

INPATIENT HOSPICE FACILITIES IN MAINE

A WHITE PAPER

Prepared by

The Maine Hospice Council

May 24, 2001

The Maine Hospice Council wishes to express sincere thanks to the Clinical Regulatory Committee for their efforts developing this paper.

Thank you to the following Board and Committee members for their contributions: Arlene Wing, Barbara Bell, Terry Cronin, Patricia Eye, Connie Guare, Lauren Michalakes, and Debbie Riley.

And a special thanks to Sue Farra, RN who did the bulk of the research with the inpatient facilities.

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INPATIENT HOSPICE FACILITIES IN MAINE

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May 24, 2001

Executive Summary

We are now in an era with heightened awareness concerning the needs of the dying and a culture that is demanding appropriate and humane settings in which to meet these needs. Several individuals and organizations around the state of Maine are now working toward the development of inpatient hospice or palliative care facilities. This white paper is being written to identify barriers, clarify processes, and recommend needed legislative changes in order to aid in the development of inpatient hospice or palliative care programs in Maine.

History

Originally, the term hospice dates back to medieval times and referred to a place where travelers could find respite, shelter, and comfort. The travelers were typically on a religious pilgrimage. The modern hospice concept involves a comprehensive service model that provides care across the continuum. The person credited with founding the modern hospice movement is Dame Cicely Saunders, a physician, who opened St. Christopher's Hospice in London in 1967. Hospice came to the United States in the mid 1970s. The Medicare hospice benefit was implemented in 1983.

Hospice first came to Maine in 1976 with the advent of Hospice of Maine, a volunteer hospice program. The first Medicare certified hospice was developed by Kennebec Valley Regional Home Care (now HealthReach) in 1989. Hospice licensing rules were implemented in 1994. Hospice licensing was created to ensure that any organization calling itself hospice or advertising hospice services would be truly adhering to hospice philosophy. There was concern at that point in time that some organizations in other states were creating organizations called hospices that were not providing true hospice services. Maine hospice licensing rules require inpatient hospices to be Medicare certified. This was required by the state so that only Federal dollars would be drawn upon to fund inpatient care.

Currently, as of Spring 2001, there are no licensed hospice inpatient units in Maine. There are ten volunteer only hospices and sixteen Medicare certified hospice programs in Maine. There are thirty-six hospitals, and one hundred twenty-three nursing facilities. Of these, all hospitals have contracts with hospice programs as do approximately two thirds of the nursing homes. Interestingly, Maine has the lowest rate of access to the Medicare hospice benefit of any state in the nation.[†] Even though there are sufficient numbers of hospice programs and contracted facilities, there is not adequate access to end of life care.

There is now great interest in end of life issues due to recent publicity related to this subject. A citizens' referendum was presented on the ballot for vote in the fall of 2000 concerning physician-assisted suicide. This generated a great deal of media attention and both sides campaigned heavily. The referendum was defeated by a narrow margin. During

[†] NHO Senior Management and Leadership Conference, May 1997, "Hospice Penetration: The Use of Public Data to Measure Hospice Performance." Cushman, Jay D., et. al.

the campaign, it became clear that Maine needs to pay increased attention to enhancing end of life care, including hospice care services. In the fall of 2000 the Bill Moyer series titled “On Our Own Terms: Moyers on Dying” conducted programming on death and dying. This television presentation brought tremendous attention to the needs of the dying and highlighted the benefits of inpatient hospice care. This increased attention has created great interest in creating hospice inpatient units throughout the state.

There is much work to be done, but much work that has already been done. For example, the Maine Hospice Council received a Robert Wood Johnson (RWJ) community state partnership grant in the amount of \$450,000, which has been used to increase knowledge and awareness of death and dying issues. The RWJ grant includes ten projects and fourteen partners throughout the state of Maine. Many other programs around the state have created innovative programs and are continuing to further the work of improving end of life care.

Regulatory Processes

Maine does not require a certificate of need for any hospice programs or services. Certificate of need (CON) issues would only apply to inpatient programs desiring to have beds licensed in a venue that requires a CON. Certificates of need are required for nursing facility beds, (there is currently a freeze on these), hospital beds, and assisted living beds. See Appendix I for office phone numbers, addresses and contact names of regulatory departments.

In order to become a hospice in Maine a program must apply for a license as a hospice. This application is provided by the Department of Certification and Licensing.

Upon completion of the application and preparing for a licensing survey, the prospective hospice is surveyed for compliance with the licensing regulations. Upon successfully demonstrating compliance with licensing regulations and being conditionally licensed, the hospice then may submit application for Medicare hospice certification and begin caring for patients. This will entail another survey for hospice certification. Once this survey has been completed for hospice certification, the hospice may receive reimbursement via Medicare for recipients electing the Medicare hospice benefit. After the hospice is certified, it may take several months to receive the provider number that is needed for billing. The hospice has to have enough cash to survive until the provider number is received and billing to Medicare can commence. Some hospices choose to limit admissions until the provider number is received in order to allow enough resources to serve the patients and families.

To summarize the purposes of licensing and certification: licensing allows an organization to do business as a hospice and must be the first step. Medicare hospice certification allows the hospice to receive reimbursement from federally funded programs i.e., Medicare and Medicaid. Once a program is Medicare certified, it may, if it chooses, fill out an application to become a hospice Medicaid provider.

The Maine hospice license rules state that any inpatient hospice in Maine must be Medicare certified. Not all other states have hospice licensing that ties Medicare certification to the inpatient hospice facility, and some states have no hospice licensing at all. Medicare certification requires that at least 80% of all patient days (in the aggregate) must be home care days. This requirement in effect mandates therefore that any inpatient hospice must also have a home care hospice program. The Medicare hospice conditions of participation at 418.80 state that core services must be provided by employees who are

direct employees of the hospice. This would prohibit the inpatient hospice from contracting with an existing home care hospice for these services. The inpatient hospice would be required to hire staff and provide home visits directly or merge with a home care hospice. This has been a hurdle for inpatient programs who are not already hospice providers. See Appendix II for Maine hospice licensing rules, Medicare hospice rules, and Maine Medicaid hospice rules.

Life and safety codes, and local zoning requirements would have to be met by any inpatient facility, regardless of model or regulatory oversight. The Life Safety Code originated from the work of the National Fire Protection Association, which was appointed in 1913. The intent of the code is to ensure building safety in the event of fire. The code addresses such issues as sprinkler systems, safe egress and fire retardant building materials. The code is comprised of four major parts. The first part consists of chapters 1 through 4 and 6 through 11; these are referred to as the base or fundamentals chapters. The second part is chapter 5, which details the performance-based option. The next part consists of Chapters 12 through 42, which are occupancy chapters. The fourth and last part consists of Annexes A and b, which contain useful information. See Appendix I for contact information and how to order a manual. A life safety code manual is on file for reference in the Maine Hospice Council office.

