

HEB

171

Alaska State Legislature

Session Address
STATE CAPITOL BUILDING
ROOM 502
JUNEAU, ALASKA 99801-1142
(907) 465-3878
FAX (907) 465-2293

Inform Address
P.O. BOX 53
PALM BEACH, ALASKA 99645
(907) 746-1046 - Palmer
(907) 746-3560 - FAX
(907) 746-4028 - Wasilla

Representative Ronald L. Larson
District 27

MEMORANDUM

TO: Senator Steve Rieger, Chairman
Senate HESS Committee

FROM: Representative Ron Larson *R.L.*

DATE: April 8, 1993

RE: Request for a hearing - HB171

I respectfully request that HB171, An Act providing coverage for hospice care under the Medicaid program; reordering the priorities given to optional services under the Medicaid program; and providing for an effective date, be scheduled for a hearing in the Senate HESS Committee.

Hospice care is already a Medicaid-covered service for children and is available to people who qualify for Medicare. This bill would extend that coverage of Hospice service to Medicaid-eligible adults who do not qualify for Medicare.

Hospice care allows a terminally-ill person to receive medical care and psychological, social, and/or spiritual counseling through a single agency, the hospice care provider.

I am attaching a fiscal note, Department Position Paper, and additional back-up information for your packets.

Thank you for your consideration of this request.



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Session Address:
STATE CAPITOL BUILDING
ROOM 502
JUNEAU, ALASKA 99801 1182
(907) 465-3878
FAX (907) 465-2293

Interim Address:
P.O. BOX 53
PALMER, ALASKA 99645
(907) 748-1048 - Phone
(907) 748-3560 - FAX
(907) 376-8829 - TDD

Representative Ronald L. Larson

District 27
HB 171- Hospice Care
Sponsor's Statement

Hospice care is already a Medicaid-covered service for children and is available to people who qualify for Medicare.

This bill would extend coverage of hospice service to Medicaid-eligible adults who do not qualify for Medicare. Medicaid eligible adults are the aged, blind, disabled, and families with dependent children, as well as pregnant women. The "optional eligibles" also included, in Alaska are individuals under 21 who don't qualify for Aid to Families with Dependant Children because they aren't dependent children, and institutionalized individuals under a specified income level.

To qualify as a hospice care provider, a hospice care agency must be Medicare-certified.

Hospice care allows a terminally-ill person to receive medical care and psychological, social and/or spiritual counseling through a single agency, the hospice care provider. Lacking hospice care, an individual may require extensive hospital and/or nursing facility care or have to rely on the sometimes fragmented or piecemeal provision of supportive services in the community.

- In addition to meeting physical needs, Hospice care offers a wealth of emotional, spiritual and practical supports to the patient and the family. Quality of life is maximized through an interdisciplinary team of physicians, nurses, physical, occupation and speech therapists, home health aides, social workers, chaplains, and volunteers. The patient and family are actually a part of the team, helping to plan and prioritize care.

- It will be the role of Hospice to provide all medications, medical equipment and supplies necessary for management of the terminal illness.



- Bereavement care is also available to the family for a period of 13 months after the death. Hospice offers written resources, phone calls, visits from volunteers, a support group and, as needed, bereavement counseling.

- Most important are the trained Hospice volunteers who give a wide range of services from staying with a patient while the caregiver takes a break to nursing care, homemaking services, or a listening ear.

In addition to all the positive services that Hospice care can offer a family, crucial facts make the Medicaid Hospice option a wise decision. **Hospice is a budget-neutral program.** Hospice care is one of the few programs existing in our present health care structure that models fiscal responsibility and cost-effective quality care. Hospice offers the resources to allow terminally ill persons to spend the rest of their lives, or at least more of their lives, at home.

Quite often, the alternative to Hospice care is costly nursing home placement or frequent hospitalization.

POSITION PAPER

STATE OF ALASKA * DEPARTMENT OF HEALTH & SOCIAL SERVICES

Position Paper CSHS 171 (FIN)

The Department of Health and Social Services supports CS for House Bill 171 (FIN), which would include coverage of hospice care under the Medicaid program.

Hospice care is already a Medicaid-covered service for children and is available to people who qualify for Medicare. This bill would extend coverage of hospice service to Medicaid-eligible adults who do not qualify for Medicare. To qualify as a hospice care provider, a hospice care agency must be Medicare-certified. There are currently no Medicare-certified hospices in Alaska.

Hospice care allows a terminally-ill person to receive medical care and psychological, social, and/or spiritual counseling through a single agency, the hospice care provider. Lacking hospice care, an individual may require extensive hospital or nursing facility care or have to rely on the sometimes fragmented or piecemeal provision of supportive services in the community.

The Department supports this effort to expand the availability of a valuable alternative for terminally ill people. It also concurs with the placement of hospice services on the Medicaid priority list. Under CSHB 171(FIN), in the case of a budget shortfall, hospice care would be eliminated before most other long term care services, but after most optional Medicaid services.

Recommended by:

Kimberly B. Busch

Kimberly B. Busch
Director
Div. of Medical Assistance

Date:

4-12-93

Approved by:

Theodore A. Maia

Theodore A. Maia, MD, MPH
Commissioner

Date:

13 April 1993

FISCAL NOTE

STATE OF ALASKA
1993 LEGISLATIVE SESSION

BILL NO. CE112171(FIN)

Effective Date: 02/23/93 Dept. Affected: Health and Social Services
 Title: An Act providing coverage for hospice care BRU: Medical Assistance Administration
 Component: Claims Processing
 Sponsor: Larson
 Requestor: _____ COMPONENT SERIAL NO. 00243

Expenditures/Revenues:

(Thousands of Dollars)

OPERATING	FY94	FY95	FY96	FY97	FY98	FY99
PERSONAL SERVICES	0.0	0.0	0.0	0.0	0.0	0.0
TRAVEL	0.0	0.0	0.0	0.0	0.0	0.0
CONTRACTUAL	10.0	0.0	0.0	0.0	0.0	0.0
SUPPLIES	0.0	0.0	0.0	0.0	0.0	0.0
EQUIPMENT	0.0	0.0	0.0	0.0	0.0	0.0
LAND & STRUCTURES	0.0	0.0	0.0	0.0	0.0	0.0
GRANTS, CLAIMS	0.0	0.0	0.0	0.0	0.0	0.0
MISCELLANEOUS	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL OPERATING	10.0	0.0	0.0	0.0	0.0	0.0

