The principles of care set forth in a hospice setting are applicable in any setting in which sensitive caregivers are found.

MUCH can be learned from nurses in hospices that can help older persons and their families experience death in a more comfortable and satisfying way. This article will relate the principles of a program of care designed by the Hospice of Cincinnati to better meet the needs of dying persons and their families.

The Hospice of Cincinnati began in 1979 as a home health agency caring exclusively for terminally ill clients. Seventy percent of the clients of the hospice are 65 years of age or older. Care, therefore, is directed toward the needs of older adults. Hospices are a part of the continuum of health care, rather than an alternative to traditional care. Hospice care is usually chosen as the preferred mode of care when the patient and family judge that the burdens of aggressive treatment are greater than the benefits that can be expected from it. The objective of care then changes from cure to comfort and satisfying death. Treatment is directed toward controlling pain, relieving other symptoms, and focusing on the special needs of the hospice patient and the patient’s family. This care is being delivered with increasing frequency in the home. Nursing homes are also a common place for death of an older person. The principles of care set forth are applicable in any setting in which sensitive caregivers are found.

Care of the dying in any setting is best carried out by a multidisciplinary care team including a nurse, physician, social worker, and pastoral or other counselor. Home health aides and volunteers are also important considerations in the home.

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THE DEATH EXPERIENCE

For purposes of discussion, death will be divided into three distinct periods: the time of realization of terminal status, the time of imminent death, and the time following death. During each of these periods, the designated client and family members have distinct needs. Family is defined in an expansive sense to include any relative or individual who has significant personal ties to the individual.

At the time of realization of terminal status, the situation for patient and family is frequently chaotic; emotions are high, family members are exhausted, and symptoms are out of control. In both hospice and non-hospice settings, the nurse caring for a terminally ill person assesses family members as well as the client on the first visit, because family support is the key to an enriching death.

In the home setting, if family members appear exhausted or if such a possibility seems likely in the future, relief is offered through home health aides and volunteer services. Home health aide services focus on personal care, grooming, and home management support. The latter includes meal preparation, feeding, and light housework, such as dishwashing and laundry. Volunteers assist through companionship, help with light care needs, errands, shopping, letter writing, and reading.

Acquiring basic equipment needed, such as a hospital bed, bedside commode, or wheelchair, makes caring for the patient at home safer and easier for the family. Finally, reliable communication between the family and the health-care network is necessary on a 24-hour basis.

CONTROL OF PAIN

When care replaces cure, the nurse focuses on client symptoms and family support. Initial work with the client includes pain control, an interdisciplinary care plan, and equipment needs. A pain crisis is the first matter to be handled. Hospice of Cincinnati’s protocol for pain management consists of standing physician orders, level of consciousness assessment, and a pain diary. The physician’s orders may read as follows:

- Motrin (ibuprofen) 400 mg orally every 6 hours, ATC or as needed.
- Tylenol 3 (acetaminophen) one or two tablets every 4 hours as needed or ATC.
- Morphine sulfate 5 to 20 mg orally, suppositories, or intramuscularly every 4 hours as needed or ATC.
- Roxanol (morphine sulfate) if the patient unable to take pills.

- MS Contin (morphine sulfate) 30 mg tablets orally every 8 or 12 hours.

Compazine (prochlorperazine) is ordered for nausea and Ativan (lorazepam) is prescribed for anxiety or agitation. Orders for an infusion pump and supplemental bolus dosages are also requested for continuous IV pain therapy when orally and rectally administered medication for pain has been ineffective.

Level of Consciousness

The level of consciousness assessment is an important aspect of pain control. The objective is to prevent breakthrough pain while maintaining an acceptable level of consciousness. The following information on level of consciousness and the appropriate action was adapted by Hall and colleagues of Hospice of Cincinnati.

In Level I, the client is fully alert and all responses are appropriate. Analgesics, hypnotics, and sedatives are effective and no change in medication is made.

In Level II, the older person is essentially alert but may have periods of confusion and may sleep longer. The person is easily aroused and is able to maintain alertness. The dosage of analgesics, hypnotics, and sedatives is kept the same.

In Level III, the client is able to focus on incoming stimulation but is unable to maintain that focus, appearing lethargic or sedated. At this level of consciousness, all analgesics, hypnotics, or sedatives should be reduced by 50%. If breakthrough pain occurs in the hours following the reduction and the level of consciousness has increased, 75% of the intoxicating dose is given at the next scheduled medication time.

