HB
152

HOUSE COMMITTEE REPORT

(7)
Date Referred to Committee: February 24, 1997 FURTHER REFERRALS: Finance

Date of Committee Action: 3/27/97

The HEALTH, EDUCATION AND SOCIAL SERVICES Committee considered: HB 152

HOUSE BILL NO. 152 REGULATION OF HOSPICE CARE

"An Act regulating hospice care."

recommends it be replaced with the following committee substitute CS HB 152(HES)
[X] the same title
[ ] a new title

[ ] additional referral to ______ Committee
[ ] attached amendment(s)

ADOPTS: ______ Letter of Intent

ATTACHES NEW FISCAL NOTE(s): (Dept)

[X] fiscal note(s) H+SS

[ ] zero fiscal note(s)

APPROVES PREVIOUS: (Dept/Date)

[ ] fiscal note(s)

[ ] zero fiscal note(s)

SIGNING WITH RECOMMENDATIONS	DP	DNP	NR	AM
[signature]			✓	
[signature]			✓	
[signature]	✓			
[signature]			✓	
[signature]	✓			

CHAIR'S SIGNATURE [signature]

FISCAL NOTE

STATE OF ALASKA
1997 LEGISLATIVE SESSION

BILL NO. HB 152

Revision Date:
Title: Regulating Hospice Care
Sponsor: Ryan
Requestor: House HESS

Dept. Affected: Health and Social Services
BRU: Medical Assistance Admin
Component: Certification & Licensing
COMPONENT SERIAL NO. 245
See also (SN#):

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY98	FY99	FY00	FY01	FY02	FY03
PERSONAL SERVICES						
TRAVEL	7.5	8.9	10.4	12.0	13.7	1
CONTRACTUAL						
SUPPLIES						
EQUIPMENT						
LAND & STRUCTURES						
GRANTS, CLAIMS						
MISCELLANEOUS						
TOTAL OPERATING	7.5	8.9	10.4	12.0	13.7	15
CAPITAL EXPENDITURES						
CHANGES IN REVENUES ( )						

FUND SOURCE (Thousands of Dollars)

FUND SOURCE	FY98	FY99	FY00	FY01	FY02	FY03
1002 Federal Receipts						
1003 GF Match						
1004 GF	7.5	8.9	10.4	12.0	13.7	15
1005 GF/Program Receipts						
1037 GF Mental Health						
Other (please specify)						
TOTAL	7.5	8.9	10.4	12.0	13.7	15

POSITIONS:

POSITIONS	FY98	FY99	FY00	FY01	FY02	FY03
FULL-TIME						
PART-TIME						
TEMPORARY						

Estimate of any current year (FY97) cost: $0.0

ANALYSIS: (Attach a separate page if necessary)

Bill 98 would require licensure of 5 new hospice facilities outside of Anchorage. These travel costs were arrived at by using FY97 calculations for travel for one surveyor to travel for a 4 day survey to each of these agencies. Additionally, it is expected at least one new initial survey would be expected each year at a cost of about $1,000.00 each. Also, anticipating the increased cost of travel, lodging and car rental we added 5% per year.

Prepared by: Shelbert Larsen
Division: Medical Assistance
Phone: (907)561-8081
Date: 02/25/97

Approved by Commissioner: Karen Perdue, Commissioner
Agency: Department of Health & Social Services
Date: 3/5/97

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FISCAL NOTE - H&SS- CERTIFICATION & LICENSING

0-LS0649\F
Lauterbach
3/26/97

CS FOR HOUSE BILL NO. 152( )

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTIETH LEGISLATURE - FIRST SESSION

BY

Offered:
Referred:

Sponsor(s): REPRESENTATIVE RYAN

A BILL

FOR AN ACT ENTITLED

1 "An Act regulating hospice care."

2 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

3 * Section 1. AS 18 is amended by adding a new chapter to read:

4 Chapter 18. Hospice Care Programs.

5 Article 1. Licensing of Hospice Programs.

6 Sec. 18.18.005. Policy declaration. It is the policy of the state that regulation
7 of hospice programs should ensure an appropriate standard of care for hospice clients
8 without unduly burdening the programs with requirements that consume staff time and
9 financial resources that are essential for the delivery of services to hospice clients. In
10 furtherance of this policy, this chapter establishes two sets of standards for hospice
11 programs that recognize the more limited staff time and financial resources available
12 to voluntary hospice programs while requiring all programs to comply with basic
13 minimum program standards.

14 Sec. 18.18.010. License required. A person, including a partnership,
15 association, or corporation, may not represent itself as a hospice program or operate

1 a hospice program unless the person, partnership, association, or corporation has
2 obtained a license from the department.
3 **Sec. 18.18.020. Issuance and renewal of license.** (a) Upon receiving an
4 application and fee, if any, for a license under this chapter, the department shall issue
5 a license if the applicant meets the applicable requirements of this chapter.
6 (b) If an applicant under (a) of this section does not meet the applicable
7 requirements but makes continued efforts to comply with them and any noncompliance
8 does not directly affect the safety of clients, the department may issue a temporary or
9 provisional license that is valid for a reasonable period of time, as determined by the
10 department.
11 (c) A license under this chapter shall be issued in the name of the person,
12 agency, or other entity specified in the application and is not transferable or assignable
13 without the written approval of the department.
14 (d) The department shall, by regulation, establish the application fee, license
15 fee, length of time that a license is valid, and the standards for license renewal. A
16 license is not renewable during the time it has been suspended or revoked under this
17 chapter.
18 **Sec. 18.18.030. Denial, suspension, or revocation of license.** (a) The
19 department may deny a license, reduce a license to a provisional license, or revoke a
20 license if the department finds that the applicant or licensee, as appropriate, or the
21 program director or medical director of the applicant or licensee, as applicable, has
22 (1) endangered the health, safety, or welfare of a client;
23 (2) a history of deficiencies in quality of care;
24 (3) had a license to operate a hospice program suspended or revoked
25 in another licensing jurisdiction for a reason other than failure to pay a licensing fee;
26 (4) been convicted of operating a hospice program without a license in
27 any jurisdiction;
28 (5) an insufficient number of staff with the training, experience, or
29 judgment to provide adequate hospice care;
30 (6) committed fraud, deceit, misrepresentation, or an offense involving
31 dishonesty associated with the license application or with the operation of a hospice

1 program in any jurisdiction; or

2 (7) violated this chapter or a regulation adopted under this chapter.

3 (b) The department may, without a hearing, summarily suspend a license of
4 a hospice program if it finds that the actions or deficiencies of the program have
5 caused, or present an immediate threat of causing, serious injury to a hospice program
6 client. A licensee is entitled to a hearing before the department to appeal the summary
7 suspension within seven days after the order of suspension is issued. A licensee may
8 appeal an adverse decision of the department on an appeal of a summary suspension
9 to the superior court. A summary suspension remains in effect until the department
10 finds that the actions or deficiencies are corrected, the license is revoked, or the
11 licensee is successful in appealing the suspension.

12 (c) The department may, without a hearing, reduce a hospice license to a
13 provisional license for a period of time established by the department if the department
14 finds that the licensee is temporarily unable to comply with this chapter or is in the
15 process of becoming decertified under the Medicare program but is taking appropriate
16 steps to bring the program into compliance with this chapter or Medicare certification
17 requirements. A licensee is entitled to a hearing before the department to appeal a
18 reduction to a provisional license under this subsection within seven days after the
19 order to reduce the license is issued. A licensee may appeal an adverse decision of
20 the department on an appeal of the order reducing the license to a provisional license
21 to the superior court. A program with a provisional license under this subsection may
22 not accept new clients. If the program fails to correct its deficiencies and does not
23 successfully appeal the order reducing the license to provisional status within the
24 period stipulated in the provisional license, the department shall revoke the license.

25 **Sec. 18.18.040. Right of entry and inspection.** A duly designated employee
26 of the department may enter the premises of a hospice program that has applied for
27 a license or who is licensed under this chapter. These employees may inspect
28 documents of the hospice program to determine whether the program is in compliance
29 with this chapter and regulations adopted under this chapter. The right of entry and
30 inspection extends to premises and documents of persons whom the department has
31 reason to believe are operating a hospice program without a license.