Models

Inpatient hospice units are categorized by location and type of reimbursement received. The location often determines the reimbursement due to licensing and certification rules.

Inpatient hospices can be located in hospitals, nursing facilities, assisted living facilities, residential facilities, or be freestanding hospices. Many models include beds of different types. For example: a unit might include some skilled level beds and some surrogate family home beds. All hospices strive for a homelike setting and an environment that allows room for family members to stay with the dying person.

A surrogate family home would serve as an alternate home for those without primary care givers. This facility would not use the name hospice if the organization did not want to be licensed and Medicare certified. If the facility was not licensed and certified as a hospice, the reimbursement would be solely room and board. Room and board would be paid out of pocket, or by commercial insurers, if allowed per the patient's policy. A sliding fee scale could be instituted if desired.

Medicare reimbursement can be paid directly to the inpatient hospice or via contract from another hospice organization. Medicare reimbursement can be received for four levels of care. The four levels are: general inpatient, inpatient respite, continuous, and routine. The general inpatient level of care can be provided in a skilled nursing facility, hospital, or freestanding hospice that meets the Medicare inpatient hospice standards at 418.100. The inpatient respite level of care can be provided in a nursing facility, skilled nursing facility, hospital, or freestanding hospice that meets the Medicare hospice inpatient standards at 418.100. Continuous care and routine care are provided in a patient's home.

The criteria for accessing reimbursement at the general inpatient level of care are that the patient must need symptom management that cannot be feasibly provided in other settings. The hospice receives the Medicare hospice per-diem payment for this level

(approximately \$475 per day as of spring 2001). If the hospice is contracting with another facility to provide the service, then the hospice pays the facility the rate that was previously negotiated according to the contract. If the hospice has an inpatient facility and is providing the service directly, the hospice keeps the full reimbursement.

The inpatient respite level of care may occur for up to five days at a time and is intended to be for the occasional relief of caregivers in need of respite. The hospice receives the Medicare hospice per-diem payment for each day this level is utilized (approximately \$100.00 per day as of spring 2001). If the hospice is providing service through a contracted facility, the hospice pays the facility the negotiated room and board rate and bills the patient 5%. If the hospice provides the service directly, the hospice keeps the full Medicare payment and bills the patient 5%.

The routine level of care that is provided at the patient's residence (own home, nursing home with which the hospice has a nursing home as home contract, or inpatient hospice) when the patient is not in a crisis and no other level of care is necessary. This is billed to Medicare for each day the patient is receiving this level of care and is paid on a per-diem basis (approximately \$100.00 per day as of spring 2001). The hospice would not contract for this service, so would retain the payment.

The continuous level of care is provided in the patient's residence during times of crisis. There must be a minimum of eight hours out of a twenty four hour period and at least 50% of the hours must be licensed nursing (LPN or RN). The billing cycle runs midnight to midnight. This is the only level of care that is paid on an hourly basis (approximately \$28

per hour as of spring 2001). This level of care would not be provided by contract, so the hospice would retain the reimbursement.

Commercial insurers may pay for inpatient services according to their contract with the beneficiary and the inpatient hospice. The coverage will vary and may or may not mirror the Medicare levels of care.

Private payment may be made by patients for services received in an inpatient facility. Most often this payment would be for room and board in a surrogate family home bed. There is currently no Medicare or Medicaid reimbursement for room and board in a hospice facility.

Hospice Inpatient Models and Regulations					
Model	Life safety code, zoning (not required if 2 beds or less)	CON	Hospice License	Hospice Certification	Facility license and or certification
Surrogate Family Hospice	x		x	x	
Surrogate family home not hospice	x				
Assisted living hospice unit	x	X (if new beds)	x	x	x
Nursing facility hospice unit	x	X (if new beds)	x	x	x
Hospital hospice unit	x	X (if new beds)	x	x	x
Inpatient hospice (all 4 levels of care)	x		x	x	

If combination units are utilized, the rules and regulations for each type of bed would have to be adhered to. For example, a unit with assisted living beds and inpatient hospice beds would have to adhere to assisted living rules and regulations for the assisted living beds and adhere to hospice licensing, and Medicare hospice rules for the hospice beds. The facility would have to adhere to life safety codes for both types of beds.

See Appendix III for algorithm on Maine regulations for inpatient hospices.

Of the 20 inpatient hospices surveyed from around the United States, none reported that special legislation was required in order to meet regulatory requirements. Of the 20

reporting, 8 states had hospice licensing, 2 hospices were licensed as Level I boarding homes, and 1 was licensed as assisted living.

Reimbursement Assessments

A needs formula is used to aid in determining whether the catchment area for the proposed inpatient facility will support an inpatient unit. A formula for surrogate family homes (also called residential facilities) recommended by the National Hospice and Palliative Care Organization (NHPCO) is $(\text{Number of persons with no/limited primary care giver}) \times 30 \text{ days} \div 365 = \text{total projected bed days} \times \text{total market share (not less than 50\%)}$. A detailed needs formula for freestanding hospice facilities is outlined in the Hospice Operations manual in Appendix II-I. This manual can be obtained from NHPCO and is on file at the Maine Hospice Council office.

In simple terms, the needs formula determines the total market as the first step. The total market is the number of deaths that could potentially be hospice deaths as determined by diagnosis. Then a determination is made as to the number out of the total that would be served by the hospice in that particular hospice's catchment area. The rule of thumb in 1991 was to use 50% as the total hospice patients that would access hospice services out of the total possible hospice patients. The utilization in Maine is typically much lower than that. The rate of utilization would have to be looked at individually in each community. After the number of patients in total is determined, then the number of patients who would utilize inpatient services would be calculated. Rules of thumb vary somewhat based on cost per day in the hospice unit, but current ranges are that there needs to be sufficient volume to keep 6-10 beds filled. After a feasibility study (see attached model) is completed using the needs formula, a determination is made as to whether to proceed or not. This decision is

based on detailed financial studies that look at market statistics, design, building, maintenance, capital, personnel, and supply costs. Depending on many variables, the cost per bed per day can range significantly. Most inpatient hospices rely on a significant amount (average 27%) of fundraising to keep their facilities viable.

The next phase would involve decisions concerning models, location, fund raising, building design, possible construction/renovation, regulatory applications and preparation for survey.

Please see Appendix IV for information from inpatient hospices throughout the United States.

Recommendations

Whereas the Department of Certification and Licensing agrees that the Maine Hospice Licensing regulations and the Medicare Hospice Certification rules are sufficient as regulatory oversight for an inpatient hospice in Maine, the Maine Hospice Council requests the Department consider granting waivers to inpatient hospices desiring to contract for home hospice services from another provider.