CAPITAL	0.0	0.0	0.0	0.0	0.0	0.0
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REVENUE FUND SOURCE						
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FUNDING:

(Thousands of Dollars)

1002 Federal Receipts	5.0	0.0	0.0	0.0	0.0	0.0
1003 GF Match	5.0	0.0	0.0	0.0	0.0	0.0
1004 GF	0.0	0.0	0.0	0.0	0.0	0.0
1005 GF/Program Receipts	0.0	0.0	0.0	0.0	0.0	0.0
1006 GF/MHTIA	0.0	0.0	0.0	0.0	0.0	0.0
Other	0.0	0.0	0.0	0.0	0.0	0.0
TOTAL	10.0	0.0	0.0	0.0	0.0	0.0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year (FY93) impact: 0.0

ANALYSIS: (Attach a separate page if necessary)

FY 94 funds are required to modify the Medicaid Management Information System to allow the payment of claims for hospice care.

Studies suggest that hospice care tend to be cost neutral or produce cost savings. Hospice care is already available to children covered by Medicaid and to Medicare-eligible adults. There are currently no Medicare-certified hospice providers in the state. We anticipate that only a small number of recipients will use hospice care as a result of this bill. Therefore, no other fiscal impact is projected.

Prepared by: Kimberly Busch, Director
 Division: Medical Assistance

Phone: 465-5826
 Date: 03/01/93

Approved by Commissioner: Theodore A. Mala, MD, MPH
 Agency: Department of Health & Social Services

Date: 4/13/93

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WHAT DOES HOSPICE MEAN?

PHYSICIAN INFORMATION SHEET

WHAT IT MEANS TO THE PATIENT

When a patient elects the Medicare hospice benefit, they revoke their other part A benefits for treatment of their terminal illness? The hospice becomes the sole provider for their service needs, and whatever products are necessary for palliation and symptom control. This includes:

- professional services,
- pharmaceuticals
- DME
- in-patient respite
- in-patient care for symptom management

The hospice becomes a managed care program for the patient.

Benefit periods: 2 90-day periods, 1 30-day period,
Indefinite 4th period

The fourth indefinite period was recently enacted. They do not go off the benefit if they fail to die in 7 months.

Revocation of benefit is possible during any benefit period, but there are limitations regarding reelection of benefit.

Admission criteria:

- * Certified by physician that terminal illness with 6 months or less life expectancy.
- * Choose palliative care; treatment mode past

When a person has a terminal illness, consider Hospice as an information resource on options--to patient & physician. The ultimate choice regarding treatment options (including hospice enrollment) is made by client.

WHAT IT MEANS TO THE FAMILY

The family is included as client in the plan of care:

- Support
- Respite
- Bereavement program
- Assessment
- Care

WHAT IT MEANS TO THE HOMECARE PROGRAM STAFF

Philosophy of approach to care.

- Emphasis on living fully
- Self determination
- Palliation --complete
- Totality of care

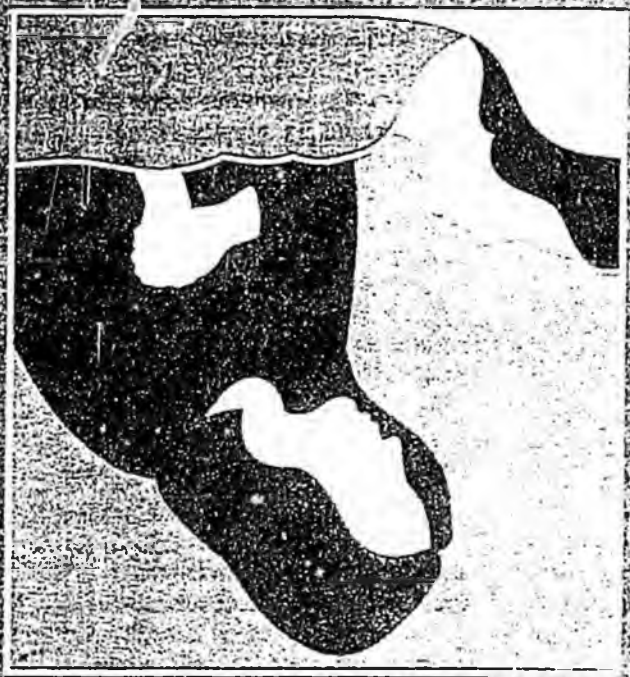
HOSPICE AND YOUR OTHER MEDICARE BENEFITS

Hospice under Medicare is designed to be more than just a collection of existing benefits with a new name. Many items and services are covered under hospice that are not covered through any other type of facility or provider.

This chart shows a comparison between hospice benefits and benefits available through hospitals and home health agencies.

SERVICE ITEM	MEDICARE COVERED IN		
	HOSPICE	HOSPITAL	HOME HEALTH AGENCY
Drugs for pain & symptom control to be used at home	YES	YES	NO
Services covered whether or not the patient is homebound	YES	---	NO
Deductibles waived	YES	NO	NO
Inpatient care to provide respite for family caring for the patient at home	YES	NO	NO
Continuous care at home during periods of crisis	YES	NO	NO
Counseling services at home for both the patient and the family	YES	NO	NO
Home Health Aides	YES	NO	YES
Bereavement Counseling	YES	NO	NO
Volunteers must be available	YES	NO	NO
Care must be continued if benefits run out	YES	NO	NO
Inpatient unit must have homelike decor	YES	NO	---

Standard of Hospice Program, Care Recommended by the National Hospice Organization



For more information, contact the American Cancer Society, 1515 Reisterstown Road, Baltimore, MD 21218, or call 1-800-4-A-CANCER.

Standards For A Hospice Program

A DEFINITION

A hospice program is a coordinated program of palliative and supportive services provided in both home and inpatient settings which provides for physical, psychological, social and spiritual care for dying persons and their families. Services are provided by a medically directed interdisciplinary team of professionals and volunteers. Bereavement care is available to the family following the death of the person.