1 **Sec. 18.18.100. Requirements for licensure.** (a) Except as provided in
2 AS 18.18.200 for volunteer hospice programs, a hospice program shall meet the
3 requirements of this section. If a hospice program meets the requirements of this
4 section and AS 18.18.010 - 18.18.040, the department shall issue a license for the
5 program.
6 (b) A hospice program shall have a clear mission statement that is consistent
7 with hospice philosophy.
8 (c) A hospice program shall have at least the following features:
9 (1) a governing body;
10 (2) an established set of admission criteria for determining appropriate
11 clients;
12 (3) a program director;
13 (4) an interdisciplinary team;
14 (5) volunteers; and
15 (6) a medical director.
16 (d) A hospice program may only provide services to a person if the person
17 (1) consents to receive those services; and
18 (2) fits the admissions criteria of the hospice program.
19 (e) Hospice services shall be delivered in accordance with a care plan
20 approved by the interdisciplinary team regardless of whether the hospice services are
21 provided by hospice program staff or by contractors. The care plan must be reviewed
22 periodically by the interdisciplinary team and revised as needed. The client, and the
23 client's family if the client desires, must be given the opportunity to participate in the
24 development of the care plan and must be informed of the opportunity to attend
25 interdisciplinary team meetings. The interdisciplinary team must consider the need for
26 at least the following services when developing the care plan:
27 (1) social services;
28 (2) nursing care;
29 (3) counseling;
30 (4) pastoral care;
31 (5) volunteer visits to provide comfort, companionship, and respite;

1 (6) bereavement services for at least one year after the death of the
2 person who is terminally ill; and
3 (7) medical services.
4 (f) Nursing services provided by a hospice program shall be provided in
5 accordance with a care plan and must be under the direction and supervision of a nurse
6 supervisor. The nurse supervisor shall
7 (1) develop nursing objectives, policies, and procedures consistent with
8 hospice philosophy;
9 (2) develop job descriptions for nursing personnel consistent with
10 hospice philosophy;
11 (3) establish staffing and on-call schedules for nursing staff to ensure
12 the availability of nursing services 24-hours a day, seven days a week; and
13 (4) develop and implement orientation and training programs for
14 nursing staff.
15 (g) Before providing a hospice service in a hospice program, a direct service
16 provider shall receive an orientation of at least four hours specific to hospice service.
17 The policy and procedures of the hospice program define the agenda of the hospice
18 orientation program. The hospice program shall document in personnel files that staff
19 members have completed the four-hour orientation. Indirect service volunteers shall
20 be oriented according to program policies. The hospice orientation program must
21 include the following subjects:
22 (1) hospice philosophy;
23 (2) personal death awareness;
24 (3) communication skills;
25 (4) personnel issues;
26 (5) identification of hospice resource people;
27 (6) stress management;
28 (7) ethics;
29 (8) stages of dying; and
30 (9) funeral arrangements.
31 (h) 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, received within a one-year period, including four hours of orientation, is required for all direct service providers delivering hospice care. Documentation of completion of this program is transferable from one hospice program to another. The educational program must include the following subjects:

(1) hospice philosophy;

(2) family dynamics;

(3) pain and symptom management;

(4) grief, loss, and transition;

(5) psychological perspectives on death and dying;

(6) spirituality;

(7) communication skills;

(8) volunteer roles; and

(9) multidisciplinary management.

(i) Direct service providers in a hospice program shall complete a minimum of eight hours of continuing education or in-service training each year after the first year, based on date of hire.

(j) A hospice program shall maintain, at a minimum, the following records:

(1) a record for each client that includes copies of the client's care plan, progress notes, assessments, and a description of services provided to the client and the client's family;

(2) minutes of governing body meetings;

(3) all receipts and expenditures; and

(4) training provided to paid staff and volunteers.

(k) A hospice program shall have and follow written policies and procedures governing its operation, including policies relating to confidentiality, training, and admissions.

(l) A person who enters a hospice program shall be given information regarding living wills and durable health care powers of attorney.

(m) The hospice program shall have a functional quality assurance or improvement plan in place that

1 (1) continually monitors and evaluates the care provided;
2 (2) identifies issues and potential issues;
3 (3) proposes and implements improvements; and
4 (4) reevaluates the care provided to determine if further improvement
5 is possible or needed.
6 **Article 2. Licensing of Volunteer Hospice Programs.**
7 **Sec. 18.18.200. Licensing requirements.** (a) The department shall issue a
8 license to a volunteer hospice program that complies with this section and with
9 AS 18.18.010 - 18.18.040 and 18.18.100(a), (b), (c) (1) - (3) and (5), (d), (g), and (j) -
10 (l).
11 (b) A direct service volunteer must
12 (1) submit a written application;
13 (2) undergo a screening interview and an interview after training;
14 (3) attend an 18-hour standard training program;
15 (4) submit a confidentiality statement in which the volunteer agrees to
16 follow the program's policy regarding confidentiality required by AS 18.18.100(k) and
17 (a) of this section; and
18 (5) if the volunteer will transport individuals, have proof of auto
19 insurance and a valid driver's license.
20 (c) Volunteer hospice programs shall develop and maintain policies and
21 procedures that address the following with respect to volunteers in the program:
22 (1) recruitment, retention, and dismissal;
23 (2) screening;
24 (3) orientation;
25 (4) scope of function;
26 (5) supervision;
27 (6) ongoing training and support;
28 (7) team conferencing;
29 (8) records of volunteer activities; and
30 (9) bereavement services.
31 (d) Volunteer services in a volunteer hospice program must be directed by a

1 coordinator of volunteer services who shall
2 (1) implement a direct service volunteer program;
3 (2) coordinate the orientation, education, support, and supervision of
4 direct service volunteers; and
5 (3) coordinate the use of direct service volunteers with other hospice
6 staff and community resources.
7 **Article 3. General Provisions.**
8 **Sec. 18.18.300. Individual licenses.** A program license received under this
9 chapter does not relieve an individual who is an employee, volunteer, or contractor
10 with the licensed hospice program from requirements outside this chapter pertaining
11 to licensure of the individual.
12 **Sec. 18.18.310 Sanctions.** A person who violates this chapter commits a civil
13 violation for which a fine not to exceed $100 a day of violation may be assessed by
14 a court.
15 **Sec. 18.18.320. Administrative Procedure Act.** Regulations and contested
16 cases under this chapter are governed by AS 44.62 (Administrative Procedure Act).
17 **Sec. 18.18.330. Regulations.** The department may adopt regulations to
18 implement this chapter that are consistent with the policy expressed in AS 18.18.005.
19 **Sec. 18.18.390. Definitions.** In this chapter,
20 (1) "bereavement services" means emotional support services related
21 to the death of a family member, which may include counseling, provision of written
22 material, social reorientation, and group support for up to one year following the death
23 of the client who was terminally ill;
24 (2) "care plan" means a written service delivery plan that the
25 interdisciplinary team, in conjunction with the client, shall develop to reflect the
26 changing care needs of the client;
27 (3) "client" means the person who is receiving the hospice services;
28 (4) "department" means the Department of Health and Social Services;
29 (5) "direct service provider" means employees or volunteers who
30 provide hospice services directly to a client under a hospice program;
31 (6) "family" means a spouse, primary caregiver, biological relatives,

1 and individuals with close personal ties to the client;

2 (7) "governing body" means the entity that establishes policy and is
3 legally responsible for the overall operation of a hospice program;

4 (8) "hospice philosophy" means a philosophy that is life affirming,
5 recognizes dying as a normal process of living, focuses on maintaining the quality of
6 remaining life, neither hastens nor postpones death, strengthens the client's role in
7 making informed decisions about care, and stresses the delivery of services in the least
8 restrictive setting possible and with the least amount of technology necessary by
9 volunteers and professionals who are trained to help clients with the physical, social,
10 psychological, spiritual, and emotional issues related to terminal illness so that the
11 clients can feel better prepared for the death that is to come;

12 (9) "hospice program" means a program that provides hospice services;

13 (10) "hospice services" means a range of interdisciplinary palliative and
14 supportive services provided in a home or at an inpatient facility to persons who are
15 terminally ill and those persons' families in order to meet their physical, psychological,
16 social, emotional, and spiritual needs;

17 (11) "interdisciplinary team," for a hospice program providing
18 comprehensive services, means a group comprised of at least a primary health care
19 provider, a licensed registered nurse, a social worker, a pastoral or other counselor, and
20 a volunteer coordinator or representative;

21 (12) "medical director" means a licensed physician who oversees the
22 medical components of hospice services and the interdisciplinary team;

23 (13) "nurse supervisor" means a licensed registered nurse with
24 education, experience, and training in hospice nursing care who is designated by the
25 program director to oversee nursing services for the hospice program;

26 (14) "primary health care provider" means the physician or advanced
27 nurse practitioner identified by the client or by the person authorized to make decisions
28 for the client under a durable health care power of attorney;

29 (15) "program director" means the person designated by the governing
30 body of a hospice program as responsible for the day-to-day operations of the program;

31 (16) "terminally ill" means that a person has a life expectancy of less

1 than one year, in the opinion of the person's primary physician or the medical director,
2 and is no longer recei'ing curative treatment;
3 (17) "volunteer" means a trained individual who works for a hospice
4 program without compensation;
5 (18) "volunteer hospice program" means a hospice program that
6 provides all direct patient care at no charge.