Whereas there are no inpatient hospice facilities or surrogate family homes in the state of Maine, the Maine Hospice council recommends that the Department of Licensing and Certification and the regional fiscal intermediary allow a pilot program to be implemented for a surrogate family home with the least restrictive regulatory oversight possible. Regulatory oversight would include: 1) Life Safety Codes with the consideration from the Department of Certification and Licensing for a waiver, where appropriate, to ensure a homelike environment, and 2) no other regulatory oversight or perhaps room and

lodging level only. The surrogate family home would serve as a change of address for a patient who lacked an appropriate primary care giver and would be staffed by volunteers who would serve as surrogate family members.

The goal for the provision of hospice inpatient care is to allow the dying person to stay in one bed during changes in levels of care, and to provide appropriate care resources for those who lack a primary care giver or appropriate home setting. Inpatient hospice programs should be developed according to the needs of each community area. The programs that are instituted will likely be very different depending upon population, referral patterns, and cultural norms that vary from area to area.

There is an identified gap in our end of life health care delivery system in that the state of Maine has no inpatient hospice programs. The citizens of Maine, provider programs, and regulatory bodies can work together to effect change for the benefit of all who are dying and those who care for them.

APPENDIX I: Licensing and Certification

LICENSING AND CERTIFICATION

Department of Certification and Licensing, hospice, hospital, and home health, State House Station 11, 35 Anthony Avenue, Augusta, Maine 04333. Sandy Bethanis, Assistant Director, voice 624-5419 or FAX 624-5378.

Assisted Living Unit, State House Station 11, 35 Anthony Avenue, Augusta Maine 04333, Nadine Marchant, Licensing Manager, voice 624-5258 or FAX 624-5228.

CERTIFICATES OF NEED

Nursing Home CON: Long Term Care Community Resource Development Unit, State House Station 11, 35 Anthony Avenue, Augusta, Maine 04333, Catherine, Cobb Director of Community Resource Development Unit, Voice 624-5251 or FAX 624-5361.

Hospital CON: Certificate of Need Unit, Bill Perfetto. Director Certificate of Need Unit, 1 VA Way Building 205, State House Station 11, Augusta, Maine 04333, Voice 287-1835 or FAX 287-1832.

APPENDIX II: Regulations

Life Safety Code Handbook

The *Life Safety Code Handbook* brings you the practical facts you need to make informed decisions and apply the latest requirements with confidence. Sections by section, the new *Life Safety Code Handbook* explores the code. Expert commentary, interpretations, and examples explain the reasoning behind requirements and give you important tips on applying the code to specific situations. Plus, you get useful supplements, including a guide to fire alarms, an illustrated overview of sprinkler types and how they relate to the *Life Safety Code*, an overview of fire tests and more. To order this handbook, call toll-free 1-800-344-3555.

Maine Hospice Licensure Regulations

CHAPTER 1681

LICENSING OF HOSPICE PROGRAMS (HEADING: PL 1993, c. 692, §1 (new))

SUBCHAPTER I

LICENSING OF REIMBURSED HOSPICE PROGRAMS (HEADING: PL 1993, c. 692, §1 (new))

22 § 8621. Definitions

As used in this chapter, unless the context otherwise indicates, the following terms have the following meanings. [1993, c. 692, §1 (new).]

1. Bereavement services. "Bereavement services" means emotional support services related to the death of a family member, including, but not limited to, counseling, provision of written material, social reorientation and group support for up to one year following the death of the client who was terminally ill. Bereavement services must be consistent with the bereavement care plan.

[1993, c. 692, §1 (new).]

2. Care plan. "Care plan" means a written service delivery plan that the interdisciplinary team, in conjunction with the client, shall develop to reflect the changing care needs of the client. A care plan must specify what hospice services are needed and how they will be delivered.

[1993, c. 692, §1 (new).]

3. Client. "Client" means the person who is receiving the hospice services.

[1993, c. 692, §1 (new).]

4. Council. "Council" means the Maine Hospice Council established by section 8611.

[1993, c. 692, §1 (new).]

5. Direct service provider. "Direct service provider" means employees or volunteers who provide hospice services directly to a client.

[1993, c. 692, §1 (new).]

6. Durable health care power of attorney. "Durable health care power of attorney" has the same meaning as contained in Title 18-A, section 5-506.

[1993, c. 692, §1 (new).]

7. Family. "Family" means a spouse, primary caregiver, biological relatives and individuals with close personal ties to the client.

[1993, c. 692, §1 (new).]

8. Governing body. "Governing body" means the entity that establishes policy and is legally responsible for the overall operation of a hospice program.

[1993, c. 692, §1 (new).]

9. Hospice philosophy. "Hospice philosophy" means a philosophy of palliative care for individuals and families during the process of dying and bereavement. "Hospice philosophy" is life affirming and strengthens the client's role in making informed decisions about care. "Hospice philosophy" stresses the delivery of services in the least restrictive setting possible and with the least amount of technology necessary by volunteers and professionals who are trained to help clients with the physical, social, psychological, spiritual and emotional needs related to terminal illness.

[1993, c. 692, §1 (new).]

10. Hospice program or hospice provider. "Hospice program" or "hospice provider" means a distinct, clearly recognizable entity that exists to provide hospice services.

[1993, c. 692, §1 (new).]

11. Hospice services. "Hospice services" means a range of interdisciplinary services provided on a 24-hours-a-day, 7-days-a-week basis to a person who is terminally ill and that person's family. Hospice services must be delivered in accordance with hospice philosophy.

[1993, c. 692, §1 (new).]

12. Interdisciplinary team. For a hospice providing comprehensive services, "interdisciplinary team" means a group comprised of at least a medical director, a licensed nurse, a licensed social worker, a pastoral or other counselor and a volunteer coordinator or representative. For a volunteer hospice program, "interdisciplinary team" means a regularly scheduled case conference as defined by program policy. The client, and the client's family if the client desires, must be given the opportunity and encouraged to attend interdisciplinary team meetings.

[1993, c. 692, §1 (new).]

13. Medical director. "Medical director" means a licensed physician who oversees the medical components of hospice services and serves on the interdisciplinary team.

[1993, c. 692, §1 (new).]

14. Nurse supervisor. "Nurse supervisor" means a licensed registered nurse with education, experience and training in hospice nursing care who is designated by the program director to oversee nursing services for the hospice program.

[1993, c. 692, §1 (new).]

15. Primary physician. "Primary physician" means the physician identified by the client or by the person authorized to make decisions for the client pursuant to a durable health care power of attorney.

[1993, c. 692, §1 (new).]

16. Program director. "Program director" means the person designated by the governing body of a hospice program as responsible for the day-to-day operations of the program.

[1993, c. 692, §1 (new).]

17. Terminally ill. "Terminally ill" means that a person has a limited life expectancy in the opinion of the person's primary physician or the medical director.