HOSPICE PHILOSOPHY

Hospice provides support and care for persons in the last phases of incurable disease so that they may live as fully and comfortably as possible. Hospice recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life. Hospice affirms life and neither hastens nor postpones death. Hospice exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

ACCOUNTABILITY

Principle: The hospice operates as an integral part of the health delivery system at the community level and is accountable to the community it serves and the public at large. In order to provide care in this system, a hospice must meet the fundamental requirements for operation and delivery of health services, as regulated by local, state and federal laws.

Standard 1: The hospice program establishes and maintains appropriate reports, policies and procedures to assure that the hospice is accountable to the community for the services it provides.

Standard 2: The hospice program complies with applicable local, state and federal laws and regulations governing the organization and delivery of health care to patients and families.

ACCESS TO HOSPICE CARE

Principle: Admission to the hospice program is based on an assessment of the patient and family needs, their desire for services and the program's specific admission criteria. The level of care received, including the frequency and type of services provided, is based on both initial and subsequent assessments of the patient and family's needs. Care may be provided on either a part time, intermittent basis, a regularly scheduled basis, or a continuous basis, depending upon the needs of the patient and family as reflected in ongoing assessments.

Standard 3: Access to hospice medical and nursing services is available to identified hospice patients on a 24 hour basis, 7 days a week. During hours covered by on-call staff, hospices provide for at least a minimum of medical and nursing coverage, with visit capability should further assessment or treatment be needed. Provisions are made to assure that on-call staff are informed and updated regarding care plans and level of care. Reporting mechanisms are in place to assure continuity and coordination among members of the hospice interdisciplinary team.

Standard 4: The hospice program has admission criteria that reflect the patient/family's desire and need for hospice care; the extent and role of physician participation; and diagnosis and prognosis. To the maximum extent possible, the hospice program will admit patients regardless of their diagnosis or ability to pay for services.

CONTINUITY OF HOSPICE CARE

Principle: Hospice patients and their families may experience physical, social, emotional and spiritual concerns and problems. Hospice addresses these by providing a comprehensive and coordinated program of care which includes an ongoing assessment of needs and determination of the level of care and scope of services necessary. Continuity implies that services, whether provided directly or contracted for, are coordinated in both home and inpatient settings. Services are reflective at all times of patient/family needs, and that the hospice is accountable for its care and services in both home and inpatient care settings.

Standard 5: The hospice program organizes its services to respond to patient/family needs whenever they arise. It provides both structure and staff to ensure continuation of the hospice care plan in all settings.

ACCESS TO HOSPICE INPATIENT CARE

Principle: Not all patients can be maintained at home throughout their terminal illness; some may require short term inpatient care. When such a need arises, hospice care is provided in an inpatient hospice unit. The hospice provides access to hospice inpatient services which reflect the hospice philosophy and emphasizes symptom control and enhancement of a quality of life acceptable to dying patients and their families.

Standard 6: Access to hospice inpatient care is available either directly by the hospice or through contract or arrangement with an inpatient facility. This hospice inpatient unit must comply with all applicable local, state and federal regulations, including fire and safety code regulations.

Standards For A Hospice Program

Standard 7: At a minimum, the hospice inpatient unit provides for: medical direction and coverage for all patients either directly or through agreement with the patient's personal physician; staffing coverage by an interdisciplinary team available to meet the needs of the patient/family on a 24 hour basis as needed; and, specific policies and procedures, as well as personal comfort amenities and courtesies that support and encourage a non-institutional, "home-like" environment for the patient/family. All hospice inpatient personnel must be appropriately trained in the provision of hospice interdisciplinary team care.

PATIENT/FAMILY AS THE UNIT OF CARE

Principle: Inclusion of the family in the hospice care program is essential. The wishes and desires of the patient/family are reflected in assessments and plans of care developed by the interdisciplinary team. The family members are seen both as primary caregivers and as needing care and support so that their own stresses and concerns may be addressed. Attention is also given to assisting with the development of a community support network when family and friends are not available and a patient needs and wants that support.

Standard 8: The patient/family is the unit of care in hospice and support is provided to both the patient and the family. The hospice program encourages patient/family participation in the development of the interdisciplinary team plan of care and in the provision of hospice services.

Standard 9: The hospice program acknowledges that each patient/family has its own values and beliefs and is respectful of them.

Standard 10: The hospice program seeks to identify, teach, coordinate and supervise those persons acting as primary caregivers for the patient. If a primary care person is not available, the hospice program seeks to develop a substitute network. If the hospice program does not accept patients without primary caregivers, then it must provide adequate information about community resources available to them.

PAIN AND SYMPTOM CONTROL

Principle: For the hospice program, the goal of all interventions is to maximize the quality of the remaining life through the provision of palliative therapies that control and symptoms and minimize the negative side effects of interventions. Hospice programs recognize that when a patient and a family are faced with terminal disease, stress and concerns may arise in many aspects of their lives. Optimum symptom control includes addressing these stresses and concerns, in addition to the use of appropriate therapies.

Standard 11: The goal of hospice care is to provide optimum relief of pain and control of symptoms through appropriate palliative therapies.

Standard 12: Symptom control includes assessing and responding to the physical, emotional, social and spiritual needs of the patient/family.

VOLUNTEERS

Principle: An essential component of hospice care is the direct personal support for the patient/family by volunteers. Volunteers provide important perspectives in developing the interdisciplinary team plan of care

and in the provision of significant hospice services.

Standard 13: A hospice program offers volunteer support to each patient/family admitted to its program of care.

Standard 14: A hospice program has an organized training program and procedures for the selection, supervision and continuing evaluation of volunteers.

HOSPICE INTERDISCIPLINARY TEAM

Principle: Hospice care is provided by an interdisciplinary team which includes at least the following members: patient and patient's family, physician, nurse, social worker, volunteer, and clergy. Ancillary staff are added to the team when appropriate. The team meets regularly to develop and maintain an appropriate plan of care.

Standard 15: The hospice identifies and maintains an appropriately qualified interdisciplinary team of health professionals and lay persons.

Standard 16: Emotional support for staff/volunteers is provided as an integral part of a hospice program.

Standard 17: Inservice training and continuing education are offered on a regular basis to both paid and volunteer staff.