Ketchikan Hospice
PO Box 7973
Ketchikan AK 99901
(907) 225-[illegible]
Dana [illegible], RN

Written Testimony:

Ketchikan Hospice agrees with the philosophy and intent of Bill # 152.

We believe this bill must adhere to the National Hospice Organization Standards. We believe the bill must take into account small communities and their resources. We need to provide Hospice Service at the "grass Roots" level.

We need to be able to be innovative, flexible and creative in maximizing available Resources and Personnel. We do this in Ketchikan by forming a joint partnership with our Certified / licensed Home Health Department. We want to be able to continue to provide this unique combination of Services to meet the needs of all our families and provide Service to Hospice families at no charge. We follow NHO guidelines and are in support of this bill as long as we can continue to meet the needs of our families. We do no charge for Hospice Services. We are committed to this. We do not want Licensing to increase Administrative Costs. We Run on a Shoe String budget as it is.

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To Rep Brunde [illegible]	From [illegible]
Co. Jill HESS	Co.
Dept. [illegible]	Phone #

March 21, 1997

Chairman Bunde and Committee Members,

Due to the very brief time allowed for testimony concerning HB 152, I wish to share my complete comments here My name is Paula McCarron I have been employed with Hospice of Anchorage since 1982

First, I wish to address the concerns expressed by some that this bill would hinder or dissolve the volunteer hospices in our state In fact, it is my belief that the bill provides legitimization of these programs that could lead to increased opportunities for funding More importantly, I believe the bill provides assurance that consumers seeking the help and services of a hospice program in Alaska can be assured of quality and consistency in care.

Like most hospice programs in Alaska and across the country, Hospice of Anchorage grew from the volunteer efforts of concerned community members and health care workers who wanted to create an alternative in caring for terminally ill persons The majority of hospice care then and now is provided to terminally ill persons who wish to remain in their own homes

Since that time, significant change has occurred in the health care system The average length of stay for hospitalized patients currently is 3 - 4 days Hospitals once provided what was known as a "social admission" to alleviate the distress of family members in caring for a dying loved - this is now rarely an option Nursing homes or assisted living homes are not an option as coverage is limited and "out of the reach" of most Alaskans at $3000 a month

Combined with these changes in health care, an aging population and increasing numbers of people living alone translates into a growing need for hospice services HB 152 is primarily a consumer protection act as it ensures a consistent level of standards and quality assurance measures for receiptants of hospice services

Personally, I do not see this bill so much as a regulatory issue but a compassionate and humane response to meeting the needs of terminally ill persons in our state In my work, I often hear patients and families say, "It is not death that I fear It's the journey." I believe HB 152 would help ensure that terminally ill Alaskans and their families would find care and support for that journey

Submitted by

Paula S. McCarron

Paula S McCarron
205 E Dimond Blvd #167
Anchorage, Alaska 99515

561 - 5322 w
248 - 6317 h

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To Rep Bunde | From
Co HESS | Co
Dept. | Phone #
Fax # 465-3871 | Fax #

on HB152

3200 Hospital Dr. Suite 100 ♥ Juneau, Alaska 99801
(907) 463-3113 ♥ FAX 463-3835

March 21, 1997

Hon. Con Bunde, Chair
House HESS
Room #104
State Capitol, Juneau, AK 99801-1182

Dear Representative Bunde:

While I was grateful to have the opportunity to testify in support of House Bill 152, my comments were incomplete because of the lateness of the hour. The following is a brief elaboration of the reasons why I believe it is important for the bill to pass, and remain intact.

The intent of the bill is to prevent just anyone from hanging out a shingle and claiming to provide hospice services. The terminally ill and their families are a vulnerable population, bearing the emotional and physical burden of facing death. While these people are frequently overwhelmed with their situation, it is an unfortunate reality that there is potential opportunity for companies to make money, and provide less than acceptable services. This bill will help to maintain the integrity and the quality of services provided by hospices through the licensing process.

The bill is well written, and adequately differentiates between voluntary hospices and certified hospices. As the administrator of a voluntary hospice, I do not believe that the bill is too restrictive, or puts too much administrative or financial burden on voluntary hospices. I believe that these are *minimum* standards which every agency calling themselves a hospice is ethically obligated to meet to ensure quality of care for its clients.

I encourage you to pass the bill, as it is written, in order for all terminally ill persons in Alaska to be guaranteed high quality hospice care.

Sincerely,

Ritchie Sonner
Executive Director

Alaska State Legislature

House of Representatives

COMMITTEE ASSIGNMENTS:

LABOR & COMMERCE
MILITARY & VETERANS AFFAIRS
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Representative Joe Ryan

1 800-922-3875 http://www.akrepublicans.org

MEMORANDUM

TO: Rep. Con Bunde, Chairman
House Hess Committee

FROM: Rep. Joe Ryan JR

DATE: March 20, 1997

IN RE: revised sectional analysis of CS For HB 152 (work draft)

A revised summary by section of CS For HB 152 follows. This bill adds a new chapter, entitled Hospice Care Programs, to Title 18 of Alaska Statutes.

Please note that a sectional analysis is not generally considered to be the most authoritative interpretation of a bill; the bill itself is the best statement of its purposes and effects.

Section 1 remains CS For HB 152 only section. It adds Chapter 18 to Title 18 of Alaska Statutes. Chapter 18 contains three articles, the first of which sets out standards for certified, professional hospice programs. Article II establishes a shorter set of standards for volunteer hospice programs. Article III clarifies individual licensing requirements and defines a number of terms germane to the regulation of hospice care. An analysis of each of these three articles follows.

1. *Article I* sets out parameters for licensing certified hospice programs and mandates that all hospice programs must be licensed to operate in Alaska. It enables the Department of Health & Social Services (DH&SS) to issue licenses, temporary licenses, and provisional licenses, and to deny, suspend, and revoke such licenses.

Article I specifies procedures for license applications, hearings, and modifications of license status, and gives DH&SS the right to enter hospice facilities, to inspect documents and premises.

Article 1 continues by requiring specific regulations a hospice program must meet in order to be licensed, including a mission statement, a governing body, admission criteria, a program director, an interdisciplinary team, volunteers, and a medical director. It requires a hospice program to follow admission criteria for potential clients. It mandates that services be provided in accordance with a care plan, and lists services for the interdisciplinary team to consider when crafting a care plan. It states that nursing services must be provided only under a nurse supervisor.

Article 1 ensures that direct service providers will go through orientation before providing hospice services, that they will complete an educational overview of hospice philosophy and care, and that they will then receive continuing education or in-service training over time. It further requires a minimum level of record-keeping and written policies and procedures.

Article 1 necessitates provision of information about 'living wills' and 'durable health care powers of attorney' to hospice clients. It also provides for quality assurance and improvement planning for certified hospice programs.

2. *Article 2* establishes standards for volunteer hospice programs, citing the specific elements of Article 1 that constitute the licensing framework for volunteer operations. These include the first four (4) sections of Article 1 that govern licensing and the licensing process, and specified parts of AS 18.18.100. It requires volunteer hospice programs to have a minimum structure that includes a mission statement, admission criteria, a director, and volunteers.

