



Hospice Care...A Special Kind of Care

The Definition of Hospice Care

What is hospice care? It is a special kind of care that can be provided when families learn that their loved one has been diagnosed with a terminal illness. Hospice care is considered to be the model for quality, compassionate care. The family experiences a myriad of emotions: some of those are fear, distress, and/or a feeling of helplessness. Today, too many Americans die alone and in pain. Many have learned that they need not be alone during this trying time. They seek the compassionate, supporting services available through hospice programs, allowing their loved one to spend their last days at home. The person can remain alert and pain-free with the people they love in his or her own home. The focus of hospice care lies in the belief that each of us has the right to die pain-free and with dignity.

The care provided in hospice involves a team-oriented approach, provided by a “team” of professionals. This team consists of physicians, social workers, chaplains or clergy members, nurses, pharmacists, volunteers, bereavement counselors, hospice aides, and other healthcare professionals as needed. Expert medical care can thus be provided to the patient as well as the family while under the care of hospice.

Hospice care is defined as a compassionate, specialized method of care for the truly ill persons. It is defined this way because this care encompasses not just the physical, but also the emotional and spiritual preparation needed before death. It focuses equally on the patient and family in the delivery of care and support. Hospice care provides a family with bereavement support during and after the dying process. Hospice care shifts the focus of medical attention and nursing care from curative treatment to palliation and supportive care. It provides central case management and continuity across both the home and inpatient care settings. Services are available to the patient on a 24-hour, seven-day a week basis.

The benefits and services provided by the hospice team are: managing the patient's pain and symptoms, assisting the patient with the emotional and psychosocial aspects of dying, providing needed drugs, medical supplies and equipment. Hospice providers pay for any medications or supplies that are related to the terminal diagnosis. Hospice team members also coach the family in how to care for the patient. Spiritual care, as well, is offered, either with the

patient's current clergy or with our Spiritual Coordinator if the patient chooses. Special services like speech and physical therapy are available when needed. Short-term inpatient care is available when pain or symptoms become too difficult to manage at home or the caregiver needs respite time. Bereavement care and counseling services are available to surviving family and friends.

Bereavement care is a unique service that deals specifically with the care and support of those that have been affected by the loss of a loved one. At Community Hospice Care, bereavement services are offered to the families, relatives, and friends of the patient, as well as being offered to the community. Community Hospice Care is committed to making bereavement services available directly or through collaboration with other community agencies. Resources available include various support groups, one-on-one consultation, newsletters, books, videos, and more. Community Hospice Care hosts a bereavement camp each summer for the community to help young children cope with loss and begin the healing process. Holiday workshops, teen workshops, and information on infant or child loss, suicide, and pet loss are also available. While life is a series of changes, each individual's way of coping with change, including death, is unique. When people come together to express their feelings, to listen to others, and to encourage one another, wonderful changes can take place.

Hospice aides and volunteers are available to assist in activities of daily living, such as bathing, feeding, and housekeeping, running errands, or just "being there" with the patient. Respite time is also provided by hospice aides and volunteers, which is the "caregiver relief time". It allows the caregiver time to sleep, run errands, attend support groups, or just have time away from the responsibilities of caregiving. Aides and volunteers are specially trained in hospice care and are integral members of the "hospice team". They are prepared to serve the dying and also bound by an oath of confidentiality, but more importantly, they are selected for their warm and generous spirit. As a member of the team, each person is able to care for the unique physical or emotional needs of the terminally ill and their caregivers.

How to Obtain Hospice Care

All persons, regardless of their age, diagnosis, or financial need, are eligible for hospice care if they meet the hospice criteria. It is the belief of hospice that, through appropriate care, all persons and their families may be able to attain a degree of mental and spiritual preparation for death that is satisfactory to them.

The first, major criteria for hospice services, includes that a patient must have a terminal diagnosis with a limited life expectancy of six months or less if the disease runs its normal course. Some of the types of diagnoses that are acceptable for hospice care are cancer, congestive heart failure, HIV or AIDS, failure to thrive, and Alzheimer's disease or dementia. It is a common misconception that only cancer patients need hospice care. In fact, cancer patients

are only approximately half of the population served. A second criterion is that the patient must have a primary caregiver at home or live in an assisted living or skilled nursing facility. Also, the patient can no longer be seeking any aggressive treatments or cures, have a certifying physician, and live in the geographical area the hospice serves.

