Testimony in Support of SB 2226

Residential End-of-Life Facilities
House Human Services Committee
March 9, 2021 • 2:45 p.m. • Pioneer Room

Kilee Harmon
kilee@rockstadfoundation.org • cell: 701.226.4546

Chairman Weisz and members of the committee, my name is Kilee Harmon. I am the Rockstad Foundation team member with the responsibility of creating Gaia Home, which will be licensed as a residential end-of-life facility if Senate Bill 2226 is enacted, providing a new option for end-of-life care. Today I am here to testify in support by 1.) Explaining the vision for our model, 2.) Who residential end-of-life facilities can benefit, and 3.) Why they are needed.

1) **First, the Gaia Home Vision.** Our model will offer a community of 12 private twin homes, in which people can receive hospice services from a provider of their choosing and receive 24-hour supportive care provided by the home's caregiving staff with a significantly low guest-to-caregiver ratio. Family members could live with their loved one, not have to worry about being the caregiver, and focus on spending quality time making lasting memories.

   We anticipate each home will be roughly 1,400 to 1,800 square feet offering two bedrooms, two bathrooms, and an open concept living space with a kitchen, living room and dining area. Each will have its own laundry space, garage, and outdoor gathering spaces. The patient's room would be extra-large to accommodate a person's personal belongings and to allow for extra sleeping arrangements if family members want to comfortably sleep in the same room as their loved one.

   All twin homes would be connected by hallways leading to the main home which will house staffing areas, a family conference room, a hydrotherapy spa, a chapel area, a general kitchen and other amenities.

   To make this beautiful vision become reality, the intent of the Rockstad Foundation is to create a separate non-profit entity to fundraise for, start and operate Gaia Home. It would be 100% privately funded.

   It is currently estimated that a $35 million campaign is needed to build the 12-twin home facility, fund initial operations, and to begin an endowment for sustainability as we will provide compassionate care funds for those who cannot afford private pay. Currently, $3.5 million has been committed thus far. Shortly after legislation is passed and enacted, the silent phase of a capital campaign would begin, and construction would commence when funds have been secured.

   Based upon a successful campaign and initial projections, Gaia Home could open in 2025 and 35% of Guests, or 84-139 people on an annual basis, could have 100% of the costs defrayed in year one, and for the next 13 years without ANY additional donations. A business plan details

that privately raised funds will aim to subsidize the cost of the care, so the private pay component is only $500 per day, which is the market rate for comparable facilities. According to 2018 data, the median length-of-stay for individuals on hospice care in the Bismarck region is 11 days, therefore a family could expect an estimated cost of up to $5,500. However, the overall goal is to grow the endowment to continue to push down costs so all guests are fully fund.

2) Now that we understand the overall vision, I'd like to explain who **residential end-of-life facilities can benefit**, as they will enhance the continuum of services available. They will offer a solution for:

- People who need hospice but have limiting factors which make it difficult or impossible to receive hospice services at their home, and who want to be in a private home setting.
- Families who want to honor a loved one's wish of being in a home during life's final season but are unable to provide 24-hour support in their loved one's home.
- People who are outside of a hospice service area as they could move to a facility like this and receive care in a true home setting.
- Current caregivers who need relief from providing care for longer than the 5-day Medicare respite benefit and their loved one wants to be in a home setting.
- And, lastly, hospice patients whose homes are no longer a viable option, but they desire a home setting.

3) Lastly, **why residential end-of-life facilities are needed.** To qualify for hospice, a person needs to have 24-hour caregiver support, and that caregiver role typically falls on family members' shoulders. If someone does not have 24-hour caregiver support, does not want to put family in the caregiver role, or they do not want to receive hospice in their home, but they also do not want to be in a non-home setting, there is currently no option out there for them. Thus, residential end-of-life facilities fill a gap in the continuum of care.

That concludes my testimony. I thank you again for your time and attention, and I will happily stand for any questions you may have.

