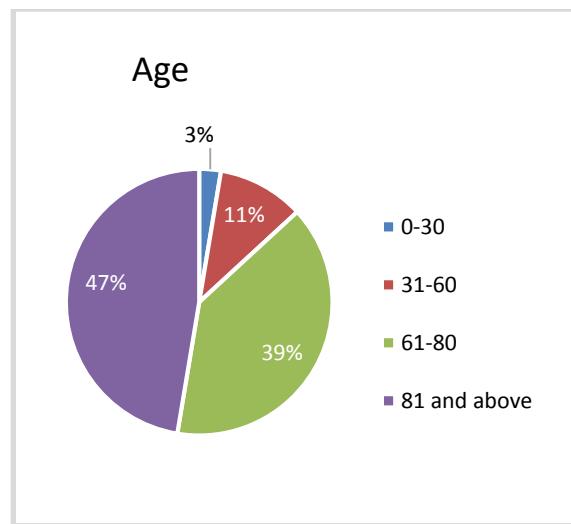
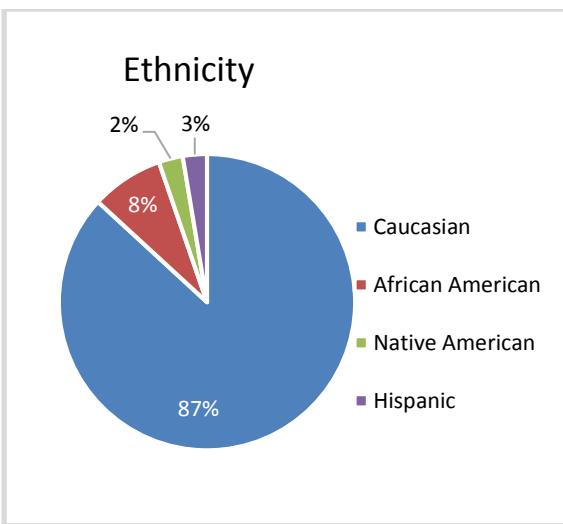
Inquiry

	A	B	C	D	E	F	G	H	I	J	K	L	M
1	Date	By	Name	Diagnosis	Age	Sex	Hospice	Status	Wait List Date	Admit Date	DC Status	Notes	
2	5/22/2019	RN		CAD	75	M	Saint Francis	WL- hold went GIP 5/22-	5/22/2019				
3	5/22/2019	RN		Brain Cancer	97	F	Seasons	WL- went to PCH	5/22/2019				
4	5/22/2019	SW		Sarcopenia	85	M	Physicians Choice	WL- went to PCH 5/31	5/31/2019				
5	5/22/2019	LPN		CHF	92	M	Avow	admitted	5/23/2019	5/24/2019	5/31/2019	RM 4	
6	5/22/2019			Multiple myeloma	79	M	compassus	WL-died 5/23	5/22/2019				
7	5/23/2019	RN		Metastatic Rectal Ca	89	M	Good Shepherd	admitted	5/24/2019	5/28/2019	died-6/5/19	RM 6	
8	5/23/2019	RN		Cerebral Vascular Disease	87	F	Saint Francis	WL- went to PCH	5/23/2019				
9	5/23/2019	RN		ESRD	37	F	ST John	WL- died 5/24	5/23/2019				
10	5/23/2019	RN		Pancreatic Ca	84	F	Compassus	WL-*- went home 5/26	5/23/2019				anxiety/behaviors to be assessed prior to bedof
11	5/23/2019	RN		Intercranial Hemorrhag	92	F	Rose Rock	WL- died 5/26/19	5/23/2019				
12	5/23/2019	RN		Non Small cell lung ca w/	49	M	Saint Francis	Bed offered-hold 5/27	5/23/2019				family wants to take guest home
13	5/23/2019	RN		Lung cancer w/mets	40	M	Saint Francis	admitted	5/23/2019	5/27/2019		RM 10	
14	5/24/2019	SW		Breast Ca w/ Bone mets	62	F	Saint John	WL- died 5/29	5/28/2019				
15	5/24/2019	SW		COPD	85	M	Saint Johns	Pending-died 5/25					Pending family Goals of care regarding Insulin
16	5/24/2019	RN		End Stage Heart Failure	70	F	Compassus	WL- went to PCH	5/24/2019				
17	5/24/2019	LPN		Hypertension Heart Disease	95	F	Roserock	incomplete- died 5/28/19					Need: HCP or medical POA PW
18	5/24/2019	RN		Lung CA w/mets	77	F	Roserock	admitted	5/25/2019	5/31/2019	died 6/4/19	RM 4	
19	5/25/2019	RN		Renca Cell Cancer	54	F	RoseRock	admitted	5/28/2019	5/31/2019	died-6/6/201	RM 9	
20	5/25/2019	SW		CVA	95	F	HOGC	incomplete- died 5/26/19					Need: NN, NA
21	5/26/2019	RN		Lung Cancer w/mets	58	M	Saint Francis	Tba 6/3- went to PCH 6/1	5/28/2019				Need: smoking plan and alcohol plan
22	5/27/2019	RN		ICH	79	F	Saint Francis	WL- died 6/1/19	5/28/2019				
23	5/28/2019	RN		CVA	79	M	Saint Francis	Pending-GIP 5/28- died 5	5/28/2019				GIP 5/28
24	5/28/2019	RN		Esophageal/lung Ca?	83	F	Saint Francis	admitted	5/29/2019	6/3/2019		RM 3	