INTERDISCIPLINARY TEAM PLAN OF CARE

Principle: Documentation of services is necessary for the delivery of quality hospice care. Of critical importance is the development of an integrated plan of care which records assessments, proposed interventions by all

Standards For A Hospice Program

interdisciplinary team members and documents all services provided to the patient/family and their outcomes. Hospice clinical records reflect the full range of problems identified; services provided by level of care across both the home and inpatient settings; and progress notes documenting the care given on a day-to-day basis.

Standard 18: The hospice program has a written, interdisciplinary team plan of care for each patient/family unit that includes assessments, identified problems, proposed interventions, level and frequency of services and their outcomes.

Standard 19: The hospice program maintains accurate, current, integrated clinical records for all patient/family units and provides assurances for the confidentiality of these records.

Standard 20: These clinical records must include a signed informed consent form completed by the patient or a designated representative. The consent form must inform the patient/family of the palliative nature of hospice care; the avoidance, if at all possible, of injections, diagnostic testing and curative measures; and the non-use of heroic measures to prolong the dying process.

Standard 21: These clinical records must include specific, signed instructions regarding actions to be taken when life threatening situations occur to the patient. These instructions should be prepared by the physician and the interdisciplinary team, following consultation with the patient/family, and must be consistent with the patient/family's wishes.

BEREAVEMENT

Principle: Death of a family member may result in a wide range of physical, emotional, social, familial, economic and spiritual disruptions. Grief and bereavement are normal reactions to loss and death. Grief is the highly personal response to loss; bereavement is the extended period of deprivation following the loss of a loved one. Grieving may precede an anticipated death or may be delayed for a considerable period of time. Grief may manifest itself in emotional and/or physical distress and may affect family members in different ways at different times. Some persons can resolve grief with time and their own resources; others may require formal assistance and support over an extended period of time.

An important element of hospice care is an assessment of the needs of the bereaved family, and the development of a care plan that meets these needs, both prior to, and following, the death of the patient. Hospice encourages the expression of grief, recognizes social/religious and ethnic variables in bereavement and supports staff and family participation in meaningful funeral services and rituals.

Standard 22: The hospice program provides bereavement services to the surviving family members for at least one year after the death of the patient.

Standard 23: The hospice program maintains a process of risk assessment for surviving family members that identifies those individuals at risk of pathological grief. For those individuals at high risk, appropriate referrals are made to mental health professionals in the community.

QUALITY ASSURANCE AND UTILIZATION REVIEW

Principle: Hospice is committed to developing methods to measure and assure the quality of patient/family care and the appropriate utilization of hospice resources.

Standard 24: The hospice program has quality assurance and utilization review programs that include the following: statement of goals and objectives and established policies for conducting an ongoing assessment program that reflects the interdisciplinary nature of hospice services; designation of person(s) responsible for implementing policies and procedures; provisions for addressing specific problems identified in the quality assurance and utilization review processes.

Standard 25: At a minimum, the hospice program conducts on a regular basis the following activities: evaluation of services provided by both professionals and volunteers, audit of patient charts for outcomes of interventions, organizational review of hospice program, interdisciplinary team care plan review, evaluations provided by patient/families of care received, a review of appropriate/inappropriate use of services, facilities and personnel.

A Hospice Glossary

This glossary was prepared using a variety of source materials to provide definitions. These include: *NHO Standards of Care* (1983), *Joint Commission on Accreditation of Healthcare Organizations* (manuals, 1985), *Introduction to Health Education* (Bates, Wynder, 1984) and *Webster's New Collegiate Dictionary* (1986).

Ability to pay: A phrase used to describe a patient's capability to pay for health services received. Some health providers limit their services to patients who can pay for their services.

Access: An individual's or group's ability to obtain health care. Access has geographical, financial, social, ethic and psychological elements. Many health programs have as their goal improving access to care for specific groups or equity of access for the whole population.

Accountability: To provide for an organization substantial reasons or convincing explanations for actions; to be accountable means to furnish a justification or detailed explanation of financial activities or responsibilities. Accountability entails an obligation to periodically disclose, in adequate, detailed and consistent form the purposes, principles, procedures, relationships, results, incomes, and expenditures involved in any activity, enterprise, or assignment, so that they can be evaluated by interested parties.

Accreditation: A voluntary process, generally developed and implemented by a non-governmental body composed of professionals within the field, with input from providers, and based on optimal standards of quality care.



Administration: The fiscal and general management of a hospice program, as distinct from the general policies and procedures of the hospice program.

Admissions: Numbers of patients/families that enter a hospice program and agree to accept the services provided by a hospice program.

Admission criteria: Guidelines or policies of a hospice program that specify the conditions under which a patient/family will be admitted. The purpose of the criteria is to control entry/admission to services, e.g., most hospices require a diagnosis of terminal illness by a physician as a prerequisite for admission.

Ancillary staff: Health professionals who provide additional services to support or supplement hospice interdisciplinary team services, including physical therapy, occupational therapy, speech therapy, nutritional counseling, respiratory therapy, and other services.

Appropriate: Descriptive of an action or policy that is suitable or compatible with a hospice program's objectives and philosophy.

Approved: Acceptable to the appropriate authority.

Assessment: Procedures by which strengths, weaknesses, problems, and needs are identified and addressed.

Audit, financial: An independent review of a hospice program's financial records that accurately reflects its financial status.

Bereavement: An important element of hospice care is an assessment of the needs of the bereaved family, and the development of a care plan that meets these needs, both prior to, and following the death of a patient. Hospice encourages the expression of grief, recognizes social/religious and ethnic variables in bereavement and supports staff and family participation in meaningful funeral services and rituals.

Bereavement services: The hospice program makes available bereavement services to the surviving family members for a period of at least one year after the death of the patient. They may include: cards to families; home visits; phone calls; group counseling; individual counseling; newsletters; and social activities.

Bylaws: The rules, regulations, or laws adopted by a hospice program for the regulation of its internal affairs and its dealings with other persons and the community at large.

Certification: A voluntary mechanism used to qualify organizations to receive public funds. If a provider chooses to participate in Medicare, for example, it must comply with a set of conditions of participation based on laws and regulations.