[1993, c. 692, §1 (new).]

18. Volunteer. "Volunteer" means a trained individual who works for a hospice program without compensation.

[1993, c. 692, §1 (new).]

19. Volunteer hospice program. "Volunteer hospice program" means a hospice program that provides all direct patient care at no charge.

[1993, c. 692, §1 (new).]

Section History:

1993, c. 692, § 1 (NEW).

22 § 8622. Licensing of hospice programs

1. License required. Beginning January 1, 1995, a person, partnership, association or corporation may not represent itself as a hospice program, operate a hospice program or otherwise provide hospice services unless the person, partnership, association or corporation has obtained a license by the department.

[1993, c. 692, §1 (new).]

2. Licenses. If, after receiving an application for a license, the department finds that all the conditions of licensure are met, it shall issue a license to the applicant for a period of 2 years. If the department finds less than full compliance with the conditions of licensure, it may issue a conditional license.

The department may issue a conditional license if the applicant fails to comply with applicable laws and rules but the best interest of the public would be served by issuing a conditional license. The conditional license must specify when and what corrections must be made during the term of the conditional license.

When an applicant fails to comply with applicable laws and rules, the department may refuse to issue or renew the license.

[1993, c. 692, §1 (new).]

3. Appeals. An applicant who is denied a license, or whose application is not acted upon with reasonable promptness, has the right of appeal to the commissioner. The commissioner shall provide the appellant with reasonable notice and opportunity for a fair hearing. The commissioner or a member of the department designated and authorized by the commissioner shall hear all evidence pertinent to the matter at issue and render a decision within a reasonable period after the date of the hearing. The hearing must conform to the procedures detailed in this

subsection. Review of any action or failure to act under this chapter must be pursuant to Title 5, chapter 375, subchapter VII. An action relative to the denial of a license provided under this chapter must be communicated to the applicant in writing and must include the specific reason or reasons for that action and must state that the person affected has a right to a hearing.

[1993, c. 692, §1 (new).]

4. Deemed status. A Medicare-certified hospice is deemed to meet the licensure requirements for a hospice program if it attests in writing that it meets all state licensure requirements.

[1993, c. 692, §1 (new).]

5. Medicare certification and requirements. Beginning July 1, 1996 any hospice program except a volunteer hospice program must be Medicare-certified and meet Medicare requirements to be eligible for licensure as a hospice program.

[1995, c. 486, §1 (amd).]

6. Right of entry and inspection. A duly designated employee of the department may enter the premises of any hospice provider who has applied for a license or who is licensed pursuant to this chapter or rules adopted pursuant to this chapter. These employees may inspect relevant documents of the hospice provider to determine whether the provider is in compliance with this chapter and rules adopted pursuant to this chapter. The right of entry and inspection extends to any premises and documents of providers whom the department has reason to believe are providing hospice services without a license. These entries or inspections must be made with the permission of the owner or person in charge unless a warrant is first obtained from the District Court authorizing that entry or inspection under section 2148.

[1993, c. 692, §1 (new).]

7. Application fee. Each application for a license under this chapter must be accompanied by a fee established by the department, based on the cost of survey and enforcement. All fees collected under this subsection must be deposited into the General Fund.

[1993, c. 692, §1 (new).]

8. Sanctions. A person who violates this chapter commits a civil violation for which a forfeiture not to exceed \$100 per day of violation may be adjudged.

[1993, c. 692, §1 (new).]

9. Compliance. A hospice program must meet all appropriate state rules and federal regulations.

[1993, c. 692, §1 (new).]

10. Minimum survey requirement. Notwithstanding subsection 4, a hospice program is not eligible for licensure or renewal of licensure unless the hospice program has had a Medicare survey or a state licensure survey within the previous 3 years.

[1993, c. 692, §1 (new).]

Section History:

1993, c. 692, § 1 (NEW).

1995, c. 486, § 1 (AMD).

22 § 8623. Rules

The department shall adopt rules in accordance with Title 5, chapter 375 that specify the requirements for licensure under this chapter. The rules must require, but are not limited to, the following provisions. [1993, c. 692, §1 (new).]

1. Mission statement. A hospice program must have a clear mission statement that is consistent with hospice philosophy adopted by the council.

[1993, c. 692, §1 (new).]

2. Discreet entity. A hospice program must be a discreet entity with at least the following features:

- A. A governing body; [1993, c. 692, §1 (new).]
- B. A program director; [1993, c. 692, §1 (new).]
- C. An interdisciplinary team; [1993, c. 692, §1 (new).]
- D. Volunteers; and [1993, c. 692, §1 (new).]
- E. A medical director. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

3. Clients. A hospice program may provide services to any person who consents to receive those services.

[1993, c. 692, §1 (new).]

4. Services. Hospice services must be delivered in accordance with a care plan approved by the interdisciplinary team, regardless of whether the hospice services are provided by hospice program staff or by contractors. The care plan must provide for 24-hours-a-day, 7-days-a-week services. The care plan must be reviewed periodically by the interdisciplinary team and revised as needed. The interdisciplinary team must consider the need for at least the following services when developing the care plan:

- A. Social services; [1993, c. 692, §1 (new).]
- B. Nursing care; [1993, c. 692, §1 (new).]
- C. Counseling; [1993, c. 692, §1 (new).]
- D. Pastoral care; [1993, c. 692, §1 (new).]
- E. Volunteer visits to provide comfort, companionship and respite; [1993, c. 692, §1 (new).]
- F. Bereavement services for at least one year after the death of the person who is terminally ill; and [1993, c. 692, §1 (new).]
- G. Medical services. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

5. Nursing. Nursing services provided by a hospice program must be provided in accordance with a care plan and must be under the direction and supervision of a nurse supervisor. The nurse supervisor shall:

- A. Develop nursing objectives, policies and procedures consistent with hospice philosophy; [1993, c. 692, §1 (new).]
- B. Develop job descriptions for nursing personnel consistent with hospice philosophy; [1993, c. 692, §1 (new).]

C. Establish staffing and on-call schedules for nursing staff; and [1993, c. 692, §1 (new).]

D. Develop and implement orientation and training programs for nursing staff. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

6. Orientation. Before providing any hospice service, a direct service provider must receive an orientation of at least 4 hours specific to hospice service. The policy and procedures of the provider define the agenda of the hospice orientation program. The provider shall document in personnel files that staff members have completed the 4-hour orientation. Indirect service volunteers must be oriented according to provider policies.

