



MINNESOTA NETWORK OF
HOSPICE & PALLIATIVE CARE

Physicians Guide to Hospice Care

This reference guide is designed to help physicians and other referral sources use hospice in the treatment of terminally ill patients. Material was prepared with the help and input of hospice medical directors and physicians throughout Minnesota.

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Project DECIDE (Discussion of Evolving Choices in Dying and Ethics) is a collaborative endeavor between the University of Minnesota's Center for Biomedical Ethics and the Allina Foundation, through which a series of applied research partnerships are funded to explore problems in end-of-life care and resource allocation in a managed care context.

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Forward

Not so long ago, the last stage of human life was a personal, familial, or religious affair. Today, 90 percent of the 40 thousand Minnesotans who die each year, do so while under medical care.

Though dying has become increasingly "medicalized," each death is a story, not a case. It is a personal and family story of profound choices, of momentous words and telling silences, and of acts of caregiving and abandonment that are recounted by the dying person's loved ones from one generation to the next. Physicians appear in these stories sometimes as stalwart expert counselors, sometimes as high-tech disease warriors, and sometimes as ill-equipped or missing-in-action.

This reference guide will help physicians use hospice to improve end-of-life health care. Hospice is a tool that we do not use often or early enough.

Hospice is not for every dying person. There are times when valiant efforts to forestall a premature or unanticipated death are warranted. But most patients die after a long and ultimately losing struggle with chronic and progressive or terminal diseases, diseases like cancer or heart disease or Alzheimers disease or AIDS. High-quality, end-of-life care often requires more than “do not” orders and good primary care. These patients have special needs for pain control, to have dying occur under the direct care of supportive (and supported) loved ones, or to have intensive and sustained palliative care that is nonintrusive and effective. For them, the multidisciplinary and specialized care of hospice is most likely the answer.

As a trusted counselor, you are the key to the timely referral and use of hospice to improve end-of-life care.

Physician's Role in Hospice Care

The importance of the physician’s relationship with a terminally ill patient and his or her family throughout the course of illness cannot be overemphasized. In a focus group discussion conducted through the Allina Foundation’s Project DECIDE, one patient commented, “You are so tied to physicians, you are relying on them for the lifeline. If they suggest an option, you think, OK, I guess I better look at this.” Another reiterated the trust relationship: “I just went along with what the doctor said...I thought he knew what to do and would take care of it” (Allina Foundation, 1994).

The physician is a key member of the hospice team. From initiating the discussion about hospice to signing the death certificate, the physician’s involvement is crucial to the patient, family and other members of the hospice team. Yet many physicians, especially those who refer to hospice only occasionally, may not be aware of the full range of services offered by hospice or the tremendous growth experience at the end of life that can occur within patients and families.

In addition to the physician, the hospice team includes nurses, home health aides and homemakers, social workers, chaplains, and volunteers. Under the physician’s direction, the hospice team specializes in pain and symptom management, and provides support for the family as well as the patient.

Preparing Patient for Hospice Care

Rarely in the course of a patient's disease and treatment is there one moment when the focus clearly shifts from curative to palliative. Just as disease treatment is a process, so is preparing a patient for the time when treatment for cure is no longer an option. Preparing a patient begins with an honest discussion of the disease and its outcomes.

According to Barry Baines, M.D. Family Practice, "Good hospice preparation begins with creating or continuing a foundation of trust with the patient. I will sometimes say to my patient, 'We are going to treat you aggressively, but a time may come when we will have to change our focus from cure to comfort. My commitment to you is that I will be honest about what I am seeing.'"

"Patients want to know, 'how long do I have?'" said Dr. Baines. "I tell them that I don't have a crystal ball, but in these types of cases we normally see a prognosis of x number of weeks or months. Then patients want to know if they will be in pain. I tell them that's one of the main issues hospice can help them with." In a recent Louis Harris Poll, 96 percent of Americans said they would want to be told if they have cancer and 85 percent would want a "realistic estimate" of how long they had to live if their type of cancer usually led to death in less than a year.

"When patients are told the truth, they have an opportunity to deal with practical and business responsibilities, establish a meaningful, emotional exchange with loved ones, and establish a realistic basis for emerging clinical developments that will be shared with the physicians."

-Edward Creagan, M.D.

Listening to Patient Needs

Introducing a patient to hospice involves more than telling them, "Now it's time for hospice." It is also an art that involves listening to what a patient is saying.