Chemotherapy: Provision of drugs (i.e., chemicals) taken orally, injected, inserted, topically applied, or otherwise administered to control pain and symptoms in hospice patients.

Clergy: A person who has met the requirements of a religious

A Hospice Glossary

organization or system to serve the constituency of that religious organization or system.

Clergy services: See spiritual services.

Clinical privileges: Authorization by the governing body to provide specific patient/family care and treatment services in the organization, within well-defined limits, based on the individual's license, education, training, experience, competence, and judgment.

Community: The individuals, groups, agencies, facilities, or institutions within the locality served by the hospice program.

Confidentiality: The relationship between the hospice staff patients/families in which information is shared and exchanged with the understanding that this information is used appropriately and with respect to the patient/families' wishes and rights to privacy.

Continuing education: Education beyond initial professional preparation that is relevant to the type of patient/family care delivered in the organization, that provides current knowledge relevant to the individual's fields of practice, and that is related to findings from quality assurance activities.

Continuity of care: Services that are organized, coordinated and provided in a way that is reflective at all times of patient/family needs, and which are structured to assure that the hospice is accountable for its care and services regardless of home or in-patient setting.

Continuous basis: Hospice care is provided in the home setting on a 24



hour basis until care is no longer needed. Usually this occurs when the patient/family goes into a medical crisis, but does not need or wish to return to an inpatient setting.

Contracted services: Services provided through a formal agreement with any organization, agency or individual. The agreement, which is approved by the governing body, specifies the services, personnel, and/or space to be provided to or on behalf of the hospice program and the consideration to be expended in exchange.

Counseling: A relationship in which a person endeavors to help another understand and cope with problems.

Curative: Medical interventions used to ameliorate the cause of a disease.

Dietetic services: Services that meet the nutritional needs of patients, with emphasis on patients who have special dietary needs.

Dietitian: A person who is registered by the Commission on Dietetic Registration of the American Dietetic Association or who has the documented equivalent in education, training and/or experience.

Discharge: The point at which the patient's active involvement with the hospice program is ended and the program no longer maintains active responsibility for the care of the patient.

The actual point of discharge is determined by the hospice program in accordance with the continuum of home care and inpatient services provided.

Documentation of services: The process of writing, recording and maintaining appropriate records of services that are provided by a hospice interdisciplinary team. This process is very important to assure continuity of services, high quality of care and to justify those services that have already been provided.

Dying: The progressive failure of body systems to retain normal functioning, thereby limiting the remaining life span.

Emotional: The feeling aspect of consciousness which is subjectively experienced and expressed by physiological reactions.

Emotional support: The provision of psycho-social services that assist and support the patient/family during that period of time when they cope with their feelings and responses to the loss, grief and change in their family structure which occurs when the patient dies.

Employees: Individuals who agree to work and provide their services under the administrative direction of the hospice program. Employees may receive wages and other compensation in exchange for their work, or they may provide their services without payment, as an in-kind contribution to the hospice program.

Facility: The building(s), equipment and supplies necessary for the

A Hospice Glossary

implementation of inpatient services for hospice patients/families.

Family: The relatives and/or other significantly important persons who provide psychological, emotional and spiritual support of the patient. The "family" need not be blood relatives to be an integral part of the hospice care plan.

Fiscal management: The policies and procedures used to plan and control a hospice program's overall financial operations.

Goal: An expected result or condition that takes time to achieve and is specified in a statement of relatively broad scope that provides guidance in establishing intermediate objectives directed toward attainment of that goal.

Governing body: The individual(s), group or agency that has ultimate authority and responsibility for the overall operation of the organization.

Grief: The highly personal response to loss. Grieving may precede an anticipated death or may be delayed for a considerable period of time. Grief may manifest itself in emotional and/or physical distress and may affect family members in different ways at different times. Some persons can resolve grief with time and their own resources; others may require formal assistance and support over an extended period of time.

Home: The patient's place of residence. Home is the place where most terminally ill patients choose to spend their remaining days.

Home care services: Formally organized services designed to provide and coordinate hospice interdisciplinary team services to

patients/families in the home.

Home health agency: An organization that provides services to individuals in their place of residence. Many home health agencies receive compensation for their services provided to Medicare beneficiaries. Some home health agencies operate a hospice program as a separate division of their total program.

Home health aide services: Personal care services provided in the home. Services may include assistance in the activities of daily living (e.g., helping the patient bathe, care for his or her hair or teeth, exercise and retain necessary self-help skills). Services may also include specific household tasks to maintain a safe environment in areas of the home used by the patient (e.g., changing the bed and doing laundry essential to the cleanliness of the patient).

Homemaker services: Services that are provided to assist patients to remain in their homes. Services may include assistance in personal care (e.g., assisting the patient to the bathroom or in and out of bed); maintenance of a safe and healthy environment (e.g., cleaning the patient's bedroom, bath and kitchen, doing personal laundry and preparing meals); and other services, as appropriate to the homemaker's responsibilities.

Hospice care: Care provided by a hospice program that is designed to meet the physical, social, emotional and spiritual needs of dying patients and their families.

Hospice program: A hospice program is a coordinated program of palliative and supportive services provided in both home and in-patient

settings which provides for physical, psychological, social and spiritual care for dying patients and their families. Services are provided by a medically-directed interdisciplinary team of professionals and volunteers. Bereavement care is available to the family following the death of the patient. Hospice provides support and care for persons in the last phases of incurable disease so that they may live as fully as comfortably as possible.

Hospice philosophy: Hospice recognizes dying as part of the normal process of living and focuses on maintaining the quality of life. Hospice affirms life and neither hastens nor postpones death. Hospice exists in the hope and belief that through appropriate care and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

Hospice program director: The chief administrative officer of the hospice program who provides overall policy direction, is responsible for the fiscal operations, and implements work plans and procedures.

Incident report: Documentation of an event of action that is likely to lead to adverse effects and/or that varies from established policies and procedures pertaining to patient/family care.

Infection control program: Organized, on-going activities within a hospice program to control and monitor the spread of infectious diseases within the hospice, including both home and in-patient settings. Part of this program involves establishing and maintaining specific policies and procedures proper

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procedures for proper disposal of human discharges and surveillance of staff and patients for infections acquired during their contact with a hospice program.