Care may be provided where ever the patient calls home. Some hospitals or other facilities may have dedicated in-patient hospice units that the person stays in until death, or the person may already be in an assisted living or skilled nursing facility before receiving the diagnosis of a terminal illness. A resident of a nursing facility is not eligible for hospice care if they are under “skilled care”. Skilled care, defined by The Centers for Medicare and Medicaid Services, is health care given such as skilled nursing or rehabilitation. The facility staff manages, observes, and evaluates the care given such as intravenous injections and physical therapy. Generally, skilled care is available only for a short time after a hospitalization.

How to Select a Hospice Provider

Many patients and families do not realize there is a choice when it comes to hospice care. While Community Hospice Care was the first hospice to be established in Seneca County, there are now several hospices that serve this geographical area. Hospices may be for-profit or not-for-profit. Hospices may be linked with another facility or be free-standing. Hospices may be just starting up, or may have several years of experience at providing quality care. Community Hospice Care of Seneca County is a freestanding, not-for-profit hospice, founded in 1983 by Mrs. Anita Gaydos, RN.

There may be several hospice agencies to choose from in any area. It is important to find out about the services that each hospice offers and ask questions. Some questions that may be asked are:

- Is the hospice provider Medicare/Medicaid certified and licensed by the state?
- Do the hospice staff members respond quickly to calls for assistance?
- Will families ever receive a bill for hospice services?
- Does the hospice provider make an effort to meet the needs of each individual patient/family by creating individual care plans?
- Is the hospice provider “For Profit” or “Not for Profit”?
- Are services from volunteers available?
- How many volunteers does the agency have?
- Can the patient’s family physician follow the patient’s care while in hospice or will the patient’s care be turned over to the hospice provider’s medical director?
- What type of bereavement follow-up programs and services are available?
- Can the patient still use his or her own pharmacy or Durable Medical Equipment (DME) company?

- Will the patient be able to go to a nursing facility if he or she is unable to be cared for at home?
- Is the hospice accredited by The Joint Commission (JCAHO) or The Community Health Accreditation Program (CHAP)?

Before or after answering these questions, families may wonder when it is the right time to begin hospice care. Anyone can inquire about hospice services by phoning, emailing, faxing, or stopping in to the hospice provider. The hospice staff may then contact the patient's physician to determine if a referral to hospice is appropriate, and obtain an order to assess and evaluate the person for hospice care. The person's physician may also make the referral to hospice after speaking about the prognosis and further treatment of his or her illness. Referrals also come from discharge planners, social workers, nurses, clergy, other agencies, family and friends, or from the patients themselves. Hospice services may begin as soon as the day of referral.

When assessing the person for hospice care, the hospice care team must evaluate the terminal diagnosis. The person's disease progression for the terminal diagnosis is typically evaluated by using a scale such as the Karnofsky Scale or the ECOG Performance Status. These types of scales allow the team to assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. They are included here as follows:

The Karnofsky Scale

The Karnofsky scale (sometimes called the Karnofsky index) was devised by two American doctors in the 1940s (David Karnofsky and Joseph Burchenal) as an attempt to try and measure the more 'subjective' side of the outcome of cancer treatment. In fact, the scale relates purely to physical ability and covers 11 points, from normal health to death, each scored as a percentage. The scale is:

Karnofsky Scale	
Physical Ability	Percent
Normal health	100%
Minor symptoms	90%
Normal activity with some effort	80%
Unable to carry on normal activity but able to care for oneself	70%
Requires occasional help with personal needs	60%
Disabled	50%
Requires considerable assistance and medical care	40%
Severely disabled, in hospital	30%
Very sick, active support needed	20%
Moribund	10%
Death	0%

The ECOG Performance Status

The Eastern Cooperative Oncology Group (ECOG) was established in 1955 as one of the first cooperative groups launched to perform multi-center cancer clinical trials. The ECOG Performance Status, like the Karnofsky Scale, also measures the physical status of a patient by representation of the level of activity.