The hospice orientation program must include, but is not limited to, the following subjects:

A. Hospice philosophy; [1993, c. 692, §1 (new).]

B. Personal death awareness; [1993, c. 692, §1 (new).]

C. Communication skills; [1993, c. 692, §1 (new).]

D. Personnel issues; [1993, c. 692, §1 (new).]

E. Identification of hospice resource people; [1993, c. 692, §1 (new).]

F. Stress management; [1993, c. 692, §1 (new).]

G. Ethics; [1993, c. 692, §1 (new).]

H. Stages of dying; and [1993, c. 692, §1 (new).]

I. Funeral arrangements. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

7. Training. A hospice program shall provide an educational program that offers a comprehensive overview of hospice philosophy and hospice care. A minimum of 18 hours of education, including 4 hours of orientation, is required for all direct service providers delivering hospice care. The educational program must include, but is not limited to, the following subjects:

A. Hospice philosophy; [1993, c. 692, §1 (new).]

B. Family dynamics; [1993, c. 692, §1 (new).]

C. Pain and symptom management; [1993, c. 692, §1 (new).]

D. Grief, loss and transition; [1993, c. 692, §1 (new).]

E. Psychological perspectives on death and dying; [1993, c. 692, §1 (new).]

F. Spirituality; [1993, c. 692, §1 (new).]

G. Communication skills; [1993, c. 692, §1 (new).]

H. Volunteer roles; and [1993, c. 692, §1 (new).]

I. Multidisciplinary management. [1993, c. 692, §1 (new).]

Hospice personnel who choose to provide direct service to patients are required to meet the minimum training requirement of 18 hours within one year. Documentation of completion of training is transferable from one hospice program to another.

[1993, c. 692, §1 (new).]

8. Continuing education and in-service training. Hospice direct service providers are required to complete a minimum of 8 hours of continuing education or in-service training each year after the first year, based on date of hire.

[1993, c. 692, §1 (new).]

9. Records. A hospice program shall maintain, at a minimum, the following records:

- A. Minutes of governing body meetings; [1993, c. 692, §1 (new).]
- B. Care plans of interdisciplinary teams; [1993, c. 692, §1 (new).]
- C. Progress notes regarding the families receiving services; [1993, c. 692, §1 (new).]
- D. All receipts and expenditures; [1993, c. 692, §1 (new).]
- E. Training provided to paid staff and volunteers; and [1993, c. 692, §1 (new).]
- F. A discharge summary for each client, a copy of which must be provided to the primary physician. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

10. Policies. A hospice program shall have and follow written policies and procedures governing its operation, including, but not limited to, a policy regarding confidentiality and a policy regarding training.

[1993, c. 692, §1 (new).]

11. Required information. A person who enters a hospice program must be given information regarding durable health care power of attorney.

[1993, c. 692, §1 (new).]

12. Quality assurance. The hospice provider shall have a functional quality assurance or improvement plan in place that:

- A. Continually monitors and evaluates the care provided; [1993, c. 692, §1 (new).]
- B. Identifies issues and potential issues; [1993, c. 692, §1 (new).]
- C. Proposes and implements improvements; and [1993, c. 692, §1 (new).]
- D. Reevaluates the care provided to determine if further improvement is possible or needed. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

Section History:

1993, c. 692, § 1 (NEW).

SUBCHAPTER II
LICENSING OF VOLUNTEER HOSPICE PROGRAMS
(HEADING: PL 1993, c. 692, §1 (new))

22 § 8631. Volunteer hospice programs

A volunteer hospice program must comply with this section and with all provisions of subchapter I that are relevant to a volunteer hospice program. [1993, c. 692, §1 (new).]

1. Direct services. At a minimum, a direct service volunteer must:

- A. Submit a written application; [1993, c. 692, §1 (new).]
- B. Undergo a screening interview and a posttraining interview; [1993, c. 692, §1 (new).]
- C. Attend a 20-hour standard training program; [1993, c. 692, §1 (new).]
- D. Submit a confidentiality statement; and [1993, c. 692, §1 (new).]
- E. If the volunteer will transport individuals, have proof of auto insurance and a valid driver's license. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

2. Policies and procedures. Hospice programs shall develop and maintain policies and procedures that address the following:

- A. Recruitment, retention and dismissal; [1993, c. 692, §1 (new).]
- B. Screening; [1993, c. 692, §1 (new).]
- C. Orientation; [1993, c. 692, §1 (new).]
- D. Scope of function; [1993, c. 692, §1 (new).]
- E. Supervision; [1993, c. 692, §1 (new).]
- F. Ongoing training and support; [1993, c. 692, §1 (new).]
- G. Interdisciplinary team conferencing; [1993, c. 692, §1 (new).]
- H. Records of volunteer activities; and [1993, c. 692, §1 (new).]
- I. Bereavement services. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

3. Duties of coordinator. Volunteer services must be directed by a coordinator of volunteer services who shall:

- A. Implement a direct service volunteer program; [1993, c. 692, §1 (new).]
- B. Coordinate the orientation, education, support and supervision of direct service volunteers; and [1993, c. 692, §1 (new).]
- C. Coordinate the use of direct service volunteers with other hospice staff. [1993, c. 692, §1 (new).]

[1993, c. 692, §1 (new).]

4. Demonstrated knowledge. Volunteers must demonstrate knowledge of and ability to access community resources that reflect the full scope of hospice care.

[1993, c. 692, §1 (new).]

Section History:

1993, c. 692, § 1 (NEW).