Informed consent: A full understanding by a competent body of the risks and benefits of particular medical procedure or set of procedures. Prior to admission to hospice, the patient/family must sign an agreement that states they understand the nature and scope of hospice care, including the fact that hospice care is palliative and not curative, and that they agree to cooperate in the provision of care.

Inpatient services: Formally organized services designed to provide and coordinate hospice interdisciplinary team services to patients/families in an inpatient setting.

Inpatient settings: Services provided in a setting where the needs of acutely ill patients/families can be met. This care is provided on a 24 hour basis and involves the full hospice interdisciplinary team. During the last months of life, a dying patient may have episodes of acute illness that require the intensive services capability of an in-patient setting.

In-service education: Organized education designed to enhance the skills of interdisciplinary team members or teach them new skills relevant to their responsibilities and disciplines.

Interdisciplinary team: Hospice care is provided by an interdisciplinary team which includes at least the following members: patient and patient's family, physician, nurse, social worker, volunteer, and clergy. The team is coordinated by a qualified health care professional and is

medically supervised. The team meets regularly to develop and maintain an appropriate plan of care. (See Interdisciplinary team services.)

Interdisciplinary team conference: A meeting during which interdisciplinary team members review one or more interdisciplinary team care plans to update patient/family physical and/or psychological status and initiate any changes in the care plan.

Interdisciplinary team plan of care: Documentation of services is necessary for the delivery of quality hospice care. Of critical importance is the development of an integrated plan of care which records assessments, proposed interventions by all interdisciplinary team members and documents all services provided to the patient/family and their outcomes. Hospice clinical records reflect the full range of problems identified, services provided by level of care across both the home and inpatient settings, and progress notes documenting the care given on a day-to-day basis.

Interdisciplinary team services: A group composed of individuals from various professions and disciplines who interact on a regular basis and have a working knowledge of the assessment and care of the patient/family by each member of the team. The team services are characterized by the ability by all members and disciplines to allow their roles to overlap while simultaneously providing emotional support to each other and maintaining a respect for each other's skills, training and interventions.

Intermittent basis: Provision of hospice services at intervals as they are needed by the patient/family. During the final six months of life, the patient/

family may go through a number of crises that require a higher level of intensity of hospice services than at other times.

Interventions: Specific actions designed to interfere, stop or ameliorate the natural course of an illness or human disease. In hospice, interventions are limited to those that are palliative and not curative. These interventions may, however, address a range of patient/family needs, including physical, spiritual, social and emotional concerns.

License: Authorization to practice in the professional discipline by an individual may be mandated by state law. The state grants permission to a provider organization to operate or individual to practice. It is a matter of specific state law and violation imposes a penalty.

Licensure: Licensure standards are the minimum standards which must be met to provide service as a hospice. In contrast to accreditation and certification, licensure is mandatory if specified by state law. The state grants permission to a provider organization to operate or individual to practice. It is a matter of specific state law, and violation imposes a penalty.

Medical director: A fully licensed physician who is charged with the responsibility of acting as consultant to the interdisciplinary team and, as requested, to attending physicians with regard to pain and symptom management, as well as acting as liaison with physicians in the community.

Medical records: Specific records maintained by a hospice that document all services provided by the

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interdisciplinary team to a patient/family.

Medical staff: A single organized body that is accountable to the governing body and has the overall responsibility for the quality of professional services provided by individuals with clinical privileges.

Medication: Any substance, whether prescription or over-the-counter drug, that is taken orally, injected, inserted, topically applied, or otherwise administered to the patient.

Nursing services: Patient/family care services pertaining to the palliative, curative, rehabilitative and preventive aspects of nursing, performed and/or supervised by a registered nurse pursuant to interdisciplinary team care plans.

Objective: An expected result or condition that takes less time to achieve than a goal, is stated in measurable terms, has a specified time for achievement and is related to the attainment of that goal.

Outcomes: The final results or consequences from specific interventions taken. In hospice, the death of the patient is anticipated and is not defined as an outcome. Appropriate hospice outcomes focus on control of pain and symptoms and quality of the remaining days that the patient/family spends together.

Pain and symptom control: For the hospice program, the goal of all interventions is to maximize the quality of the remaining life through the provision of palliative therapies that control pain and symptoms and minimize the negative side effects of interventions. Hospice programs

recognize that when a patient and a family are faced with terminal disease, stress and concerns may arise in many aspects of their lives. Optimum symptom control includes addressing those stresses and concerns, in addition to the use of appropriate therapies. Symptom control includes assessing and responding to the physical, emotional, social and spiritual needs of the patient/family.

Palliative care: Intervention that focuses primarily on reduction or abatement of the physical and psychosocial symptoms of terminal illness.

Patient/family as unit of care: The specific unit for whose needs hospice is organized. In hospice, this unit is the patient/family. Services are structured (e.g., record/keeping) and then delivered (e.g., visits at home with family members). In contrast, most health providers have, as their unit of care, the individual patient.

Personal care: Assistance rendered to the patient in bathing, dressing, mobility, or any other activities of daily living and personal hygiene.

Pharmacist: A person who has a degree in pharmacology and is licensed and registered to prepare, preserve, compound and dispense drugs and chemicals in the state in which he or she practices.

Physical: Relating to the body, its structure, characteristics and functions.

Physician: A doctor of medicine or doctor of osteopathy who is fully licensed to practice medicine in conformity with applicable law.

Physician, attending: The primary physician selected by the patient to be

responsible for his or her medical care.

Physician, hospice: Any licensed medical practitioner on the hospice staff (compensated or not) who is knowledgeable about hospice principles and active in the development and implementation of interdisciplinary team plans of care for patients and families.

Primary caregivers: The person designated by the patient to give emotional support and/or physical care to the patient. This person may be an individual who has personal significance to the patient but no blood or legal relationship (e.g., significant other), such as a neighbor, friend or other person. If the patient has no designated primary careperson, the hospice may, according to individual program policy, make an effort to designate a primary careperson.

Prognosis: The prospect of recovery, or a forecast of the natural history of a disease or illness. In hospice, usually prior to admission, a patient must have been given a prognosis by a physician of less than six months to live.