"Sometimes a patient is ready for hospice before we are," said Eric Anderson, M.D., Internal Medicine. "We offer every possible therapy in an attempt to be supportive, but the patient is thinking 'I just want to go home and be comfortable.' In this instance our best support is to listen and acknowledge these wishes."

Fear of the Unknown

For many people, fear of the unknown is at least as great as fear of death itself (Fletcher, 1992). Presenting hospice as a medical option for treating a terminal illness can help with many unknowns – "fear of uncontrollable pain, nausea, vomiting, embarrassment and especially abandonment" – that often accompany end stage disease (Creagan, 1994).

Not all patients are ready to accept the idea of hospice care when it is introduced. Often the barriers to acceptance are less a patient's unwillingness to accept the disease prognosis and more a fear of abandonment.

According to Dr. Anderson, "We must be honest and say, 'I don't have any more treatment that will cure your disease.' Then we must be good physicians and add, 'I do have treatment that will ensure your comfort. I will be here for you.'"

Working With The Family

The patient's family is crucial in the hospice discussion. A patient can be ready to accept hospice when their family is not. Sometimes they are the ones encouraging the patient to continue treatment even when the burdens outweigh the benefits.

"It's important to talk with the key family members as well as the patient," says Timothy Moynihan, M.D., Oncology. "I say to my patient, 'This is one of the most important times of your life. Whom do you want in on this discussion?'"

Often, the family simply needs to hear that hospice is a choice the patient is making. As the physician, you can best ask the question for the family, "Given the medical information, what do you want?"

"When we send out surveys to families after a patient has died on our hospice program, one of the most frequent comments we receive is, 'Why didn't the doctor tell us about hospice sooner?'"

Common Questions From Patients and Families

Q: Does this mean there's nothing more we can do?

A: Hospice is not an end to treatment. It is a shift to intensive palliative care that focuses on allowing the patient to live his or her life to the fullest. In addition to managing pain, hospice provides extensive counseling and social service support to address the emotional and spiritual aspects of coping with a terminal illness.

Q: What about the pain?

A: A primary goal of hospice is effective pain management. Pain related to the terminal illness is aggressively treated using a wide variety of medically sound therapies.

Q: What should we do next?

A: The next step is to contact a hospice. Here are a few important points to tell your patient about hospice:

- As your physician, I will continue to see you and care for you.
- Our first priority is managing your symptoms.

- Services are available where you live.
- Your family will also receive the support of the hospice team.
- Hospice care is covered by Medicare, Medical Assistance, MinnesotaCare, and many private insurances. If the hospice is not Medicare Certified, there is usually a sliding fee scale for any billable services.

Utilizing the Hospice Team

The attending physician is the patient's primary medical doctor, provides medical services throughout the course of the illness, and is an integral part of the hospice team.

"Many services are available that help the patient. Hospice is an excellent support to the physician who no longer has to try to coordinate all the cares of the dying patient."

*-Liz Osborne, M.D.
Family Practice*

How to Refer to Hospice

An initial referral to hospice always begins with an honest discussion with the patient about care and treatment options.

Once this has occurred, a hospice program will ask for the following information regarding the patient:

- admitting diagnosis and prognosis
- current medical findings
- orders for medications and treatments
- patient and family understanding of disease and prognosis
- relevant patient and family information
- history and physical
- order for hospice care

"Hospice is an invaluable resource because a team approach allows for broader patient cares both physical and emotional. Communication is an important part of the team."

*-John Scanlon, M.D.
Internal Medicine*

Ongoing Care

Once the patient is enrolled in a hospice program, the attending physician will be a primary resource on the patient's medical condition and needs. The hospice nurse will be in regular contact regarding symptom management, changes in the patient's condition, and need for clinic or home visit follow-up.

The physician is responsible for:

- signing the initial certification of terminal illness
- reviewing the hospice plan of care for the patient
- ongoing clinic visits with the patient
- prescribing medication for comfort care
- reviewing with hospice staff the patient's condition and prognosis
- making telephone contact and house calls to the patient as necessary
- signing the death certificate
- home visits when necessary

Extending Care Through the Hospice Team

Because the care needs of a dying patient encompass more than medical treatment of a disease, the hospice team can be a valuable resource in dealing with complex issues and extending the physician's care.

"Most physicians would say hospice care is worth the investment," said Michael Levy, M.D., Ph.D., director of the supportive oncology program at the Fox Chase Cancer Center in Philadelphia. "[In many cases] the doctor doesn't get calls [or] go to the ER in the middle of the night because hospice takes the calls and the hospice nurse goes out to the home."