ECOG PERFORMANCE STATUS	
Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair
5	Dead

Barriers to Hospice Care

There are barriers to accessing hospice care. Some of those might be: the six-month prognosis requirement, a lack of professional understanding, the increased use of aggressive treatments, the rise of experimental treatments, the chilling effect of recent federal scrutiny, the patients or families own fears, and the denial of reality.

The six-month prognosis requirement to receive hospice care is currently interpreted under Medicare guidelines. Unfortunately, the interpretation often results in the patient being referred to hospice just a few days prior to the death. This is not enough time for the patient and family to fully benefit from the entire range of medical, psychological and spiritual services offered by hospice.

Late referrals are often directly related to the physician's knowledge, behavior and practice related to the end-of-life care. While hospice referrals from physicians vary, many times when the referrals come, it is very late in the dying process. Many physicians do not discuss hospice options until late in the disease course, when patients and their families are no

longer able to benefit from hospice services. Although physicians cite the patient, families and hospice structure factors as barriers, there are some things that the physician can control. Some physicians are uncomfortable discussing the terminal nature of a patient's diagnosis. Some also fear they will lose contact with their patients, believing the hospice provider's medical director will take over all care of their patient. While this may be the case with some hospices, this is again a valid reason and point to make when searching for a hospice provider. At Community Hospice Care, the physician always has the option of following his or her own patient, participating in the plan of care, and signing the death certificate at the time of death.

There is also an increased use of aggressive treatments aimed at curing disease. An increased number of physicians and patients are opting for aggressive, but ultimately futile, and expensive care, thus delaying the referral to hospice care. The physician, as well as the patients and families, may feel that end-of-life care is "giving up". Physicians are trained to cure their patients. Sometimes, however, this training in "curing" can be detrimental to the hospice philosophy of "caring".

The chilling effect of recent federal scrutiny of legitimate hospice admissions has had an adverse effect on hospice referrals. Part of this rise in federal scrutiny can be attributed to the rise in hospice providers. While the type of care that hospice provides has been around for centuries, there has been a steady rise in the number of hospice providers across the United States and other nations. With the sharp increase in this type of healthcare provider, the federal government naturally questions why this increase is happening. Again, this can be an important point to question when selecting a hospice provider, such as, how long has this provider been in service? This is also when it can be asked, what types of certification does this hospice provider hold? In referring to hospice, physicians fear having their medical opinions second-guessed by federal government.

Patients and families have their own fears regarding hospice. A person may feel that he or she is "giving up" or that control over medical decisions will be lost. The negative connotation of the words "terminal illness" can bring pictures of pain, a long and miserable dying process, and unresolved emotions. Woody Allen was quoted as saying "I don't mind dying. I just don't want to be there when it happens." The education given to families during hospice care concerning end-of-life choices can be invaluable. The hospice approach of offering dignity and quality of life while providing compassionate care can assist in fulfilling the person's end-of-life wishes. While the person or family may still be afraid, it can help to achieve a sense of control and peace concerning death.

Those that do choose hospice care and are referred to a hospice provider may still have unresolved issues due to the barriers present. Family and friends of the bereaved may voice concern that the patient did not have hospice care long enough. One study, published in the *Journal for Pain* in 2007, reflects how many persons are referred "too late" to hospice care. Surveys given to bereaved family members of persons in hospice care were reviewed. Of the surveys obtained, 11.4% of family members believed that they were referred "too late" to

hospice. Although the bereaved family members believed the end-of-life care provided was helpful, the perception of being referred “too late” was associated with more unmet needs, higher reported concerns, and lower satisfaction. The study results suggested that family members' perception of the timing of hospice referral—not the length of stay—is associated with the quality of hospice care. If the family member believed the referral was too late, the family was less satisfied with hospice care, regardless if the patient was referred 2 days before death or 2 months. Unfortunately, again, it can be observed that the person and family members are not able to fully benefit from the entire range of hospice services with the present “stumbling blocks”.