Program director: The person who has the authority and responsibility, as delegated by the governing body, to accomplish program-specific goals and objectives, implement program policy and manage personnel and resources.

Psychological/social work services: Counseling and/or therapy, as appropriate, that assists the patient/family in minimizing stresses and problems that arise from social, economic or psychological situations and assists the patient/family in maximizing positive aspects and opportunities for growth. Services are provided, as appropriate to the skill's

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required, by the persons who have education, training and/or experience in the care of hospice patients/families and demonstrated ability in counselling and casework.

Psychosocial assessment: The evaluation of a patient's/family's environment, religious background, financial status, and other pertinent psychosocial information that may contribute to the development of an interdisciplinary team care plan.

Qualified: Having the experience, education and demonstrated competence deemed appropriate by the hospice program to meet the requirements and fulfill the responsibilities of a specific function or duty.

Quality assurance: Ongoing assessment program that measures the quality of the interdisciplinary hospice services provided; It includes provisions for addressing specific problems identified and followup to determine the effectiveness of corrective actions.

Registered nurse: A nurse who is a graduate of an approved school of nursing and who is licensed to practice as a registered nurse.

Risk assessment: The hospice program maintains a process of risk assessment for surviving family members that identifies those individuals at risk of pathological grief. For those individuals at high risk, appropriate referrals are made to mental health professionals in the community.

Service: A functional division of a program or an interdisciplinary team. Also, the delivery of care.

Social: The interactions of persons with their families and communities.

Social services: See (Psychological/social work services.)

Spiritual service: Spiritual support provided by a member of the interdisciplinary team, community clergy, or a person identified by the patient/family as supportive with regard to spiritual or religious matters.

Staff: Paid or volunteer interdisciplinary team members who provide hospice services.

Staff support: Organized activities designed to provide psychological/social support to hospice employees as they respond personally to the loss, grief and change experienced by patients and their families.

Supervision: The direction of the provision of services and the individuals who provide the services, and the review of the services provided, in accordance with written program policies, procedures and job descriptions.

Terminal disease: An illness for which treatment directed toward cure or control of the disease process is no longer possible or effective.

Terminally ill: Individuals suffering from a disease with a prognosis of six months or less to live.

Transfer: Movement of the patient/family from one service or location to another (e.g., the patient and family or designated primary careperson).

Unit: A functional division of a facility or institution. Also, a person or group regarded as a whole (e.g., the patient and family or designated primary careperson.)

Utilization review: The process of using predefined criteria to evaluate whether the hospice's services and resources are necessary, cost efficient and effectively utilized.

Volunteer: An individual who agrees to provide services to a hospice program without monetary compensation. More specifically, a patient care volunteer is an individual who agrees to serve on an interdisciplinary team as a companion of the patient/family and provide psycho-social support to the patient/family during the remaining days of the patient's life. A bereavement care volunteer agrees to provide psycho-social support to the surviving family following the patient's death.

Volunteer support: Activities designed to assist and support volunteers as they work in their roles as patient care and bereavement volunteers.

Written agreement: A formal agreement with any organization, agency, or individual specifying the services, personnel and/or space to be provided to or on behalf of the hospice program, as well as the monies to be expended, if any, in the exchange. The agreement is approved by the governing body, in accordance with hospice program policy.



National Hospice Organization

Addendum to

Standards of a Hospice Program of Care
Recommended by the National Hospice Organization

Original Standard:

Standard 14

A hospice program has an organized training program and procedures for the selection, supervision and continuing education of volunteers.

Revised Standard:

Standard 14 (A)

The hospice program has an organized training program which covers at a minimum the following topics: introduction to hospice, concepts of death and dying, communication skills, care and comfort measures, understanding diseases and conditions, psychosocial and spiritual dynamics of death and dying, the hospice family, managing personal stress, the bereavement process, and the role of the volunteer in hospice.

Standard 14 (B)

The hospice program has established policies and procedures for the selection, retention and continuing education of hospice volunteers and volunteers are regularly evaluated using performance criteria defined by the hospice.

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NATIONAL HOSPICE ORGANIZATION

ABOUT HOSPICE

Hospice is a philosophy and concept of care for the terminally ill that is now one of the most frequently used terms in discussions of innovative approaches to health care. In 1990, the American College of Physicians presented to the National Hospice Organization the Richard & Hinda Rosenthal Foundation Award in recognition of the "recent original approach in the delivery of health care or in the design of facilities for its delivery [which] will increase its clinical and/or economic effectiveness." However, most people are unaware that the significant recent growth of hospice in the United States and internationally is nurtured by ancient roots.¹

The modern hospice can trace its roots to the Irish Sisters of Charity who established St. Joseph's Hospice at London in 1905. The hospice most often recognized as the model of contemporary hospice philosophy and care is St. Christopher's in London. Started by Dame Cicely Saunders, M.D. in 1968, St. Christopher's laid the basis for a philosophy that emphasizes palliative care, i.e., pain and symptom control rather than curative care for the terminally ill.

A community based service, hospice care is provided by an interdisciplinary team of health care professionals and volunteers including physicians, nurses, counselors, therapists and aides. Using a comprehensive case management approach, hospice care is guided by a plan of care which is developed by the interdisciplinary team in conjunction with the patient and family. The goal of the plan is to care for the patient and family as the "unit of care," to provide an alert, pain-free life and to manage other symptoms so that individuals can "live until they die" with personal dignity and quality of life at home or in a home-like setting.

Responding to the directives of the Medicare Hospice Benefit Conditions of Participation², as well as the National Hospice Organization and JCAHO standards, most hospices offer the

¹ The first references to "hospice care" can be found in the ancient writings of Constantine in A.D. 335, and later with the sixth century Benedictine monks and in the ninth century under the emperor, Charlemagne.

² Congress first added the hospice benefit to Medicare in TEFRA 1982. In 1986, Congress made the Medicare benefit permanent and established hospice as an optional Medicaid benefit.

following services to terminally ill patients with a prognosis of six months or less: Physician and nursing services on an intermittent basis; social work services, physical, occupational and speech-language therapy; home health aides; volunteers; drugs and medical supplies; spiritual, dietary and other counseling; short-term inpatient care; continuous home nursing care during periods of medical crisis; and bereavement care for surviving family members. Most services are available, as needed, 24 hours per day, seven days per week.