Article 2 applies the same standards regarding client consent and use of admission criteria to volunteer hospice programs as to certified ones. It calls for volunteer direct service providers to get four (4) hours of hospice service orientation. It mandates minimum record-keeping and written policies and procedures for volunteer hospice organizations, specifically volunteer policies and procedures. It necessitates provision of information about living wills and durable health care powers of attorney to volunteer hospice clients. Finally, it standardizes the co-ordination of volunteers.

3. *Article 3* specifies that certified or volunteer hospice program licensing does not remove or mitigate individual licensing requirements from any employee, volunteer, or contractor working with a hospice program. It allows for civil penalties for violations of Chapter 18. It makes the licensing process and regulations subject to the Administrative Procedures Act. Finally, *Article 3* defines numerous terms used throughout the bill.

0-LS0649\B
Lauterbach
3/12/97

CS FOR HOUSE BILL NO. 152( )

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTIETH LEGISLATURE - FIRST SESSION

BY

Offered:
Referred:

Sponsor(s): REPRESENTATIVE RYAN

A BILL

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8 a hospice program unless the person, partnership, association, or corporation has
9 obtained a license from the department.

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11 application and fee, if any, for a license under this chapter, the department shall issue
12 a license if the applicant meets the applicable requirements of this chapter.

13 (b) If an applicant under (a) of this section does not meet the applicable
14 requirements but makes continued efforts to comply with them and any noncompliance
15 does not directly affect the safety of clients, the department may issue a temporary or

1 provisional license that is valid for a reasonable period of time, as determined by the
2 department.
3 (c) A license under this chapter shall be issued in the name of the person,
4 agency, or other entity specified in the application and is not transferable or assignable
5 without the written approval of the department.
6 (d) The department shall, by regulation, establish the application fee, license
7 fee, length of time that a license is valid, and the standards for license renewal. A
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11 department may deny a license, reduce a license to a provisional license, or revoke a
12 license if the department finds that the applicant or licensee, as appropriate, or the
13 program director or medical director of the applicant or licensee, as applicable, has
14 (1) endangered the health, safety, or welfare of a client;
15 (2) a history of deficiencies in quality of care;
16 (3) had a license to operate a hospice program suspended or revoked
17 in another licensing jurisdiction for a reason other than failure to pay a licensing fee;
18 (4) been convicted of operating a hospice program without a license in
19 any jurisdiction;
20 (5) an insufficient number of staff with the training, experience, or
21 judgment to provide adequate hospice care;
22 (6) committed fraud, deceit, misrepresentation, or an offense involving
23 dishonesty associated with the license application or with the operation of a hospice
24 program in any jurisdiction; or
25 (7) violated this chapter or a regulation adopted under this chapter.
26 (b) The department may, without a hearing, summarily suspend a license of
27 a hospice program if it finds that the actions or deficiencies of the program have
28 caused, or present an immediate threat of causing, serious injury to the public health,
29 safety, or welfare. A licensee is entitled to a hearing before the department to appeal
30 the summary suspension within seven days after the order of suspension is issued. A
31 licensee may appeal an adverse decision of the department on an appeal of a summary

suspension to the superior court. A summary suspension remains in effect until the department finds that the actions or deficiencies are corrected, the license is revoked, or the licensee is successful in appealing the suspension.

(c) The department may, without a hearing, reduce a hospice license to a provisional license for a period of time established by the department if the department finds that the licensee is temporarily unable to comply with this chapter or is in the process of becoming decertified under the Medicare program but is taking appropriate steps to bring the program into compliance with this chapter or Medicare certification requirements. A licensee is entitled to a hearing before the department to appeal a reduction to a provisional license under this subsection within seven days after the order to reduce the license is issued. A licensee may appeal an adverse decision of the department on an appeal of the order reducing the license to a provisional license to the superior court. A program with a provisional license under this subsection may not accept new clients. If the program fails to correct its deficiencies and does not successfully appeal the order reducing the license to provisional status within the period stipulated in the provisional license, the department shall revoke the license.

Sec. 18.18.040. Right of entry and inspection. A duly designated employee of the department may enter the premises of a hospice program that has applied for a license or who is licensed under this chapter. These employees may inspect documents of the hospice program to determine whether the program is in compliance with this chapter and regulations adopted under this chapter. The right of entry and inspection extends to premises and documents of persons whom the department has reason to believe are operating a hospice program without a license.

Sec. 18.18.100. Requirements for licensure. (a) The department shall adopt regulations that specify the requirements for licensure under this chapter. The regulations must include the requirements of this section for hospice programs that are not volunteer hospice programs.

(b) A hospice program shall have a clear mission statement that is consistent with hospice philosophy.

(c) A hospice program shall have at least the following features:

(1) a governing body;

1 (2) an established set of admission criteria for determining appropriate
2 clients;
3 (3) a program director;
4 (4) an interdisciplinary team;
5 (5) volunteers; and
6 (6) a medical director.
7 (d) A hospice program may only provide services to a person if the person
8 (1) consents to receive those services; and
9 (2) fits the admissions criteria of the hospice program.
10 (e) Hospice services shall be delivered in accordance with a care plan
11 approved by the interdisciplinary team regardless of whether the hospice services are
12 provided by hospice program staff or by contractors. The care plan must be reviewed
13 periodically by the interdisciplinary team and revised as needed. The client, and the
14 client's family if the client desires, must be given the opportunity to participate in the
15 development of the care plan and must be informed of the opportunity to attend
16 interdisciplinary team meetings. The interdisciplinary team must consider the need for
17 at least the following services when developing the care plan:
18 (1) social services;
19 (2) nursing care;
20 (3) counseling;
21 (4) pastoral care;
22 (5) volunteer visits to provide comfort, companionship, and respite;
23 (6) bereavement services for at least one year after the death of the
24 person who is terminally ill; and
25 (7) medical services.
26 (f) Nursing services provided by a hospice program shall be provided in
27 accordance with a care plan and must be under the direction and supervision of a nurse
28 supervisor. The nurse supervisor shall
29 (1) develop nursing objectives, policies, and procedures consistent with
30 hospice philosophy;
31 (2) develop job descriptions for nursing personnel consistent with

hospice philosophy;

(3) establish staffing and on-call schedules for nursing staff to ensure the availability of nursing services 24-hours a day, seven days a week; and

(4) develop and implement orientation and training programs for nursing staff.

(g) Before providing a hospice service in a hospice program, a direct service provider shall receive an orientation of at least four hours specific to hospice service. The policy and procedures of the hospice program define the agenda of the hospice orientation program. The hospice program shall document in personnel files that staff members have completed the four-hour orientation. Indirect service volunteers shall be oriented according to program policies. The hospice orientation program must include the following subjects:

(1) hospice philosophy;

(2) personal death awareness;

(3) communication skills;

(4) personnel issues;

(5) identification of hospice resource people;

(6) stress management;

(7) ethics;

(8) stages of dying; and

(9) funeral arrangements.

(h) 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, received within a one-year period, including four hours of orientation, is required for all direct service providers delivering hospice care. Documentation of completion of this program is transferable from one hospice program to another. The educational program must include the following subjects:

(1) hospice philosophy;

(2) family dynamics;

(3) pain and symptom management;

(4) grief, loss, and transition;

1 (5) psychological perspectives on death and dying;
2 (6) spirituality;
3 (7) communication skills;
4 (8) volunteer roles; and
5 (9) multidisciplinary management.
6 (i) Direct service providers in a hospice program shall complete a minimum
7 of eight hours of continuing education or in-service training each year after the first
8 year, based on date of hire.
9 (j) A hospice program shall maintain, at a minimum, the following records:
10 (1) a record for each client that includes copies of the client's care
11 plan, progress notes, assessments, and a description of services provided to the client
12 and the client's family;
13 (2) minutes of governing body meetings;
14 (3) all receipts and expenditures; and
15 (4) training provided to paid staff and volunteers.
16 (k) A hospice program shall have and follow written policies and procedures
17 governing its operation, including policies relating to confidentiality, training, and
18 admissions.
19 (l) A person who enters a hospice program shall be given information
20 regarding living wills and durable health care powers of attorney.
21 (m) The hospice program shall have a functional quality assurance or
22 improvement plan in place that
23 (1) continually monitors and evaluates the care provided;
24 (2) identifies issues and potential issues;
25 (3) proposes and implements improvements; and
26 (4) reevaluates the care provided to determine if further improvement
27 is possible or needed.
28 **Article 2. Licensing of Volunteer Hospice Programs.**
29 **Sec. 18.18.200. Licensing requirements.** (a) A volunteer hospice program
30 must comply with this section and with AS 18.18.010 - 18.18.040 and 18.18.100(a),
31 (b), (c) (1) - (3) and (5), (d), (g), and (j) - (l).