For Reference Only

Video explaining Residential End-of-Life Facilities: https://youtu.be/nADQydzNI1I

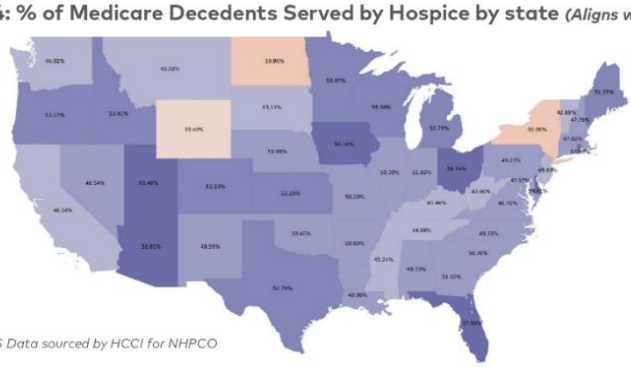
Frequently Asked Questions

1. **Why is hospice utilization so low in ND, and what can be done?**
   According to the NHPCO 2020 facts and figures, the proportion of North Dakota Medicare decedents enrolled in hospice at the time of death in 2018 was 31%, which makes ND ranked 4th from the bottom of all 50 states, territories and District of Columbia. Essentially, this indicates that the Medicare hospice benefit is not being fully utilized in North Dakota. This can be due to not having access to hospice services, and people not fully understanding what hospice all is, the hospice benefit and what it can all offer them. One way to increase hospice utilization is by increasing access to hospice services. We believe Gaia Home will help in this effort.

Figure 5: Medicare Decedent Enrollment % for 2018

Rank	State	
1	Utah	60.5%
2	Delaware	59.4%
3	Arizona	58.8%
4	Florida	57.9%
5	Rhode Island	57.5%
6	Ohio	56.7%
7	Iowa	56.2%
8	Wisconsin	55.1%
9	Idaho	53.9%
10	Michigan	53.8%
11	Minnesota	53.5%
12	Kansas	53.3%
13	Colorado	53.2%
14	Oregon	53.2%
15	Texax	52.8%
16	Maine	51.4%
17	Indiana	51.2%
18	Georgia	51.0%
19	Nebraska	50.9%
20	Arkansas	50.9%
21	South Carolina	50.8%
22	Oklahoma	50.4%
23	Illinois	50.3%
24	Missouri	50.2%
25	Louisiana	50.0%
26	New Mexico	49.6%
27	Pennsylvania	49.3%
28	Alabama	49.2%
29	North Carolina	49.2%
30	Connecticut	48.6%
31	Nevada	48.5%
32	Massachusetts	47.8%
33	New Hampshire	47.7%
34	Maryland	47.6%
35	Virginia	46.7%
36	California	46.1%
37	Washington	46.0%
38	New Jersey	45.6%
39	Montana	45.6%
40	Hawaii	45.4%
41	Mississippi	45.2%
42	Tennessee	44.9%
43	West Virginia	43.6%
44	Kentucky	43.5%
45	South Dakota	43.2%
46	Vermont	42.9%
47	Wyoming	33.4%
48	District of Columbia	33.2%
49	North Dakota	31.0%
50	New York	30.0%
51	Alaska	22.8%
52	Other	14.3%

Figure 4: % of Medicare Decedents Served by Hospice by state *(Aligns with Figure 5)*



Source: CMS Data sourced by HCCI for NHPCO

2. **What type of hospice care will hospice providers be able to provide within Gaia Home?**
    a. There are four levels of hospice care provided by the Medicare hospice benefit. They are routine home care, continuous home care, respite care, and general inpatient.

Level of Care

In 2018, the vast majority of days of care were at the Routine Homecare (RHC) level.