HOSPICE REIMBURSEMENT AND SAVINGS

As noted, hospice care is a covered Part A benefit under Medicare. Additionally, hospice care is a covered Medicaid Benefit in thirty-three states. Medicare and Medicaid directly pay hospices an all-inclusive, prospective daily rate based on a particular level of care delivered on that day. The four levels of care are: Routine Home Care, Continuous Home Care, Inpatient Respite Care and General Inpatient Care. No more than 20 percent of a hospice's aggregate days may be furnished at the inpatient level of care, and there is an annual aggregate expenditure cap per hospice, calculated on a per patient basis, of \$11,551 (1992). For 1992, the Congressional Budget Office projected a \$600 million Medicare outlay for hospice care. Approximately 60 percent of all hospice patients are Medicare beneficiaries.

Estimated expenditures for hospice care are not available from private payers; however, according to the Health Insurance Association of America, more than 80 percent of employees in medium and large companies have hospice care as a covered benefit. In 1984, only 11 percent of such employees had coverage for hospice care.

Health Care Financing Administration (HCFA) research suggests that approximately 28 percent of annual Medicare expenditures are associated with services, many of which are inappropriate and unwanted, provided to Medicare beneficiaries in their last year of life. Medicare beneficiaries electing hospice services waive their right to standard Medicare benefits for treatment of the terminal illness although their attending physician continues to bill Medicare Part B directly.

A 1988 HCFA commissioned report by ABT Associates suggested a savings of \$1,248 per patient in the last year of life, when hospice care is elected. Kaiser Permanente, an Oakland, California-based HMO, conducted a hospice cost-effectiveness study in the late 1980's focusing on non-Medicare and non-Medicaid terminally ill patients who entered hospice care. The study showed an average cost savings per hospice patient of about \$1,430 to the HMO.

A STATISTICAL PROFILE OF HOSPICE CARE

- First Hospice in the United States, New Haven, CT. 1974
- Current number of U.S. hospices, 1830 including planned and non-comprehensive programs. NHO estimates 1700 comprehensive programs, as described above.
- Approximately two-thirds of the comprehensive hospices are Medicare certified.
- Over 90 percent of hospices are non-profit or government affiliated programs. Four percent are for-profit entities.
- Hospices served approximately 210,000 patients in 1990.
- The average daily census of the typical hospice program is 25 patients per day. The average length of stay is 59 days. Approximately 90 percent of all patient days were provided in the patient's home.
- Approximately two out of three patients served are over the age of 65. One percent are under the age of 18, representing 71 percent of pediatric cancer deaths.
- Eighty-four percent of hospice patients have cancer, accounting for approximately 33 percent of all cancer deaths as reported by the American Cancer Society. People living with AIDS and those with cardiovascular disease constitute the bulk of remaining hospice patient census.
- Over 20,000 people are employed nationwide in hospices and include physicians, nurses, social workers, administrators, home health aides, clergy, therapists and bereavement specialists.
- Approximately 68,000 people volunteer in hospice programs, contributing more than 5 million hours of service annually. Two out every three hours are direct patient care hours. The Medicare Hospice Benefit Conditions of Participation require that a minimum of five percent of patient service hours be provided by volunteers.

II. Studies Showing Savings and Benefits of Hospice Care:

Through the national hospice demonstration projects conducted by the federal government, it was learned that not only was hospice care a more humane alternative of care but it resulted in cost savings as well. As a result of its cost effectiveness, the Medicare hospice benefit was created by the Tax Equity and Fiscal Responsibility Act of 1982 as a more humane alternative to the hi-technology care traditionally provided to the terminally ill. In 1986, hospice was made an option under Medicaid and the number of states offering the hospice benefit rose to 34 states by 1992.

- Savings can be realized by substituting the high cost of conventional care with the home-oriented approach of hospice care. A study by Abt Associates (Medicare Hospice Benefit Program Evaluation, Final Summary Report, July 21, 1989) stated that comparisons of hospice benefit and conventional care expenditures in the last month of life showed that conventional care was 30% higher in FY85 and 43% higher in FY86. The hospice savings were even more significant for non-cancer beneficiaries who cost \$3,135 for hospice care in the last month of life compared to \$4,730 for conventional care.

- Major savings in the cost of providing care to the terminally ill are directly related to the percentage of time patients are at home during the final months of life. Based on 1986 mortality data from the National Center for Health Statistics, an article in the Health Care Financing Review/Fall 1990, stated that there was an increase of 10% in the shift in place of death for cancer patients from hospitals to patients homes, and because about 94% of all hospice patients have cancer, the data suggests a possible impact of hospice use.

- A survey of hospital based hospices conducted by the American Hospital Association in 1986 identified a major reduction in the number of inpatient days for those patients cared for under the Medicare hospice benefit: the average

patient on the Medicare hospice benefit spent 68 days at home and 7.7 days in the hospital; the traditional Medicare patient spent an average of 58.1 days in home care and 21.3 days in the hospital; and the non-Medicare patient spent an average of 53.4 days at home and 13.8 days in the hospital.

- According to the most recent statistics gathered from Medicare certified hospice programs by the Health Care Financing Administration, the average length of stay was 48.38 days in a hospice program in 1990, and 96% of all patient days were spent in the home rather than in conventional health care settings. Additionally, the number of Medicare certified hospices in the country increased to 1,072 by April of 1992.

- Employee benefit packages surveyed by the Bureau of Labor Statistics showed 23% carrying hospice coverage in 1985 and 31% in 1986.

- General Motors Corporation covers hospice care on a per diem basis for all of its employees (Blue Cross is the intermediary for this reimbursement) and Metropolitan Life Insurance Company also uses a per diem system for all of its subscribers.

- Sixty-nine percent of Health Maintenance Organizations (HMOs) offer hospice care as surveyed by the Group Health Association of America in 1988.

- A survey conducted by Foster Higgins & Company, a benefits consulting firm, showed that 80% of major employers nationwide included hospice as an employee benefit in 1989. The survey represented over 12.5 million employees of 1,943 public and private-sector employers.