1 (b) At a minimum, a direct service volunteer must
2 (1) submit a written application;
3 (2) undergo a screening interview and an interview after training;
4 (3) attend an 18-hour standard training program;
5 (4) submit a confidentiality statement in which the volunteer agrees to
6 follow the program's policy regarding confidentiality required by AS 18.18.100(k) and
7 (a) of this section; and
8 (5) if the volunteer will transport individuals, have proof of auto
9 insurance and a valid driver's license.
10 (c) Volunteer hospice programs shall develop and maintain policies and
11 procedures that address the following with respect to volunteers in the program:
12 (1) recruitment, retention, and dismissal;
13 (2) screening;
14 (3) orientation;
15 (4) scope of function;
16 (5) supervision;
17 (6) ongoing training and support;
18 (7) team conferencing;
19 (8) records of volunteer activities; and
20 (9) bereavement services.
21 (d) Volunteer services in a volunteer hospice program must be directed by a
22 coordinator of volunteer services who shall
23 (1) implement a direct service volunteer program;
24 (2) coordinate the orientation, education, support, and supervision of
25 direct service volunteers; and
26 (3) coordinate the use of direct service volunteers with other hospice
27 staff and community resources.
28 **Article 3. General Provisions.**
29 **Sec. 18.18.300. Individual licenses.** A program license received under this
30 chapter does not relieve an individual who is an employee, volunteer, or contractor
31 with the licensed hospice program from requirements outside this chapter pertaining

1 to licensure of the individual.

2 **Sec. 18.18.310 Sanctions.** A person who violates this chapter commits a civil
3 violation for which a fine not to exceed $100 a day of violation may be assessed by
4 a court.

5 **Sec. 18.18.320. Administrative Procedure Act.** Regulations and contested
6 cases under this chapter are governed by AS 44.62 (Administrative Procedure Act).

7 **Sec. 18.18.390. Definitions.** In this chapter,

8 (1) "bereavement services" means emotional support services related
9 to the death of a family member, including counseling, provision of written material,
10 social reorientation, and group support for up to one year following the death of the
11 client who was terminally ill;

12 (2) "care plan" means a written service delivery plan that the
13 interdisciplinary team, in conjunction with the client, shall develop to reflect the
14 changing care needs of the client;

15 (3) "client" means the person who is receiving the hospice services;

16 (4) "department" means the Department of Health and Social Services;

17 (5) "direct service provider" means employees or volunteers who
18 provide hospice services directly to a client under a hospice program;

19 (6) "family" means a spouse, primary caregiver, biological relatives,
20 and individuals with close personal ties to the client;

21 (7) "governing body" means the entity that establishes policy and is
22 legally responsible for the overall operation of a hospice program;

23 (8) "hospice philosophy" means a philosophy that is life affirming,
24 recognizes dying as a normal process of living, focuses on maintaining the quality of
25 remaining life, neither hastens nor postpones death, strengthens the client's role in
26 making informed decisions about care, and stresses the delivery of services in the least
27 restrictive setting possible and with the least amount of technology necessary by
28 volunteers and professionals who are trained to help clients with the physical, social,
29 psychological, spiritual, and emotional issues related to terminal illness so that the
30 clients can feel better prepared for the death that is to come;

31 (9) "hospice program" means a program that provides hospice services;

1 (10) "hospice services" means a range of interdisciplinary palliative and
2 supportive services provided in a home or at an inpatient facility on a 24-hours-a-day,
3 seven-days-a-week basis to persons who are terminally ill and those persons' families
4 in order to meet their physical, psychological, social, emotional, and spiritual needs;
5 (11) "interdisciplinary team," for a hospice program providing
6 comprehensive services, means a group comprised of at least a primary health care
7 provider, a licensed registered nurse, a social worker, a pastoral or other counselor, and
8 a volunteer coordinator or representative;
9 (12) "medical director" means a licensed physician who oversees the
10 medical components of hospice services and the interdisciplinary team;
11 (13) "nurse supervisor" means a licensed registered nurse with
12 education, experience, and training in hospice nursing care who is designated by the
13 program director to oversee nursing services for the hospice program;
14 (14) "primary health care provider" means the physician or advanced
15 nurse practitioner identified by the client or by the person authorized to make decisions
16 for the client under a durable health care power of attorney;
17 (15) "program director" means the person designated by the governing
18 body of a hospice program as responsible for the day-to-day operations of the program;
19 (16) "terminally ill" means that a person has a life expectancy of less
20 than one year, in the opinion of the person's primary physician or the medical director,
21 and is no longer receiving curative treatment;
22 (17) "volunteer" means a trained individual who works for a hospice
23 program without compensation;
24 (18) "volunteer hospice program" means a hospice program that
25 provides all direct patient care at no charge.

Alaska State Legislature

House of Representatives

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Representative Joe Ryan

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CS FOR House Bill NO. 152 (Work Draft)
SPONSOR STATEMENT

CS For House Bill 152 will provide for licensing of hospice care programs in Alaska, ensuring that terminally ill persons receive comfort, support, and care consistent with hospice philosophy and concepts through a uniform level of services. There is no federal regulation or licensing requirements for either certified or volunteer hospice programs. As of the January 1997, forty (40) states are licensing or regulating hospice programs. Of the ten (10) states without hospice licensing, five (5) have laws or regulations pending. The licensing and appropriate regulation of volunteer and certified hospice programs in Alaska will assure consumers of consistent standards in the delivery of hospice services.

Hospice is a unique component of the health care delivery system, one that has evolved over the past 20 years in the United States. Hospice provides care and support for people with terminal illness. The goal of hospice care is to enable patients to live an alert, pain-free life and to manage symptoms so the last weeks and months of life may be spent in dignity and peace. One out of every three people who die of cancer or AIDS in this country are served by a hospice program.

Annual growth in hospice programs averaged about eight per cent (8%) in the early '90s. In the last five (5) years growth has averaged seventeen per cent (17%). Hospice services are provided through a variety of means, including independent community-based organizations, divisions of hospitals or home-health services, and government agencies. Rapid growth of hospice programs is due to increased demand for home care services, the desire of terminally ill persons to keep control over the remainder of their lives, and a trend towards reimbursement for home-care services. ***Consumers need to be aware of specific characteristics that differentiate hospice from other health care providers. Hospice offers comfort and care, not curative treatment.*** Hospice addresses emotional, spiritual, and social needs in addition to physical needs. Hospice considers the patient and loved ones as the unit of care. ***Hospice affirms life and regards dying as a normal process, seeking neither to hasten nor postpone death.*** Hospice care extends beyond a patient's death to include bereavement care for grieving family members.

Fear of painful suffering, of abandonment, and of losing control are primary concerns of people experiencing terminal illness. Hospice care is designed to address these concerns by providing support, care, and needed services to help the terminally ill *live their lives* in *maximal comfort and control.*

Passage of CS For House Bill 152 will standardize hospice care and guarantee the Alaskan public the opportunity to access quality hospice care from both volunteer and certified hospice programs.

(revised March 19, 1997)

Alaska State Legislature

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MEMORANDUM

TO: Rep. Con Bunde, Chairman
House HESS Committee

FROM: Rep. Joe Ryan

DATE: March 18, 1997

RE: sectional analysis of HB 152

A summary, by section, of House Bill 152 follows. This bill adds a new chapter, entitled Hospice Care Programs, to Title 18 of Alaska Statutes. Please note that a sectional analysis is not generally considered to be the most authoritative interpretation of a bill; the bill itself is the best statement of its purposes and effects.

Section 1 is HB 152's only section. It adds Chapter 8 to Title 18 of Alaska Statutes. Chapter 18 contains three articles, each of which pertains to a different aspect of regulating hospice care. An analysis of each of the three articles follows.