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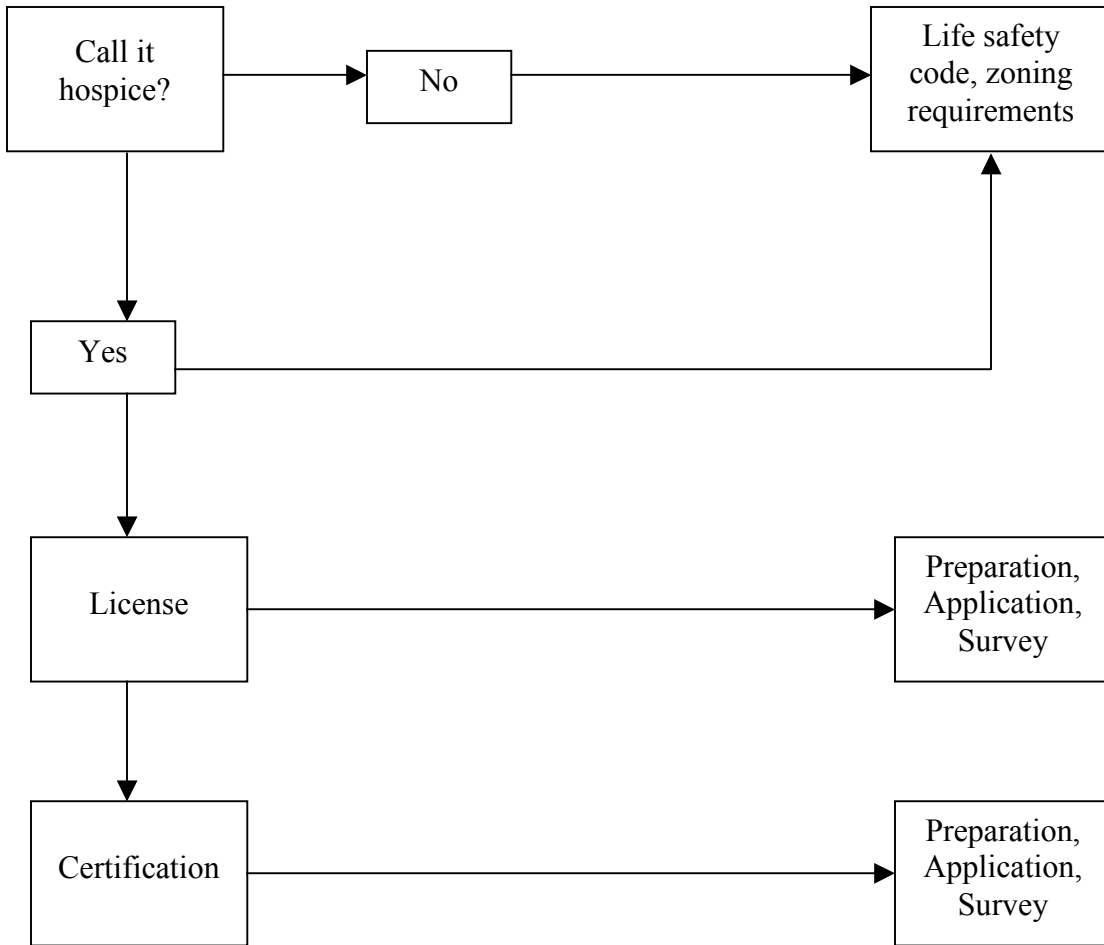
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Appendix III: Hospice Regulations in Maine

Hospice Regulations in Maine



APPENDIX IV: Inpatient Hospice Data

FACILITY	Laguna Honda Hospice 375 Laguna Honda Blvd. San Fran., CA 94116 Dr. Derek Kerr (415) 664-1580			Sun Health Hospice Care 12740 N Plaza del Rio Blvd. Peoria, AZ 85381 Stephanie (623) 815-2800			Odyssey Healthcare of Phoenix 202 E Earll Drive, Suite 320 Phoenix, AZ 85012 (602) 279-0677			Hospice East PO Box 115 Winchester, KY 40392 Carol Richardson (606) 744-9866			Hospice of Cape Cod 923 Route 6A Yarmouth, MA 02675 Ann Pratt (508) 362-1103			
DATA COLLECTED																
Room and Board Rates: Cost:	\$300 per day ?			\$170 per day residential, \$455.47 Medicare rate, \$111.30 Respite Cost: \$250 - \$300			\$471.50 per day ?			\$457 per day \$300 per day			\$130 per day, (uses sliding scale) Cost: \$130 per day			
Model:	Hospital			Free standing			Free standing X 2			In hospital			Free standing hospice house. 6 residential care beds and inpatient with hospitals or LTC (contracted using IP Medicare benefit)			
# of Beds by Type:	25			12 (all hospice)			11 in each, 22 total			3						
Licensing / New Legislation Required:	Yes / No			Yes / No			Yes / No			No / No			Yes / No			
Utilization:	90%			9 – 10			18			Full			Full			
Population:	700,000			? (< 1 million)			> 2 million			50,000			500,000			
Referral Sources:	Hospital, Home, and In-House			Hospital			Hospital, MD offices, families, LTC facilities			Hospital and MD			MD, self referrals, hospital			
Pitfalls to Avoid:	<ul style="list-style-type: none"> Would be freestanding with no affiliation to hospital or skilled unit 			<ul style="list-style-type: none"> Wall oxygen and suction, more storage space 			<ul style="list-style-type: none"> No 			<ul style="list-style-type: none"> No 			<ul style="list-style-type: none"> Should all be on 1 floor. Avoid nursing home look. Private decks are great! 			
Budget / Percent from Fundraising:	Not separate from hospital / None			\$3 – 6 million ?			? None (for profit)			Not separate from hospital / None			(No info)			
Staffing Ratio:	7-3	3	4	5	2	1	1-2				1:10	1:10	1	1	2	1
	3-11	1	2	5	2	1	1-2	?	?	?	1:10	1:10	1	1	1	1
	11-7	1	2	0	1	1	0				On Call	1:10	0	1	1	0
		RN/ LPN	CNA	VOL	RN/ LPN	CNA	VOL	RN/ LPN	CNA	VOL	RN/ LPN	CNA	VOL	RN/ LPN	CNA	VOL

FACILITY	Southwest Christian Hospice 7225 Lester Road Union City, GA 30291 Merna (770) 969-8354			Hospice Savannah PO Box 13190 Savannah, GA Merna (912) 355-2289			Hospice & Homecare By the Sea 1531 W Palmetto Park Road Boca Raton, FL 33486, Sue Horner (561) 395-5031			Exempla Lutheran Hospice 8300 W 38 th Avenue Wheat Ridge, CO 80033 Pat Archer (303) 425-4500			Desert Hospital Hospice of the Desert Comm 1150 N. Indian Canyon Drive Palm Springs, CA 92262 Cheryl Hunhoff (760) 323-6642			
DATA COLLECTED																
Room and Board Rates: Cost:	No charge – voluntary contributions from health insurance reimbursement Cost: \$211 per day			\$85 sliding scale for non-Medicare (\$40-\$42/day average) \$495.46 Medicare \$115 Respite Cost: \$425 per day			\$472 for skilled \$275 for non-skilled Cost: \$3,900/patient stay \$136.70 per patient day			\$126 per day ?			\$509 Medicare, \$116 Respite ? cost			
Model:	Free standing			Free standing			Free standing			In hospital			In hospital			
# of Beds by Type:	12 – all hospice			15 – all hospice			30 – all hospice			9 residential care			18 hospice/inpatient			
Licensing / New Legislation Required:	Yes with DHR / No			Yes / No			Yes / No			Yes / No			Yes / No			
Utilization:	Full			Full			24			Full			Full, 10 hospice patients			
Population:	1 million			\$350,000			> 2 million			> 2 million			250,000-500,000 seasonal			
Referral Sources:	Hospital, community and church, MD offices			Hospital, MD offices			MD offices, hospitals, LTC, *uses marketing team*			Community, MD offices			Hospital			
Pitfalls to Avoid:	<ul style="list-style-type: none"> More storage space needed. 			<ul style="list-style-type: none"> All private rooms are a <u>must</u>. Need piped-in O₂. Need built in sleepers (window seat). 			<ul style="list-style-type: none"> Get an architect who understands the hospice concept 			<ul style="list-style-type: none"> Expand to include skilled and inpatient hospice Case management model Free standing 			<ul style="list-style-type: none"> Add more staff Physician education Need > LOS 			
Budget / Percent from Fundraising:	\$911,000 100%			\$2,350,000 \$50,000 - \$60,000 \$135,000 hospice house			\$15 million \$1.5 million			\$750,000 \$500,000			Not clearly separated from hospital / No, (for profit)			
Staffing Ratio:	7-3	1:2	2 RN/1 LPN	4	1				2	3-4	4	3	2	1-2	2	3
	3-11	1:2	LPN	4	1	?	?	?	1	3	4	2	2	0	2	2-3
	11-7	1:3	2 RN/1 LPN	4	1				1	0	4	0	1	0	1	0
		RN/ LPN	RN/ LPN	RN/ LPN	RN/ LPN	RN/ LPN	CNA	VOL	CNA	VOL	CNA	VOL	CNA	VOL	CNA	VOL
			RN/ LPN										CNA			