Table 3: Level of Care by % of Days of Care

LOC Metrics	2014	2015	2016	2017	2018
RHC Days	97.7%	97.9%	98.0%	98.0%	98.2%
CHC Days	0.3%	0.3%	0.3%	0.2%	0.2%
IRC Days	0.3%	0.3%	0.3%	0.3%	0.3%
GIP Days	1.7%	1.6%	1.6%	1.3%	1.2%

Source: MedPAC March Report to Congress, Various years

        i. Routine Home Care is the most utilized level of hospice care. According to NHPCO 2020 facts and figures, in 2018, 98.2% of the days of care was under Routine Home Care. That is when the hospice program's interdisciplinary team (Patient and family, Physician including the medical director and attending physician, Registered nurse, Medical social worker, trained volunteers, providers of special services including a spiritual counselor, a registered pharmacist, a registered dietitian, or professional in the field of mental health may be included in the hospice care team as determined appropriate by the hospice program) creates the patient's plan of care, sets up the medical equipment needed wherever the patient calls home, organizes the medication schedule, trains the patient's caregivers on how to provide care per the plan, and more.
        ii. Continuous Home Care (CHC) is care provided for between 8 and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services and are intended to maintain the terminally ill patient at home during a pain or symptom crisis. In 2018, .2% of days of care were CHC.
        iii. Inpatient Respite Care (IRC) is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in certified facilities such as a hospital, hospice facility, or a long-term care facility. In 2018, .3% of days of care were CHC. Even though hospice programs would not be able to offer respite care in our home, they would be able to offer "relief care" in which people can stay longer than the 5-day respite benefit. This portion of the benefit does pay for room and board of a certified facility, where our daily fee will be private pay.
        iv. Lastly, General Inpatient Care (GIP) is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility that has a registered nursing available 24 hours a day to provide direct patient care. In 2018, 1.2% of days of care were GIP. Hospice programs would not be able to offer GIP in our home.

v. In researching this concept and visiting with hospice providers we are confident they will be able to provide routine home care and continuous home care in residential end-of-life facilities, which are the most utilized levels of care.

3. **What about employment and the shortage of nursing personnel?**
    a. We fully understand there is a nursing shortage on a national level and state level. Our hope is to help supplement the staffing with qualified volunteers which is what you will see in other similar places. However, even with that being the case, we do not foresee the nursing shortage as a reason to not offer this type of option for people's end-of-life care.

4. **Why not just become a hospice program?**
    a. We want to focus on running the home and let hospice partners do what they do best, which is provide wonderful hospice care. A home's caregivers would collaborate with hospice providers to ensure the goals and priorities of the patients and families are met.

5. **Why are we seeking licensure at all?**
    a. We believe licensure is the correct course as it creates rules in which govern a residential end-of-life facility, protecting the families who could receive hospice services and support care in these homes.
    b. If your opinion is that this type of facility doesn't need to be licensed, we only would ask that law would be enacted to state that we can exist without licensure. Our only objective is to create confidence to the public that this is a safe facility for loved ones who are vulnerable adults.

6. **What supportive services are offered?**
    a. Ultimately, the services residential end-of-life facilities will be able to provide will be determined by the administrative rules. However, we foresee them being able to help with the following:
        i. Services that help a hospice patient with his or her activities of daily living, and may also include preparation of special diets, medication administration, or other activities that do not require constant attention of medical personnel.
            1. Activities of daily living are the tasks of transferring, moving about, dressing, grooming, toileting, bathing, and eating performed routinely by a person to maintain physical functioning and personal care.
        ii. Provide non-personal care tasks such as housekeeping, laundry, shopping, and cooking.
        iii. Could also include massages, music therapy, pet therapy and other therapies that help people through their end-of-life journey.

7. **If a hospice patient revokes from the hospice agency, are they still able to live in this home?**
    a. If they choose to be a hospice patient of a different hospice program that provides services in the residential end-of-life facility, we believe they could stay.
    b. If they are not a hospice patient, we do not believe they will be able to stay in a residential end-of-life facility.

8. **Are hospice programs responsible for supervising nurses/aids at the facility?**
    a. No. The residential end-of-life facility will supervise its nurses, aids and volunteers.