1. *Article 1* sets out parameters for licensing of hospice programs. It mandates that any and all hospice programs must be licensed to operate in Alaska. It sets out that the Department of Health & Social Services (DH&SS) can issue licenses and conditional licenses, and can revoke or suspend licenses so issued. It specifies that Medicare-certified hospice programs automatically meet this bill's criteria, and are eligible to receive a state hospice facilities and access their records, although a warrant must obtained if the facility refuses permission to DH&SS.

Article 1 continues by outlining specific requirements a hospice must meet in order to get a license, including a mission statement, a governing body, admission criteria, a program director, an interdisciplinary team, volunteers, and a medical director. It requires a hospice program to adopt admission criteria for potential clients. It mandates that services be provided in accordance with a care plan, and lists services that the interdisciplinary team must consider when crafting a care plan. It sets out that nursing services be provided only under the auspices of a nurse supervisor.

Article 1 provides that direct service providers go through orientation before providing hospice services, requires direct service providers to complete an educational overview of hospice philosophy and care, and mandates continuing education or in-service training over time. It further requires a minimal level of record-keeping and written policies and procedures. *Article 1* necessitates provision of information about living wills and durable health care powers of attorney to hospice clients. Finally, the first article in Chapter 18 of Title 18 mandates quality assurance and improvement planning, and requires Medicare certification of a facility used for an inpatient hospice program as a condition of state licensing.

2. *Article 2* sets out standards for volunteer hospice programs, primarily the things direct service volunteers must do in order to prepare to provide hospice services. It mandates policies and procedures dealing with direct service volunteers, including coordination of such volunteer efforts. *Article 2* also requires volunteer programs to meet the "relevant" requirements of *Article 1*.

3. *Article 3* specifies that program licensing under Chapter 18 of Title 18 does not remove or mitigate individual licensing requirements from any employee, volunteer, or contractor working with a hospice program. It allows for civil penalties for violations of Chapter 18. Finally, *Article 3* defines numerous terms used throughout the bill.

Our Philosophy

Hospice is a philosophy of care for those experiencing the dying and/or bereavement process. Our goal is to allow the patient to die in peace and with dignity, and enable the family to surmount the experience and go forward. The mission of Hospice of the Tanana Valley is: to provide support for people who are dying, their families and loved ones; to provide individual, group, and community support for those who have experienced a loss through death.

Our History and Funding

Hospice of the Tanana Valley was incorporated in October, 1986 as a tax-exempt, non-profit corporation. We have been a member of the National Hospice Organization since 1988 and a United Way Member Agency since 1995. We are supported by annual membership dues, lifetime memberships, annual business sponsorships, donations, fund raisers, grants and volunteer time.

Our Services

Hospice of the Tanana Valley coordinates care with other health care agencies and with the patient's physician. Our staff and volunteers care for the terminally ill patients and their families, providing services which may include:

- Short-term respite care
- Emotional support
- Funeral Planning
- Transportation
- Errands and shopping
- Chaplain Referral
- Bereavement counseling

Our staff and volunteers are carefully selected and trained. Arrangements for services, whether in the home or institutional setting, are made on an individual basis depending on the family's needs and the availability of volunteers. Expenses for all our services are paid for by memberships and donations.

Who We Serve

Our care is available to everyone, regardless of age or diagnosis, who:

- Has a terminal illness
- Accepts the principles of hospice care

When To Refer

Referrals are accepted from the patient, the family and loved ones, as well as from physicians, nurses, and other care providers. Hospice can be of great service when there is sufficient time to assess, plan, coordinate, and most importantly establish a relationship of trust with the patient, family, and loved ones. A call to Hospice as early as possible will enable staff to most effectively meet the patient and family needs.

For More Information

If you are in need of our services or if you would like to help through a donation or by becoming a volunteer, call or write:

Hospice of the Tanana Valley
P.O. Box 82770
Fairbanks, AK 99708
Tel: (907) 474-0311
Fax: (907) 452-7643

Feb-26-97 01:09P Hospice of Anchorage

Caring Thoughts

THE SPIRIT OF HOSPICE

by Diane H. Jones, ACSW

Hospice and home care: two concepts that are as similar as they are different. In fact, when hospice was just getting started, home care providers were apt to say, "What is it that you can do that we haven't already been doing for 100 years—caring for the dying people in their own homes? What makes you think you can do it any different or any better?"

And hospices would reply, "You are the experts in short-term, restorative nursing; your goals are to care for the patient and to return a functioning individual back to the community. We are the experts in terminal care; our goals are to care for the patient and family and to return a functioning family back to the community after the patient has died."

Hospice is a special kind of home care that cares for terminally ill patients and their families in their own homes, in nursing homes, or other inpatient facilities, even on a park bench if that is where the patient happens to be. Hospice services are comprehensive, inclusive, specialized, and compassionate. Nurses, physicians, social workers, home care aides, counselors, chaplains, volunteers, and therapists all form the hospice interdisciplinary team, meeting the patient and family where they are, and caring for them. The interdisciplinary team meets regularly to discuss and update the plan of care for each patient and family. The plan of care includes assessing for nursing, social work, and home care aide visits, spiritual counseling needs, volunteer support, bereavement plans, and medications, supplies, and equipment.

Hospice patients do not have to be homebound; in fact, early admissions give hospice staff and patients and families time to get to know one another. Hospice patients are encouraged to live as fully as possible for as long as they are with the hospice. Stories abound about how hospices are able to help patients fulfill their final wishes by living long enough to celebrate a family wedding, a baby's birth, an anniversary, a last trip, or even just a visit to the community park.

Hospices treat the patient and family as the unit of care, which means the family unit is included in the plan of care. An admission to a hospice program often precipitates a crisis in the family because family members must face the reality that the patient is terminally ill with a limited life expectancy. Denial, grief, anger, bargaining, and acceptance may all be present at different times and with different members of the family. The hospice interdisciplinary team assesses the situation and plans interventions that will support, comfort, and enable them to do the very hard work that lies ahead.

Hospice staff follow patients across all settings of care, providing a comprehensive continuum of care. Patients are usually in their own homes but there are times when hospital or respite care in an inpatient facility is needed to treat the patient's symptoms or the family's fatigue. If a patient is hospitalized, the hospice team visits the patient and works closely with the hospital staff to get him or her home as quickly as possible. The hospice nurse communicates frequently with the patient's physician to ensure that the patient's wishes are honored in terms of treatments and procedures. Respite care gives family members a break—time to renew themselves for a short period before resuming their roles as primary caregivers.

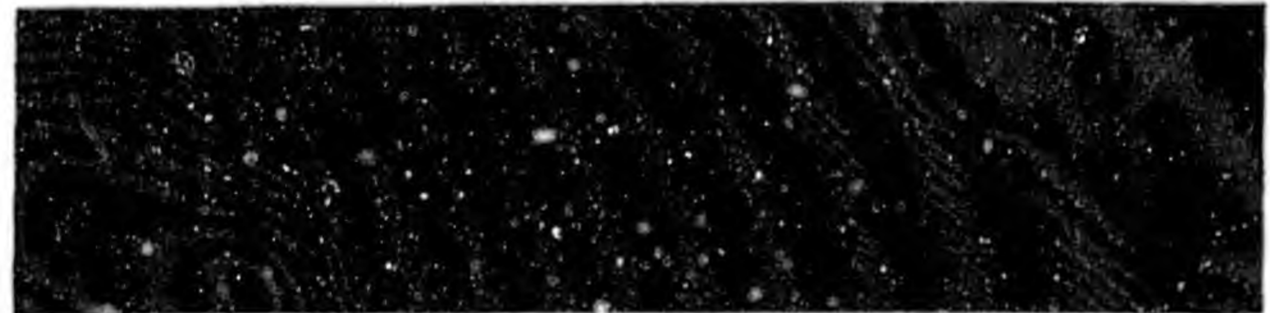
The specialness and spirit of hospice is exemplified through trained volunteers who devote their time and talents in many ways. Volunteers, often referred to as the backbone of hospice, find innovative and creative ways to fulfill a patient's last wishes, whether it is as adventuresome as taking the patient on one last sailing trip or as quiet as sitting by the bedside of a patient who doesn't want to die alone.