Clarehouse Report April 2019

General Information

Hospice Utilization



2018 Family Evaluation Tool

2nd Quarter

Surveys returned: 45

1. **I was satisfied with the quality of care my family member received.**
Strongly agree 98% Agree No opinion Disagree Strongly disagree 2% Did Not Respond
2. **My family member was treated with dignity and respect.**
Strongly agree 98% Agree No opinion Disagree Strongly disagree 2% Did Not Respond
3. **I was satisfied with the support given our family.**
Strongly agree 96% Agree No opinion Disagree Strongly disagree 2% Did Not Respond 2%
4. **Clarehouse is welcoming, accessible and homelike.**
Strongly agree 96% Agree 2% No opinion Disagree Strongly disagree 2% Did Not Respond
5. **I was satisfied with Clarehouse staff's efforts to cooperate with our hospice provider.**
Strongly agree 94% Agree 4% No opinion Disagree Strongly disagree 2% Did Not Respond
6. **Clarehouse is focused and knowledgeable on end-of-life care.**
Strongly agree 96% Agree No opinion Disagree Strongly disagree 2% Did Not Respond 2%

I would appreciate a call from the Director and/or the President of the Board of Directors of Clarehouse to discuss questions or concerns. Four Executive Director calls requested – one struggling with grief but doing better, Thankful for the care received at Clarehouse; one expressed thanks; two no return calls. Three Board President calls requested – one expressed what a blessing Clarehouse is, will volunteer in the future; two no return call.

Comments or Suggestions:

- I would like to say “thanks” to each and all workers. Everyone showed their care and love – so caring. Everyone gave my husband wonderful care. I can’t thank everyone enough. Thanks so much. God bless everyone.
- There was a gap in the early mornings. I exited at 6:00 am and returned at 10:00 – 11:00 am to my husband cross-wise in bed, arms and legs entangled in rails, wet diaper – seemed unattended or checked on. Week day night shift was wonderful. Weekend evening, night team much less attentive (male aide, no warmth) Observation of a former hospice RN.
- My father was able to stay at Clarehouse through respite care. St. Francis Hospice made these arrangements. My husband and I were/are very appreciative of this service. We have sent a donation thanking you for housing and caring for our father.
- Clarehouse is a blessing. Thank you so much. Everyone there is truly an angel from God. It was so peaceful there. We felt very blessed. Thank you for everything.
- Our family appreciated the warm, loving and caring staff. They, along with the environment, made a heart-breaking event easier to handle. Thank you so much.
- Thanks so much!
- I loved the facility and the staff. I would recommend it to anyone. You are the best!
- What a blessed and wonderful experience for us. You are truly a blessing to our community.
- The staff was very nice. They kept my mom very cozy.
- Wonderful facility and staff.
- There are no words to express how I feel about Clarehouse. Everyone knew what to say, how to say it, what to do and how to do it. They showed the utmost respect for my dad. Thank you for everything.
- This was such a blessing at one of the most difficult times in my life. I had no family members locally and Clarehouse provided the family I needed. I will always be grateful for the love and support from the staff and volunteers!