At Level IV, the older person responds only to maximum stimulation, such as vigorous shaking of the shoulder or loud calling by name. Verbal response may be a grunt or groan but no intelligible sentences. The physician is notified of the decreased level of consciousness. If breakthrough pain occurs and the LOC has increased, 50% of the intoxicating dose of medication is given at the appropriate time.

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In Level V, the client is in a coma and is unable to respond at all. All analgesics, hypnotics, or sedatives are held and the physician is notified. Levels of consciousness and pain behavior should be documented hourly. Medications used for seizure or nausea control are usually not changed unless ordered by the physician.

PHYSICAL AND PSYCHOSOCIAL ASSESSMENT

The nurse also completes a physical assessment of the patient and the findings are incorporated into an interdisciplinary care plan. The eight problems or needs most frequently encountered are self-care deficit; impairment of skin integrity; alteration in nutrition; knowledge deficit (particularly of medication); alterations in elimination; alterations in comfort; alterations in family processes; and spiritual distress.

It is helpful for a social worker to conduct a psychosocial assessment following the initial visit of the nurse. The most frequent challenges of the social worker are assessing patient and family emotional needs, addressing grief and loss issues, and working with everyday problems, such as financial concerns and disagreement among family members regarding care issues. The social worker, in addition, helps family members prepare for the death by imaging how they will feel if they walk into the room and the person has died. Experience has shown that the client is often more at peace with the dying process than family members are. The social worker attempts to bring the client and family together in respect to the dying process.

The care plan is reviewed periodically by the multidisciplinary team and changed as the needs of the older person and the family change. In intervening weeks, the focus shifts to prepare the family for the final stage of the dying process. Families are taught that the body will go through a physical shutting-down process, while business that is emotionally, spiritually, and mentally unfinished may need to be completed, relationships reconciled, and a general process of letting go finished. Families are taught appropriate responses to nine physical signs and symptoms: coolness, sleeping, disorientation, incontinence, congestion, restlessness, fluid and food reduction, urine reduction, and breathing pattern change. The Hospice of Cincinnati has prepared the following instructions for family members/caregivers in each of these areas.

Coolness is a normal response to the dying process. Families are informed that color and temperature of hands, arms, feet, and legs may change. The cool temperature is a normal sign indicating that circulation to extremities is decreasing to increase circulation to the vital organs. If the person feels cold, it is helpful to do such things as place socks on the feet. Electric blankets are not recommended.

Sleeping may escalate and the person may be increasingly uncommunicative, withdrawn, or unresponsive due partly to changes in metabolism. Families are instructed to spend time with the clients, to hold hands, to speak normally even if there is a lack of response, and not to say anything in their presence that the family does not want the client to hear.

Disorientation may also occur as metabolism changes, leading to confusion of person, place, and time. Family members are instructed to identify themselves by name before they speak and to speak softly, clearly, and truthfully. It is especially important to maintain a trusting relationship. Incontinence of urine and bowels may occur as consciousness decreases and muscles relax. It is important to instruct the family in ways to keep the client clean and comfortable and to protect the bed.

Congestion due to poor circulation of body fluids, immobility, and an inability to expel secretions may result in gurgling, bubbling, or rattling sounds from the chest. Although congestion may be distressing for family members to listen to, the older person often seems unaware of it. The family is taught that elevating the person's head and gently turning the head to the side assists gravity in draining the secretions.

Restlessness or repetitive motions may be present due to a decrease in oxygen to the brain and the change in metabolism. Families are discouraged from restraining these motions. Instead, they are encouraged to be calm in speech and action, reduce bright lights, gently rub the back, stroke the arms, read aloud, or play soothing music.

Food and fluid desire may decrease as the body conserves energy for other functions. Families are reminded that the emphasis is on comfort, not healing; therefore, the client should not be forced to eat or drink. Offering small chips of ice, soft drinks, juice, and ice pops may help to prevent discomfort from dehydration. Petroleum jelly can be applied to dry lips, and swabs can keep the lips moist. If the person is breathing through the mouth, the lips and mouth may need to be moistened every hour or two.

Urine output decreases as fluid intake decreases. Output also drops as circulation through the kidneys decreases. Changes in the breathing pattern occur frequently. It is important for family members to know that apnea (several seconds when there is no breathing) is not uncommon. Instructing the caregiver to elevate the head, hold hands, speak gently, and to be reassuring are actions that can be taken.

In addition to the nine physical signs of approaching death, seven emotional/spiritual/mental signs of approaching death have been identified. These include withdrawal, vision-like experiences, restlessness, decreased socialization, unusual communication, giving permission, and saying goodbye.