Hospice families continue to be cared for by the hospice even after the patient has died. For up to a year after the death, family members receive support through the mail, by phone, and in person. Hospice staff and volunteers make sure that special occasions, holidays, birthdays, and anniversaries are not forgotten. Hospices know that these are the times when the pain of loss can seem unbearable, when the world stops going around, when comfort and caring of familiar voices and faces provide a way through the pain.

So yes, hospice and home care have much in common. They both provide compassionate care in times of need; they keep families together when they might otherwise be torn apart; and they are an integral and important fabric of the community. They are the same ... and they are different.

About the Author: Diane H. Jones, ACSW, is Assistant Director of the Hospice Association of America.

THE CHANGING FACE OF



INTERVIEW WITH IRA BYOCK, MD

Ira Byock has been involved in hospice care for more than 15 years. He currently is hospice medical director of Partners In Home Care, as well as director of The Palliative Care Service, both located in Missoula, Montana. A founding member of the Academy of Hospice Physicians (AHP), Byock serves on the academy's board of directors and is chair of the AHP Ethics Committee.

Byock was the featured speaker at the Hospice Association of America's annual meeting in San Francisco this past October, where he spoke on maintaining ethical responsibility in a managed care environment.

CARING is honored to have had the chance to speak with him earlier this fall. His thoughts, presented in this interview, cap this issue on hospice care and set the industry on the path for future thought and care.

Q What do you see as the ethical issues for hospice in a managed care delivery system?

A Our health care system is changing rapidly in a number of ways, changing in different ways and at different paces as the country experiments with a variety of regional delivery systems. Several trends are strongly indicated: one is integration of systems, the other is managed care.

In a sense hospice has more experience with managed care than perhaps any other segment of the health care system. For years hospice has dealt with prospective payment through the Medicare hospice benefit and similar payor systems; gradually hospice has emerged as a specialized managed care system. So we have considerable experience with providing care in a cost-effective manner, and with looking at outcome measures. It's not quite clear what the impact on hospice or palliative care will be by the adoption of a managed care model in the larger health care system. There is both opportunity and considerable danger.

The dangers first. Proprietary managed care companies at present have the sense that hospice is something toward which modern consumers of care are favorably disposed; this, in turn, gives companies a positive predisposition toward hospice care. But at present there is little real understanding by leadership in managed care organizations of what hospice is. Currently hospice is regarded as a frill. Managed care leadership does understand that a financial advantage of hospice is in keeping people out of the hospital. The real danger of hospice being incorporated into the larger managed care model is that it may be unbundled into component parts, with almost exclusive emphasis on the skilled nursing visit.

Hospice is by definition an interdisciplinary team approach to care for persons and their families who are encountering life-threatening illness. It is cost effective. A recent Lewin-VHI study confirmed that hospice saves $1.52 for every Medicare dollar spent on hospital

services for every last year in a cancer patient's life. (Lewin-VHI, Inc. 1995) It is important that we have an entire team to provide services such as patient and family education and comprehensive management. And not to stop there, hospice follows through with bereavement counseling.

All that is an essential part of hospice service. The concern is that managed care companies will use the label "hospice" and provide skilled nursing visits just to reduce hospitalizations. That is short-sighted, and will prove fiscally self-defeating as well as damaging to the goals and fundamental principles that give hospice its identity and real value. When Medicare and Medicaid certification waivers are given to enable managed care organizations to explore innovative delivery models under capitated payment arrangements and cradle-to-grave coverage, those organizations—not existing certification standards—will determine what is paid for and what personnel and resources are available. They may not have the same standards that hospice currently embodies.

So there is reason both theoretically and on a concrete level to be concerned. Hospice does face a number of challenges in a managed care environment. First, from bureaucracy, which has a legitimate need to have outcome measures that are reliable, reproducible, and that measure something meaningful. Second, hospice faces challenges from others within the health care system that are profit motivated and that would like to claim the la[illegible] of hospice without preserving its essence. The third challenge comes from within the clinical practice of hospice care. In addition to the real, ongoing challenge of improving our ability to control symptoms, hospice currently lacks sufficient clinical specificity in the psychosocial realm. This inhibits our ability to relieve suffering that is not strictly physical but is primarily psychological, emotional, or spiritual.

When hospice providers talk about the management of pain, we are very specific, detailing the various pathophysiological causes and pharmacological means of intervention. But when someone is suffering in the psychosocial realm, too often the care plan includes "psychosocial support," meaning we send in a pastor or social worker. They function to provide support on an intuitive level. Too often I hear, "The patient still has work to do." We can sense intuitively what that means, but it is unacceptable to managed care organizations or to the health care financing bureaucracy for hospice to be that nonspecific. Unless we can effectively communicate what it is we're doing, they won't let us do it for very much lo[illegible]r.

Bureaucracy has a legitimate need for outcome measures in the health care system. If we are to be as clinically effective in the psychosocial realm as we are in the symptomatic realm, we need to define and be more specific about what we do. For instance, the written goals of hospice often include treatment of symptoms and provision of adequate psychosocial support and attention to preserving quality of life. I would submit that even the phrase "quality of life" is woefully nonspecific and insufficient. Auditors of the future—who may not have the same "hospice spirit" and who have had little hands-on hospice experience—may look at our records and consider retroactively allowing counseling services of a social worker or hospice chaplain. Similarly, managed care systems may assert, "Of course we do hospice, we control symptoms." Hospice as a discipline must be able to develop meaningful and measurable outcomes and must choose a therapeutic model and language to talk about what it is that we do that is beyond symptom management. This model and language can provide a basis for meaningful research in the psychosocial realm. All these areas are things that have been as yet inadequately attended to. They are areas of much-needed development within the clinical discipline and the emerging "industry" of hospice.

Q Are managed care organizations saying that symptom management is hospice?

A Too often hospice care is equated with symptom management. I see the terms "comfort care" and "hospice-like care" used all the time. Hospice goes beyond symptom management; that's what separates it from the best of traditional health care for the terminally ill. I have come to believe that what distinguishes hospice from the most comprehensive symptom management is that hospice inherently recognizes a role in preserving the opportunity for the person and family to grow even at the end of life.

So often in clinical practice we have the privilege of witnessing people paradoxically expressing

GROWING TOGETHER: Managed care companies need to be educated to un[illegible] and that hospice is more than symptom management and pain control. Hospice offers the chance for individuals and families to learn and grow together.

a sense of wellness, even as they are dying. Anecdotal personal experience and collective clinical experience confirm that if symptoms are managed and there is adequate basic support for the patient and family, opportunity is preserved, allowing people to grow—inwardly and together—even as life wanes.

We were all taught in our college psychology classes and our early childhood development classes and in the behavioral medicine component of pediatrics or family practice that human development can be a lifelong process. We in hospice have simply confirmed that even as they die people can indeed change in ways that prove deeply meaningful and important to them.

However, having said all this, I also recognize that "hospice" is just a word. As ardent a proponent as I am for hospice care, it will matter little to me if the word goes away, as long as the health care system embodies a real commitment to preserve and even gently nurture the opportunities for the person and family that lie within the process of dying. That's a tall order, but if a managed care system can embrace those values, then the future of end-of-life care is very positive.

We're at a critical time right now. Hospice has a small window of opportunity, I would guess no more than a few years, in which to articulate very clearly, through a model that is secular and that does not rely on religious or overly spiritual terms, that dying is a profound personal experience for individuals and families. As care providers we must approach care as more than a set of medical problems to be solved, although it includes this. If we can incorporate specific language within our national professional standards and within each of our programs' mission statements and guiding principles that refers to preservation of opportunity for patients and families, there is a hope of bringing these values forward as the health care system is transformed.

However, if we are simply worried about continued existence of our own individual organizations in our own communities we will make compromises of quality and sacrifice the essence of hospice care for the continuation of something that carries a sham hospice label.

Q How can we address the national conscience so that its essence is brought forward?

A The Hospice Association of America and the National Hospice Organization have to be specific in writing professional standards that define hospice as more than symptom management. We must emphasize the potential for subjective value and importance in this time of life called dying and acknowledge openly that hospice care seeks to preserve opportunity within the dying experience.