"The hospice team is skilled at patient and family education," Dr. Levy continues, "so medicines are taken properly and side effects can be anticipated and treated."

The team approach to hospice care can ultimately alleviate much of the stress traditionally associated with care of the dying patients. According to Ira Byock, M.D., Hospice Medical Director and Chair of the Ethics Committee of the Academy of Hospice Physicians, "Care of the dying stops being a stressor and starts being a source of professional satisfaction" (Skelly, 1994).

Hospice Interdisciplinary Team

Attending Physician Patients designate an attending physician to manage their care.

Hospice Medical Director The Medical Director oversees the treatment by the hospice team and coordinates with the Attending Physician.

Hospice Nurse Hospice Nurses coordinate the individualized care plan and provide specialized palliative care services.

Social Worker Hospice Social Workers offer emotional support, counseling and community resource support services.

Spiritual Care The Hospice Spiritual Care Coordinator assists in identifying spiritual concerns and the connection with a community of faith.

Home Health Aide Hospice Home Health Aides assist with personal care and light housekeeping services.

Other Therapists Physical, occupational and speech therapists provide palliative care according to the individualized care plan.

Bereavement Coordinator Hospice Home Health Bereavement Care supports the person and family throughout the dying process and offers follow-up grief education and support .

Volunteer Trained Volunteers provide a variety of services, including companionship and respite care.

Where Hospice Care is Provided

Hospice care is available to patients in a variety of settings. While home is the most common and the preferred place for many patients, it is not always possible or even desirable for all hospice patients. Individual patient needs determine the location for delivery of hospice care. Patients can receive the services of the hospice team at home, in the hospital, or in a long-term care or other residential facility.

Nine out of ten Americans said they would prefer to be cared for and die at home.

Hospice Care in the Home

Hospice patients in the home receive regular visits from the interdisciplinary team. In addition, hospice nurses will triage phone calls 24 hours a day from patients and families, communicating with the physician as necessary. Pain, nausea, vomiting and bowel management are special areas of expertise. Hospice nurses can handle many of these issues, using standing orders from the physician. Patients at home can continue to make clinic visits or may receive visits from the physician in the home.

Most hospice patients at home are cared for by family caregivers, but more and more hospice programs are able to offer care to those patients who choose to live alone. In such cases, the hospice team assists in making special arrangements. Check with the hospice to see if this option is available.

Hospice Care in the Inpatient Setting

An acute care setting is sometimes necessary for the management of symptoms related to the terminal disease. General inpatient care is available in acute care facilities which contract with the hospice program. These facilities have made arrangements for such things as direct admission of the hospice patient to the unit and waiving of routine tests which may not be appropriate. In addition, the inpatient staff has been oriented to the special needs of the dying patient and grieving family.

The hospice nurse remains case manager for the patient throughout the inpatient stay and communicates with the physician about the patient's care. Other hospice team members make visits to the patient to ensure continuity of care.

Respite care in an inpatient setting is also available for brief periods of time when family members are in need of a rest from caregiving duties. Respite care is covered under the Hospice Medicare Benefit.

Residential Hospices

Home-like, residential facilities exclusively for hospice patients and their families are available in some areas. The hospice team remains in charge of patient care and visits frequently. Payment for residential room and board is made privately. The Medicare Hospice Benefit provides coverage for services related to the terminal illness except room and board.

Hospice in Long Term Care Facilities

Palliative care and hospice services are available for individuals living in long term care facilities. Collaborative agreements between hospice programs and long term care facilities make it possible for residents, family and staff to benefit from a unique multi-disciplinary approach to care delivery. The patient and family focus of care provides for innovative delivery of care interventions. Interventions such as pain and symptom management lead to patient acceptance of the dying process, greater patient and family satisfaction of care and improved quality of life.

The coordination of an individualized plan of care determined by the patient and family, hospice team, long term care staff and attending physician utilize the skills of nursing, social services, spiritual care, volunteers and bereavement specialists. Benefit of these services foster a relationship of trust and quality care.

Surviving family members and long term care staff receive support through hospice bereavement services for a period of time after the individual's death. This support leads to healthier expressions of grief and loss and stress management.

How Hospice Care is Paid

Hospice programs work closely with patients and families to identify reimbursement options. Care is provided regardless of the patient's ability to pay.