Funding Sources for Hospice

There are many funding sources for hospice care. The creation of the Medicare/Medicaid hospice benefit has made reimbursement for hospice care possible for a broader range of the special services this end-of-life care provides. This permits the terminally ill person to die in the comfortable surroundings of his or her own home. Passport waiver patients may also be dually eligible for hospice care. The Medicare/Medicaid hospice benefit is elected for two periods of 90 days, another one for 60 days and a fourth unlimited period. The patient may choose to revoke the benefit in writing, therefore forfeiting hospice coverage for the remaining days of any election. The patient may re-elect the Medicare/Medicaid hospice benefit for any subsequent period. The patient may elect a different hospice provider without losing any benefit days. The patient may also revoke the benefit in order to pursue care options not offered under the Medicare/Medicaid hospice benefit, such as curative treatments. Medicare/Medicaid pays the hospice directly at specified rates depending on the type of care given each day. The daily payment is made regardless of the amount of services provided on a given day, and even on days where no services are provided. The daily payment rates are intended to cover costs that hospices incur in furnishing services identified in patients' care plans. Payments are made according to a fee schedule that has four base payment amounts for the four different categories of care:

- **Routine home care:** Routine home care is provided where a person resides. This might be a home, a skilled nursing facility, or an assisted living facility. It is the level of care provided when the person is not in crisis. Care provided is dictated by the hospice plan of care, which is developed by the hospice team in partnership with the beneficiary's attending physician. It will include, but is not limited to, scheduled visits from nurses, hospice aides, and social workers, payment for palliative medications related to the terminal illness, and coverage of durable medical equipment, such as hospital beds and wheelchairs. It also includes 24 hour access to “on-call” hospice registered nurses. It does not include room and board while a beneficiary resides in a skilled nursing facility. While on routine home care, sometimes beneficiaries may be charged a five percent coinsurance for each drug furnished, but the coinsurance may not exceed five dollars per medication. Community Hospice Care does not charge this type of fee, as patients and families are never billed for services.

- Continuous home care: Occurs where a person resides when there is a medical crisis. During such periods, the hospice team can provide up to around-the-clock care. During continuous home care, hospices bill Medicare per hour rather than per day. Coinsurance responsibility for the beneficiary is the same as routine home care.
- General inpatient care: Occurs in an inpatient facility that is contracted with or provided by the hospice agency. If care cannot be managed where the patient resides, the patient will be moved to an inpatient facility until the patient's condition is stabilized. This level of care does include coverage of room and board. Beneficiary is not responsible for any coinsurance while he or she is at a general inpatient level of care.
- Inpatient respite care: Is provided in an inpatient facility that is contracted with or provided by the hospice agency. Because it is acknowledged that caring for a dying person can be difficult, this level of care is available to give the caregiver a rest. It is available for periods of up to five consecutive days. This level of care does include room and board costs. Hospices, however, may charge beneficiaries five percent of Medicare's respite care per diem, which, again, is not charged by Community Hospice Care. Community Hospice Care also contracts with several long-term care and assisted living facilities, as well as all area hospitals to provide this level of care.

Hospice providers also accept private insurance. Again, it is important to remember that providers are all different in the amounts they may or may not charge for hospice services. Community Hospice Care does not bill patients or families for the care provided. Community Hospice Care conducts many fund-raising activities to help supplement the Medicare/Medicaid benefit. Donations, memorial contributions, and United Way funding are all additional methods of payment. Fundraising activities of Community Hospice Care include the annual Baumann Car Charity Raffle, The Hospice Waddle, The Festival of Trees, Add-A-Bow, and the Cash Bonanza booklet.

Community Hospice Care also has several grants available for patients and families to use for additional services or other costs that may be incurred outside of hospice services. Possible grants that may be obtained include payment for a lifeline (including the installation and monthly fee), housekeeping, Life Review, provision of remembrance bears to children, caregiver stipend, massage therapy, and payment for other medications not covered under the hospice benefit.

No one is denied hospice care due to the inability to pay at Community Hospice Care. Our philosophy is "that the patient matters to the last moment of their life and as a hospice will do all we can, not only to help them die peacefully, but to live their life until they die".

References

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The Centers for Medicare and Medicaid Services: <http://cms.gov>

The National Cancer Institute Website:
<http://training.seer.cancer.gov/followup/procedures/dataset/karnofsky.html>

