

Care at the Time of Death

How nurses can make the last hours of life a richer, more comfortable experience.

By Elizabeth Ford Pitorak, MSN, RN, CHPN

As health deteriorates and treatments fail, a gradual shift takes place near the end of a patient's life: the focus of care changes from cure to palliation. But no matter how gradual the shift may appear, it takes time for the patient and family to come to terms with it. The patient's death may be the first the family will have experienced or the first at which they will have chosen to be present. Even if not, this experience will be unlike any other. The founder of the first modern hospice, Dame Cicely Saunders, was quoted as having said, "How people die remains in the memories of those who live on."¹

As clinicians strive to be sensitive to these changes, they shouldn't presume to know what a dying patient and his family need; instead, they should ask directly. Often, it's the questions *not* asked of them that lead to families' incorrect assumptions about and torturous memories of a loved one's death. For example, if

a patient near death begins to moan, family members may look concerned but remain silent. A nurse might ask, "Are you worried that those sounds mean your mother is in pain?" and then explain why that's unlikely.

According to the nursing literature, it's important to patients and their families that nurses help prepare them for the process of dying.²⁻⁴ In a study of 12 deaths, bereaved family members spoke of nurses' actions and attributes that helped them the most.² The data were distilled into five categories that included "ways of being" (sitting with family members and talking to them), "ways of doing" (controlling the patient's pain, offering patients reassurance), and "ways of knowing" (being aware of "the transcendent"—that is, that which isn't readily explained scientifically, such as the fact that patients sometimes seem to choose when to die).

Tarzian interviewed 10 hospice nurses and two family members who had witnessed a loved one's severe dyspnea.³ The nurses spoke of the need to prepare patients and families for the dying process, including the possibility that the patient would gasp for breath in distress. They reported that patients

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Palliative Nursing



didn't spontaneously speak of the fear of dying by suffocation, but when asked what they feared most, almost all named it. Patients were visibly relieved to learn that medication would be available to alleviate severe dyspnea, should it occur. Tarzian concluded that such care must encompass "knowing what to do as well as how to remain present during suffering."

A CASE STUDY

Lydia Jessup, a 62-year-old retired administrator, has stage IV ovarian cancer. Married for 40 years, she and her husband have a daughter and two grandchildren. She was recently hospitalized with a total intestinal obstruction and is being treated with

▲ *At Night*, by Deidre Scherer, fabric and thread, 36" × 48", 2000; photo by Jeff Baird.

Through her local hospice, the artist was invited to draw a man who had decided to leave the hospital to die "his way" at home, surrounded by his family. "Nobody counts the days of his 'survival' anymore. He says how the nurses who knew him so well throughout his dialysis treatments must think he's dead by now. He wonders if they even wonder what's become of him."

For more on the artist and her work, go to www.dscherer.com.

nasogastric intubation to decompress the digestive system. She is receiving total parenteral nutrition (TPN). Other symptoms include ascites and pain in the lumbar area, for which she's receiving IV meperi-

dine (Demerol) via pump, a drug strongly contraindicated for chronic pain. She also developed edema of the extremities secondary to receiving TPN. Her physician says that the ascites resulted from the tumor's progression.

Ms. Jessup has been in control of her health care since the diagnosis four years ago. She and her husband sought information on various types of complementary therapies; she tried several, but none of them managed the disease. For the past four months, her symptoms have been poorly controlled, but she has refused home care. At the hospital where she received outpatient care, Ms. Jessup refused to discuss the possibility of home hospice care. Now her physician says she should consider it. Aggressive, curative treatment is failing. The focus of care is shifting toward palliation: providing the best possible symptom management, with the goal of comfort rather than cure. After several discussions with the palliative care team and her family, Ms. Jessup accepts the prognosis. The next day she's admitted to a hospice facility directly from the hospital.

Within days, Ms. Jessup begins to show signs of imminent death, or "active dying": peripheral edema, the inability to swallow, and emotional withdrawal. The hospice clinicians and the palliative care teams meet with her and her family to address physical, psychosocial, and spiritual issues and to review the signs and symptoms of imminent death. Together they must decide whether to continue or withdraw TPN, for example.

Individual family members have specific concerns. Ms. Jessup's daughter, for example, is hesitant to have her children visit their grandmother. The primary care nurse, the social worker, and the spiritual care coordinator (a professional on the hospice staff) address this, asking, "How close are the children to their grandmother?" and "Have you told them how seriously ill she is?" They also discuss the matter with Ms. Jessup and with the children themselves.

There is also discord between Ms. Jessup's husband and daughter regarding the role of religion in her care. Although religion is important to both of them and they are active in a local congregation, Ms. Jessup has never felt strongly about it and says she has found peace without it. Her husband has great difficulty accepting this, fearing for his wife's salvation, but her daughter believes that "God will understand."

THE DYING PROCESS

Nurses who care for dying patients and their families often field questions about the uncertainty of

impending death: "Should I ask my brother to come home?" "Should I take my family leave from work now?" and "Why is it taking Mom so long to die?" Although the exact time of death cannot be predicted, there are signs when it is near.

Active dying is the process of total body system failure. Each patient's death takes a different course (in terms of changes in blood pressure and in heart rate, for example), but the process usually occurs over a period of 10 to 14 days (although it can take as little as 24 hours).⁵ The term "final hours" refers to the last four to 48 hours of life. Total body system failure resulting in death is best explained by addressing each system separately.