The Medicare Hospice Benefit

Hospice care provided by Medicare certified hospice programs is covered by the Medicare Hospice Benefit (Part A). Physician services can continue to be billed through Medicare Part B.

Medicare beneficiaries who choose hospice care receive non-curative medical and support services for their terminal illness. Home care may be provided along with necessary inpatient care and a variety of services not otherwise covered by Medicare.

Eligibility For Use

Medicare coverage for hospice care is available only if

- the patient is eligible for Medicare Part A;
- the patient's physician and the hospice Medical Director certify that the patient is terminally ill with a life expectancy of six months or less;
- the patient signs a statement choosing hospice care instead of standard Medicare benefits for the terminal illness; and
- the patient receives care from a Medicare-certified hospice program.

Length of Benefit

When a Medicare beneficiary elects to receive hospice care they are entitled to receive a maximum of two 90-day benefit periods, followed by a 60-day period, and when necessary, an extended period of indefinite duration. The benefit period may be used consecutively or at intervals. The patient must be certified as terminally ill at the beginning of each period.

Services Not Covered

All services required for the management of the terminal illness must be provided by or through the hospice. When a Medicare beneficiary chooses hospice care, Medicare will not pay for:

- active treatment of the terminal illness that is not for symptom management and pain control
- care provided by another hospice that was not arranged by the patient's hospice
- care from another provider that duplicates care the hospice is required to furnish

Availability of other Medicare Benefits

When a Medicare beneficiary chooses hospice care, he or she gives up the right to standard Medicare benefits for the management of the terminal illness. A patient can use all appropriate Medicare Part A and B benefits for the treatment of health problems unrelated to the terminal illness (U.S. Department of Health & Human Services Health Care Financing Administration, 1995).

Reimbursement for Physicians under Medicare

The attending physician is the physician designated by the patient to have the most significant role in his or her care. The attending physician continues to bill Medicare Part B for professional services home, inpatient, or nursing home visits in the usual manner, independent of the Hospice benefit. Medications, laboratory tests, and other non-physician services required for the management of the terminal illness are paid for by the hospice program through the hospice benefit.

Attending physicians can bill for care plan oversight for hospice patients. Payment is available for one physician per month for oversight supervision involving 30 or more minutes of the physician's time per month.

Payment under CPT code 99375 encompasses significantly complex medical management requiring the integration of new information into the plan of care or adjustments in medical therapy furnished by the physician. It identifies the coordination of care among practitioners as care plan oversight services. This excludes telephone calls to patients and family members (Federal Register, 1994).

Care plan oversight includes the following physician activities:

- development/revision of care plans
- review of subsequent reports of patient status and related laboratory studies
- coordination and communication (including the telephone calls) with other health care professionals involved in the patient's care (excluding telephone calls to patients and family members)
- adjustment and integration of medical treatments.

Other Payer Sources

Hospice Medicaid/Minnesotacare Benefit

The Medical Assistance and MinnesotaCare Hospice Benefit follows the Medicare Hospice Benefit.

Private Insurance Coverage

The majority of commercial insurance providers cover hospice care either through a specific hospice benefit or through a home care benefit. Several providers have recently developed or are developing hospice benefits that reimburse on a per diem basis (like Medicare). When there is not a specific hospice benefit, insurance companies often reimburse through a home health care benefit. Patients should be encouraged to contact their insurance carrier about coverage for hospice.

Non-Medicare-Certified Hospice Programs

Services from hospices that are not Medicare certified can be billed under regular Medicare Part A. Many of the hospice services are provided free of charge, and the patient can access grants to cover billable services.

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For More Information

FOR ADDITIONAL INFORMATION OR A REFERRAL

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National Hospice and Palliative Care Organization (NHPCO)
(800) 658-8898
www.nhpco.org

FOR INFORMATION ON MEDICARE & LICENSURE

Minnesota Department of Health
Facility & Provider Compliance Division
(651) 215-8701
[MDH website](#)

Medicare
800-MEDICARE
(800) 633-4273
[Medicare website](#)

TO FILE A COMPLAINT ABOUT A HOSPICE AGENCY

Home Care Ombudsman
(651) 431-2555
(800) 657-3591

Office of Health Facility Complaints
(651) 201-4201
(800) 369-7994

FOR MEDICARE & MEDICAID BILLING QUESTIONS

Regional Home Health Intermediary (Medicare)
(800) 531-9695

Minnesota Department of Health (Medicaid)
(651) 296-6117

FOR GENERAL HEALTH CARE INFORMATION

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