- Our short stay, although difficult, was like being home with all the family members. The staff was very professional but caring at the same time. We were honored to be present at such a great facility in our time of need for our beloved wife, mother, etc.
- I felt that my mother's passing was done with loving dignity and with all her children and one grandchild.
- There are no words to describe the gratitude I have for Clarehouse. Thank you, Clarehouse, for the care you gave my family!
- There is no better place for loved ones. We were honored by your kind care for the patient and ourselves. It was like private, loving, care in a beautiful home.
- There are not enough words to express our appreciation for the care my father and our family received from your staff during his last days. Thank you so much.
- Every community needs a Clarehouse. It was a wonderful and peaceful experience for my entire family. What a blessing!
- Everything was covered; I have nothing to add. It was all we could hope for.
- Mom told me, "It's as if they know what you need before you ask." That speaks volumes to the care your volunteers and staff provide. Thank you for welcoming my mother with open loving arms as she made her transition. She was very content at Clarehouse. That peace she felt allowed her to let go.
- Clarehouse was totally wonderful for end of life stay and all the staff and volunteers were excellent. Thank you.
- My husband was at Clarehouse for four days. He passed 4/15/18.
- I could not have asked for better care of my husband while he was experiencing the end of his life. Clarehouse is a beautiful and loving environment. We were blessed.
- Thank you all for the love you showed in taking care of my sweet wife of fifty-two years! Words cannot express the hurt I feel with her not by my side! I thank our Father God for all the years we had together and making the way for his daughter to be at Clarehouse. Thank you, sisters, in the Body of Christ Jesus. I am sorry for the way I was when they first brought my sweet wife of fifty-two years to Clarehouse! They had told me at the hospital they could do no more for her. I was hurt in my soul. My feelings were God had closed the door at the hospital and opened the door to Clarehouse. For over twenty years my wife's health had been up and down. It had been hard, but though we both suffered, I thank God for all those years good or bad! Our Father God suffers along with his children in this life until he calls us home. They had told me if we could go to Clarehouse, she would get the best care. I didn't want to let go. I asked God to please help my wife get over this. Praise God for his loving will for her. He opened the door for a short while at Clarehouse that His plan in her life would be fulfilled! He opened the door to heaven and called her home. I love you all and give praise to God for brothers and sisters who are willing vessels guided by the Holy Spirit.
- Our family would like to thank the staff at Clarehouse for the exceptional care that was given to my dad and our family during the twenty-nine days he was at Clarehouse. I honestly don't know how we could have cared for him during his final days. The nurses and other staff were so compassionate and took care of our every need. Seasons Hospice worked closely with the Clarehouse team and made this time so much more comfortable. We also were so grateful for the meals that were provided by the volunteers and restaurants. Our family will always be grateful for Clarehouse. Please let me know how our family can help with donations. In a few months I will be in contact with Clarehouse to see if I can be a volunteer. Thank you!
- I was very impressed with the care you gave my mom. The staff was great. Could not believe how much care they gave and concern for family.

Know Your Numbers

Omega Home Network Conference 2019

Determine your Occupancy Rate

1. Number of days in time period: 30 days in a month
2. Number of bedrooms: 4
3. Number of days available: $30 \times 4 = 120$
4. Total number of days of care provided (Count the number of days each guest stayed): Ex. 96
5. Divide days of care provided into days available: $96 \div 120 = 80\%$

Determine your Occupancy Goal

It's not possible to reach 100% due to turnover time in preparing a bedroom, staff and volunteers for a new admission. Consider what is reasonable for your house. Good stewardship might imply maximum use of bedrooms to help as many people as possible, but that must be balanced with acknowledgement and respect for the sacredness of care. This is a board and staff discussion. Once a goal is set, this metric should be evaluated regularly as part of monitoring trends and continuous opportunity to improve. It is also an impactful metric to communicate to funders about the impact of their dollars.

Determine Your Cost per Day

1. Number of days per year: 365
2. Times the number of bedrooms: 4
3. Times the occupancy rate: 80%
 $365 \times 4 \times 80\% = 1168$ days of care
4. Divide the program budget by the days of care:
 $\$300,000 \div 1168 = \257 per guest per day

Use this number to help donors understand what the care costs, publish it on your donor envelopes (\$257 for a day of care, \$771 for three days of care, \$1,799 for a week of care, \$7,710 for a month of care), reflect the actual cost against your sliding scale, etc.

10. Use your peer group

- Collectively, the Network has hundreds of years of experience.
- You don't have to re-invent the wheel
- Be bold and creative but stay open to the wisdom of your peers

*Nonprofits must adapt to survive.
If you get stuck, reach out.*

Kelley Scott, Board President kscott@clarehouse.org

Martha Jo Atkins, Vice President marthajo.atkins@abodehome.org

Nancy Light, Secretary/Treasurer nlight@francishouseny.org

Sister Kathleen Osbelt, Board Member kosbelt@francishouseny.org