FACILITY	Mesilla Valley Hospice, Inc 299 Montana Avenue Las Cruces, NM 88005 Terry Reed (505) 523-4700	Hospice of Dayton, Inc. 324 Wilmington Ave Dayton, OH 45420 (937) 256-4490	Sioux Valley Hospital Hospice 2710 W 12 th Street Sioux Falls, SD 57104 Cindi Slack (605) 333-4440	Hospice at the Texas Medical Center 1905 Holcombe Blvd Houston, TX 77030 (713) 467-7423	Evergreen Hospice Service 12822 124 th Ln NE Kirkland, WA 98034 Deborah Kelly (425) 899-1040											
DATA COLLECTED																
Room and Board Rates: Cost:	\$150 sliding scale (\$55 average) ? cost	? ?	\$200 deposit, \$50/day Cost: \$178/day	? ?	\$325/day residential care, \$496 Medicare Cost: \$211 direct expense only											
Model:	Free standing	Free standing	2 Free standing homes 4 residential care beds in each	Free standing	Free standing, affiliated w/ hospital											
# of Beds by Type:	9 residential care	62		25 mixed use	15 acute care											
Licensing / New Legislation Required:	No, Assisted Living license / No	Yes / No	Yes / No	Yes / No	Yes / No											
Utilization:	50% before Nov., 100% after Nov.	80%	70%	100%	10 residential care, 1-2 patients per day GIP, 1 respite care											
Population:	90,000	1-2 million	125,000	Houston area	3-4 million											
Referral Sources:	MD offices, 2 new oncologists in area since November	MD, hospital, family	Hospital, church, word of mouth	MD, family, nursing homes	MD, family											
Pitfalls to Avoid:	<ul style="list-style-type: none"> Set up as acute care Would use concentrators instead of piped-in oxygen 	<ul style="list-style-type: none"> none 	<ul style="list-style-type: none"> Would combine into one home with 8 beds 	<ul style="list-style-type: none"> none 	<ul style="list-style-type: none"> Building layout Poor visualization from nurses station 											
Budget / Percent from Fundraising:	? 50%	budget no separate from home health / 25%	\$428,000 \$77,000	? ?	1.3 million \$100,000 - \$300,000											
Staffing Ratio:	7-3 3-11 11-7	Oncall Oncall Oncall RN/ LPN	? RN/ LPN	1 1 1 RN/ LPN	2 2 1 RN/ LPN	2 2 1 RN/ LPN	1 1 1 RN/ LPN	1 1 1 RN/ LPN	2 2 1 RN/ LPN	2 2 1 RN/ LPN	1 1 1 RN/ LPN	2 2 1 RN/ LPN	2 2 1 RN/ LPN	2 2 1 RN/ LPN	2 2 1 RN/ LPN	1-2 1 0 VOL

FACILITY	Hospice of Bennington County PO Box 1231 Bennington, VT 05201 (802) 447-0307			Central Wyoming Hospice 319 Wilson Street Casper, WY 82601 Janace Chapman (307) 577-4832			Hospice of Lake and Sumten Tauares, FL Marcella Bland, Manager of Patient Family Services			Woodside Hospice House Hospice of the Suricosest in Florida Pat Sargent, Coordinator			Community Hospice House Nashua, NH					
DATA COLLECTED																		
Room and Board Rates: Cost:	No charge ?			\$80 – 0 sliding scale \$300			\$100, use sliding scale Cost: \$250 per day			Semi-Priv \$100/day Private: \$125/day Villas: \$150/day			?					
Model:	Free standing			Free standing			Free standing			Freestanding and licensed HC agency			Distinct Hospice House License					
# of Beds by Type:	2 bed residential care			10			6			87 residential/ (50 Level 4)			6 IP, 4 residential					
Licensing / New Legislation Required:	Yes / No			No / No			Yes, Med Certified			?								
Utilization:	1			90%			92% - 95%			7-10 Level 4, rest residential			?					
Population:	35,000			45,000			>50,000			?, in Pinellas County			50,000					
Referral Sources:	Hospital, Cancer Center, friends and family			Hospital, MD			Self-home hospice			80% homecare agency, 20% hospitals and county			?					
Pitfalls to Avoid:	<ul style="list-style-type: none"> Needs more funding to staff with volunteers 			<ul style="list-style-type: none"> Need to set up a trust fund that can be drawn on when needed using memorial donations 			<ul style="list-style-type: none"> Built as home-type residence. Need kitchen; more storage; larger equipment such as freezer, D/W, extra big laundry room. Some community spaces could be decreased as pt's families spend most time in pt. rooms. Air and heat in rooms <u>plus</u> central heat/air. Need hospital beds. Carpet at first in pt. rooms, now in vinyl. Used LPN's in beginning, now all RNs 1-4 staffing ratio mandated by licensing 			<ul style="list-style-type: none"> Fundraising needs to be very active to support losses. 			<ul style="list-style-type: none"> Staffing: 25 part-time, 1 full time house manager, 2 RN's, 3 aides/shift, 1 PT, cook Financial/ Sponsorship: \$1 million grant from hospital owned by HH agency, capital campaign. From vision to completion 3-4 years 					
Budget / Percent from Fundraising:	\$5,000 100%			\$50,000 40%			\$500,000 \$50,000			?			?, (\$155,00 loss first year)					
Staffing Ratio:	7-3 3-11 11-7	RN/ LPN	1 RN/ LPN	1 RN/ LPN	?	see RN/ LPN	abov e CN A	VOL	?	CNA	?	VOL	1 CNA	2 VOL	2 CNA	1-2 VOL	1-2 CNA	1 VOL