Withdrawal can occur as the client prepares for release, detaching, and letting go of relationships and surroundings. Although letting go may be difficult for loved ones, it represents a stage of increasing comfort for the older person who is dying. Families are encouraged to continue to communicate with the person who is dying in a normal manner using a normal tone of voice, identifying themselves by name, holding the person's hand, and saying whatever they want the person to hear.

Vision-like experiences may occur in which the client may claim to have spoken to persons who have died or to see things not visible to the caregiver. This is also seen as a preparation for
the transition. Families are encouraged not to contradict or argue about the reality that the client is experiencing. If clients seem frightened by the experience, they can be reassured that they are normal.

Restlessness may also have its origins in anger, fear, or unfinished business. Family members who are comfortable in discussing the dying process can listen to the client express fears, sadness, and anger associated with the dying process. When family members or the client are uncomfortable in discussing these issues, professional assistance may be needed. Family members may be helpful in recalling a favorite place or experience, reading, playing music, or giving assurance that it is all right for the client to go. Decreased socialization occurs as energy decreases and as the terminally ill person becomes involved in making the transition that must be made alone. Families are assured that decreased socialization is not a sign of rejection or lack of love, but it is rather a natural part of the dying process. Families are also told that the dying person may need the permission and support of the living to die in comfort.

Unusual communications such as out-of-character statements, gestures, or requests may be a sign of readiness that the person is ready to say goodbye but is testing to see if significant others are ready to go. Family members are supported in kissing, hugging, holding, crying, or saying whatever they need to say to the terminally ill person.

Giving permission is acknowledged as a difficult time. The Hospice of Cincinnati instructs families that, "A dying person may try to hold on, even if it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be all right. Therefore, your ability to release dying persons from this concern, and give them reassurance that it’s all right to let go whenever they are ready, is one of the greatest gifts you have to give them at this time."

Goodbyes are said when the person is ready to die and the family member is ready to say goodbye. The Hospice of Cincinnati instructs families that this is a way of achieving closure: "You may want to touch or hold them; do whatever is and has been a comfort to you both. The moment may include recounting favorite memories, places, and activities you shared. It may include saying, 'I'm sorry for... It may also include saying 'Thank you for... The dying person may wish to know that they have made a difference and that they will be remembered. Tears are a normal and natural part of saying goodbye. Tears need not be hidden and apologies are not necessary."

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**KEY POINTS**

1. Hospice care is usually chosen as the preferred mode of care when the patient and family judge that the burdens of aggressive treatment are greater than the benefits that can be expected.
2. Hospice treatment is directed at controlling pain, relieving other symptoms, and focusing on the special needs of the hospice patient and the patient’s family.
3. The objective of hospice care is to prevent breakthrough pain while maintaining an acceptable level of consciousness.
4. Family teaching in hospices is centered around appropriate responses to physical and emotional/spiritual/emotional signs and symptoms of approaching death.

The hospice maintains a formalized bereavement program. During the first month the social worker sends a pamphlet titled, "How Do You React When Someone You Love Dies?" The pamphlet describes the physical and emotional symptoms of loss and suggests several approaches to working through the grief process. Families also receive information in the mail inviting them to educational/support groups and to memorial services. Memorial services are held twice a year. Each person attending signs the name of the person they would like to have remembered during the service. The names are read aloud and candles are lit by family members in memory of the person. Family members and the chaplain read selected readings. Music is also an important part of the service.

Combination education/support groups for bereaved family members are scheduled twice a year in 1½-hour sessions for 8 weeks. The family often responds more positively to the idea of education than to support. A social worker leads the group. During sessions, family members are encouraged to tell their stories and they are asked to bring to the group a picture of the former hospice patient prior to their illness. Group members discuss issues such as personal grief reactions, stress

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management, coping with holidays, self-esteem, and safeguarding their own health. Hospice care continues for family members for 1 year after the death of the hospice patient. Families participate on a voluntary basis.

CONCLUSION
Hospice care is a coordinated, well-delineated service to meet the needs of persons who are about to die and their families. Dedication to this area of practice has revealed information that may be used by nurses in home care, acute care, and the community who work with dying older persons. Pain control for dying persons and support of the family during the dying process and the period following the death are two excellent areas of care developed by hospices. Hospice nurses are a resource for difficult problems faced by persons about to die and their families. The knowledge shared is excellent information for gerontological nurses to consider when caring for terminally ill clients and their families regardless of setting.