Nowadays health care trend writers often note that baby boomers are beginning to confront their own limited life expectancy. We "boomers" are the generation that rejected the notion that health as the absence of illness. This generation talks about health in terms of living fully and in peak performance. I think it is no longer comical or antithetical to speak of wellness in dying. If the most emotionally robust people among us will eventually die, there must be some meaning to the idea of dying well. In dying well a person has a chance to change in ways that are valuable to them: things like completing one's most important relationships, or achieving an increased sense of meaning about one's life or about life in general. For some, dying well includes coming to some peace about lifelong expectations and frustrations and having the opportunity to explore life's deepest questions.

Q Is it the health care bureaucracy or the public that doesn't yet look at dying this way?

A The culture in general does not think of dying this way. The words dying and death are often used interchangeably. They are not synonymous. Life does not actually end upon receiving a terminal diagnosis. In reality death is the opposite of life; yet dying is part of living.

I have stopped using the phrase "good death." For one thing, I have yet to meet anyone who knows anything about death. And for another, The idea of a "good death" sounds too formulaic, as if one could carefully follow strict instructions and ensure a preconceived, positive outcome. Today the notion of a good death is usually described in terms of what people don't want to have happen: people don't want to die in pain, don't want to be a burden emotionally, physically, or financially to their families. This is like a photographic negative; it only conveys what we want to avoid. We in hospice have a responsibility to contribute color, tone, and texture to that image of dying well. It's a very real experience. It's not fun and need not be easy but so many of the most important and valuable experiences of life are neither.

The idea of personal growth is helpful here. If you look at what stimulates growth in any person's life—times of crisis, of profound change—these times are rarely easy or pretty. People emerge from those periods feeling enlarged, feeling a sense of wellness. That is what I've repeatedly observed in people who are helped through this time of life.

Only now is the health care system starting to be able to accept this idea.

Q Is the US having a harder time than other cultures?

Feb-28-97 01:12P Hospice of Anchorage

WINDOW OF OPPORTUNITY: The hospice community has the chance now to educate managed care about the holistic benefits of hospice; it also has a chance to develop into the continuum of care, beginning with palliative care.

A Not inherently. Baby boomers are leading the way; they show a real openness to concepts of wellness that are different from their parents' generation.

However, in the area of financing care for persons at the end of life, the US is certainly in a particular state of crisis. Many people worry about and suffer from financial burdens directly related to health care. It is an artificial source of suffering, people fearing that they are going through their savings and leaving their families with debt. Currently Americans tend to think that financial devastation is a universal problem for the dying. They're surprised when I point out that health care systems the world over do not routinely add money woes to the worries of the terminally ill. People in the UK, for instance, do not have medically caused financial worries complicating their end of life experience. So we have some education to do. I would hope that the new health care system—whatever emerges—will address this in a way that the current system has not.

Q You have noted that hospice will have to be creative with how it provides care. In what aspect—clinical care, reimbursement, how hospices are organized? What are some examples?

A Hospice will have to be very creative. In the future it will be less important to think of hospice as a single delivery model. We should look at it in several ways. The British, for example, are now talking about a three-tiered approach to [illegible]tive care. At the apex of the system are regional academic research and training centers of palliative care. Secondly, within most communities are hospice programs that serve as local centers of expertise and can provide consultation to patients' physicians as well as providing direct patient care when necessary.

A third tier focus of palliative care lies within general health care education where an increasingly strong component of palliative medicine is required because end-of-life care is a component of basic health care and should, therefore, pervade the health care system.

This may prove a good model for this side of the Atlantic as well. We should incorporate the fundamentals of effective symptom management as well as acknowledging the poignant, personal nature of dying throughout professional health education and practice. Neither the health care setting, nor what the program of care is called, is as important as the quality of the experience for each person and family.

Q You sounded almost pessimistic in talking about the future of hospice. Is that an accurate reading? Why is that? Should others be pessimistic? What do you suggest industry members do to re-inject optimism into the idea/heart of hospice?

A We're in a time of real danger, but also a time of enormous opportunity. Remember that hospice has been demonstrated to be cost effective; thus, win-win opportunities abound! I think we have a window of opportunity to educate the health care leadership as well as the general public in the core values of hospice, in the essence of what enlightened care at the end of life is, and what lies beyond symptom management. Hospice needs not only to tout the cost benefits of its care, but also to demystify the notion of dying well and clearly acknowledge that this time of life encompasses more than merely waiting for death to come. If we incorporate this appreciation into written program and practice standards and into the mission statements of various community health care organizations, we have a real chance of doing something extremely important and lasting for this country and the American culture.

The discipline of hospice care faces critical challenge in the new health care environment. I am reminded of something Carl Jung wrote years ago: "...the greatest and most important problems of life are fundamentally insoluble... They can never be solved, but only outgrown."

Like a person who faces perilous challenges in life, I am hopeful that hospice will find a way to grow through this new set of challenges. □

Further Reading

Jung, C., Introduction to *The Secret of the Golden Flower*.

An Analysis of the Cost Savings of the Medicare Hospice Benefit. Prepared by Lewin-VHI, Inc. for The National Hospice Organization, May 2, 1995.

NEWSPAPER ARTICLE

Hospice to bring comfort to scene of death

By SARANA SCHELL
Fairbanks Daily News-Miner

FAIRBANKS — As a funeral director, Mike Hawkins was often the last to leave the scene of a death.

Years ago, as he was about to leave the home of a man whose wife had just committed suicide, he looked back. He knew it would be several hours before the man's family would arrive.

"I saw that elderly man standing on his porch in a bloodied robe, and I couldn't leave him. I just couldn't," Hawkins said. He went back and called a minister friend to come wait with the man.

Hawkins has called other ministers over the years to comfort people left alone by death. The ministers would come, but they had no training in crisis intervention. He was sure the service could be provided in a less haphazard way.

Then, last summer, a call to Hospice of the Tanana Valley became the catalyst for a team of first responders — the Emergency Grief and Bereavement Response Team — who will comfort people who have suddenly lost a loved one.

"A tour company called us to say that a couple had been touring in Denali Park, when the man died of a heart attack," said Sally Fenno of Hospice.

Hospice found someone to stay with the woman, who was from the Lower 48, until she could take a plane home, said Fenno, the bereavement services coordinator for Hospice.

At first, Hospice thought the emergency response volunteers for visitors could be an offshoot of longer-term bereavement counseling. But Hawkins, a member of the Hospice board of directors, helped broaden the effort to include regular members of the community.

It became clear there was a need for a separate program.

"Fairbanks has an awful lot of people who have families somewhere else, and a lot of visitors come through," Fenno said. "Many visitors are older."

Hospice is now training volunteers to be part of the Emergency Grief and Bereavement Response Team, on call 24 hours a day. A volunteer can quickly be at a grieving person's side, help them with practical matters such as making phone calls, and wait there until family or close friends show up.

"They may ask, do you have your address book with you? Is there anyone you want me to call?" Fenno said, or even, "Do you want me to dial the number?"

Visitors especially may need help setting up arrangements.

Please see Page B-2, FAIRBANKS

FAIRBANKS: Hospice aims to fill need

Continued from Page B-1

They may not know, for example, what to do with the body before it can be shipped out.

Once the training of volunteers is complete, Hospice will send letters to area hotels, park agencies, fire and police departments and other groups, announcing the service. Hospice will give them a pager number to call, Fenno said.

Sgt. Mike Corkill of the Alaska State Troopers said he looked forward to hearing from Hospice about the program.

"It's our most difficult job to tell people they've lost a loved one," Corkill said. "Although my folks have got some training in dealing with this, and are sensitive to people, Hospice works with this on a regular basis. I can see a lot of good coming from this."

Ingrid Hinde came close to being alone when her husband, Fairbanks newsman Chuck Hinde, died of a heart attack in the middle of a June night in 1995.

"Luckily I had a friend of my husband's in town," Hinde said, "but otherwise I would've been totally stranded."

Now Hinde, a Hospice volunteer, is training to be an emergency bereavement volunteer. The goal is to make a traumatic experience a little less traumatic, she said.

"It's way out on the cutting edge," she said. "There isn't any other program out there like it."

The group is preparing for the coming tourist season, Hinde said, by composing a list of people who speak different languages or who can provide grieving visitors with a short-term place to stay.