FACILITY	Hope Hospice & Palliative Care Cape Coral, FL	Lisaard House Waterloo, Ontario Canada	Peabody House Portland, ME	Gary's House Portland, ME	Talbot House Easton, MD										
DATA COLLECTED															
Room and Board Rates: Cost:	?	?	?	?	Free \$105 per day										
Model:	IP and residential hospice care 24 IP, 12 residential	IP, symptom and pain management 6 beds	Boarding Home HIV/AIDS Patients 6 beds/1 family room	Housing for family of hospital patients 9 bedrooms	Residential, respite if room (Program of a volunteer hospice) 6										
# of Beds by Type:															
Licensing / New Legislation Required:			Level I Boarding Home	Level I Boarding Home	Under state license, MD has 2-tier license similar to Maine										
Utilization:	?	?	?	?	48 from 6/99 – 6/00										
Population:	?	1,742 CA cases	65,000 (Portland)	65,000 (Portland)	?										
Referral Sources:	?	?	?	?	?										
Pitfalls to Avoid:	<ul style="list-style-type: none"> Financial / sponsorship: capital campaign 	<ul style="list-style-type: none"> Financial / sponsorship: private founding gift, established private foundation, fundraising From vision to completion: 4 years 	<ul style="list-style-type: none"> Staffing: 2 RN's, 1 SW, 2 residential aides per shift, 1 full time executive director, 1 full time fundraiser Financial / Sponsorship: In the beginning, no longer a priority. 	<ul style="list-style-type: none"> Staffing: 1 paid house manager plus in-kind services Financial / Sponsorship: 7 years fundraising, owned by Mercy From vision to completion: 7+ years 	<ul style="list-style-type: none"> Staffing: 3 FT including FT program manager and 5 PT CNA's. 8A–8P, 1 staff and 1 volunteer. 8P–8A, 2 staff. Finances/Sponsorship: Capital campaign raised \$1.8 M, \$1 M building (guest rooms, offices, library, group rooms, etc.), \$.8 M to endowment fund for all agency programs. All guests must be or become pts of Medicare certified Hospice agency. This staff does all care. From vision to completion: 18 months. Open 3 years. 										
Budget / Percent from Fundraising:	?	?	\$700,000 inc. \$14,000 util, \$17,000 food	\$110,000 inc. \$8 – \$9,000 heat	\$164,000, 43% donated by guest's families										
Staffing Ratio:	7-3 3-11 11-7	?	?	see	see	see	above	?	?	?	?	?	?	?	?
	RN/ LPN	RN/ LPN	RN/ LPN	RN/ LPN	RN/ LPN			CNA	VOL	CNA	VOL	CNA	VOL	CNA	VOL

FACILITY	Harbour House Fredericksburg, VA			Jefferson City Jefferson City, MO			Mother Thesesa House, Lansing, MI			Isaiah House Rochester, NY		
DATA COLLECTED												
Room and Board Rates: Cost:	Free			\$50/day or "what they can" \$125 per day			Free			Free		
Model:	?			?			?			?		
# of Beds by Type:	Residential care, (Program of a volunteer hospice)			Residential (Program of a volunteer hospice)			Residential, Independent, non-profit organization			Residential, began as outreach program of a Catholic Parish. Now indep., non-profit organization		
	2			7			3			2		
Licensing / New Legislation Required:	No, "surrogate" family"			State Division of Aging Residential Care License			No license required, considered residence with "guest" arrangement			No license required as State does not require for 2 beds, "private home"		
Utilization:	Usually 1 guest at a time			85% to 90%			278 pt. days in 2000			205 pts in 2000, current waiting list of 23		
Population:	270,000			125,000			?			?		
Referral Sources:	?			7 medical programs			?					
Pitfalls to Avoid:	<ul style="list-style-type: none"> Staffing: Paid coord., 35 vols with 1-2 at a time depend. on level of care. House donated by hospital, most renovations donated, cost to agency \$10,000 All guests pts of medical hospice prior to admission. This staff does all care. Finances/Sponsorship: House was donated by hospital. Most renovations donated. Cost to agency \$10,000. Open 4 yrs. 			<ul style="list-style-type: none"> Staffing: 5 FTE's, LPN as Clinical Coordinator, others are PCA's, moving toward all LPN's. Finances/Sponsorship: Purchased from bank, flexible payments. All renovations donated. Community project of thrift shop is major source of funding. All guests are clients of Medical Hospice Program. This staff does all care. From vision to completion: 3 yrs. Used building as offices for 3 yrs before start of renovations. Open 6 yrs. Would have hired all LPN's at beginning. Would have started thrift shop sooner. Licensing requires so much money and you will lose ownership. 			<ul style="list-style-type: none"> Staffing: 1 paid administrator, all vol. staffing. Will hire overnight staff and programmer in 2001. Finances/Sponsorship: House belongs to Catholic Diocese, free rent and maintenance. Private donations. From vision to completion: Hospice SW kept asking but no one took it on. 2001 is first year she will take salary. Open 2½ years. 			<ul style="list-style-type: none"> Staffing: Admin, nurse director, 3 per diem RN's, 3 RN's W/E call, 11-7 covered by CNA provided by Home Health & Hospice, 2 volunteers on day and evening, 85 volunteers. Finances/Sponsorship: House donated by private citizen, support from United Way, private donations, fundraising From vision to completion: 2½ years. Open 14 years. 10 similar homes in Rochester. 		
Budget / Percent from Fundraising:	< \$20,000			\$248,000 / 2000 \$268,000 / 2001			\$120,000 - \$140,000			\$80,000 in 2001		
Staffing Ratio:	7-3 3-11 11-7	see	see	see	see	above		above		above		above

APPENDIX V: Definitions

DEFINITIONS

General Hospital

An acute health care facility with permanent inpatient beds planned, organized, operated, and maintained to offer for a continuing period of time, facilities and services for the diagnosis and treatment of illness, injury, and deformity; with a governing board, and an organized medical staff, offering continuous twenty-four hour professional nursing care; with a plan to provide emergency treatment twenty-four hours a day and including the following services or organizational units:

- governing board
- administration
- organized medical staff
- nursing service
- emergency service
- dietary service
- medical records service
- radiology service
- pathology or clinical laboratory service
- pharmaceutical service
- hospital safety program
- disaster plan
- in-service education

Inpatient Hospice

A hospital, SNF, or freestanding hospice which meets the Medicare conditions of participation concerning inpatient hospice services at 418.100

Nursing Facility [NF]

A facility licensed by the Department of Human Services to provide nursing services

Skilled Nursing Facility [SNF]

A nursing facility which is certified to provide Medicare reimbursed skilled nursing services. Skilled nursing service is a service where the inherent complexity of a prescribed service is such that it can be safely and effectively performed only by or under the direct supervision of a registered professional nurse [RN]. Or where, because of special medical complications, a service necessitates the skills of an RN for the performance or supervision of the service and the observation of the patient.

Surrogate Family Home

A facility that substitutes for the patient's residence and whose staff substitutes for the patient's primary care giver.

Palliative Care

Care for the purpose of reducing the effect or intensity of a disease without curing.