Cardiovascular system. Usually, patients who are dying become dehydrated; swallowing becomes difficult, and blood volume therefore decreases. Initially, the heart rate increases, and it may even double in compensation, but as hypoxia develops, both heart rate and blood pressure decrease. The decrease in the volume of the Korotkoff sounds secondary to a change in pulse pressure is usually even more predictive of imminent death than is the blood pressure reading.⁶ Although there's no intervention for lowered blood pressure during active dying, families usually want to know about the patient's vital signs. If the family asks about blood pressure, the nurse might explain, "It's becoming more difficult to hear, and that's one of the signs indicating that your mother is closer to death."

As peripheral circulation decreases, the patient perspires, her skin feels clammy, and its appearance changes from being uniformly pale or ashen to mottled, with colors varying from the reds of rubor to the blues and purples of cyanosis. Mottling occurs late in the dying process and is a cardinal sign of imminent death. It usually occurs first on the soles of the feet and over bony prominences such as the knees. As the peripheral circulation continues to decrease, perfusion is compromised, and blood pools more in the sacrum and lower back, causing these areas to darken (if the patient is supine). The skin blanches when touched.

Simultaneously, the metabolic rate slows, reducing the amount of heat emanating from the body, while the core temperature remains normal (except when there is infection). The skin feels cold to the touch, possibly prompting caregivers to pile blankets on the patient. This, in my experience, seems to cause restlessness; most dying patients can't tolerate even the slightest weight on the feet or other extremities. Blankets and sheets should be left loose and untucked.

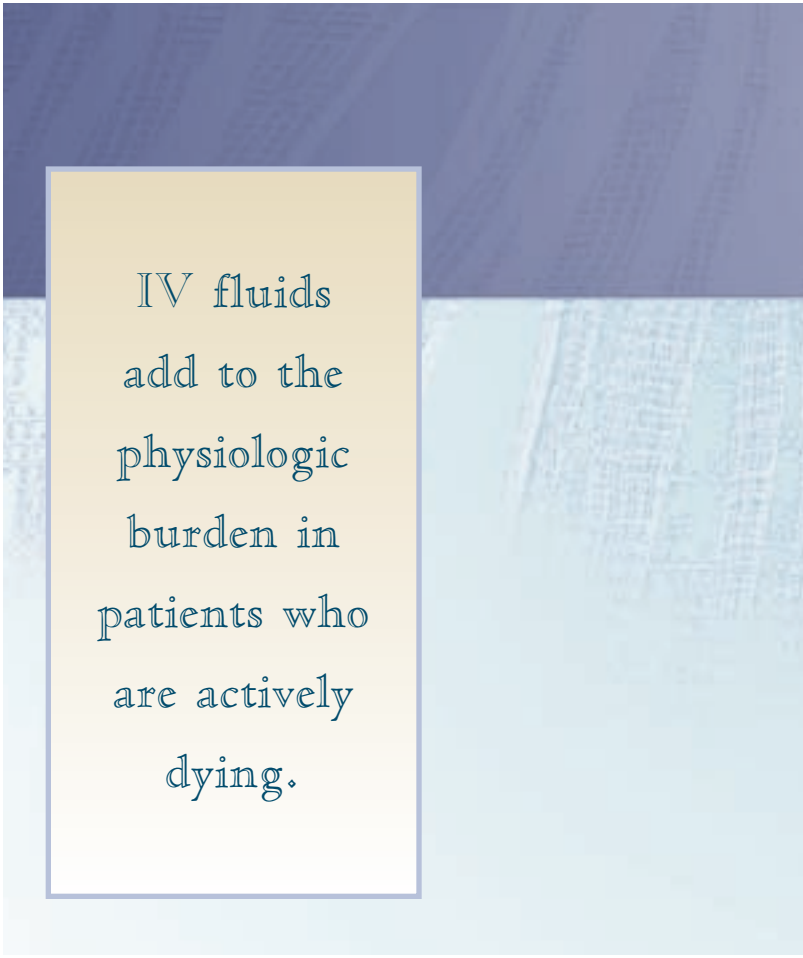
Respiratory system. Pulmonary congestion and hypoxia secondary to impaired cardiac function and lymphatic congestion are detected as diminished breath sounds, adventitious breath sounds, or both. (Dying patients often have decreased protein levels in the blood; this shifts the plasma's osmotic pressure, causing fluid to leak from the vasculature, and leads to lymphatic congestion.⁷) The incidence of dyspnea, which may be described as a subjective discomfort or distress in breathing, has been reported at 50% to 70% in actively dying patients;⁸ the most severe form is known as air hunger.

Careful assessment of air hunger will determine whether it is treatable. Patients may gasp for breath, bolt upright, and display a wild look of panic. If this happens, it's essential that the nurse respond calmly. During an acute episode of air hunger, morphine (or another opioid) is indicated. Because the classic air hunger that occurs during the dying process usually does not respond to oxygen, nurses should not routinely administer it. To some, the placebo effect may be helpful, but patients with air hunger are often so restless that the nasal cannula doesn't stay in place. Dyspnea can be alleviated by opening windows and using a fan to promote air movement, which stimulates trigeminal nerve receptors in the cheek and nasopharynx, which in turn relays information to the brainstem that inhibits the sensation of difficulty in breathing.^{1,9} Nurses should ensure that families leave enough space around the patient's bed for air to move freely.

Tachypnea may accompany dyspnea and should be treated with morphine (or another opioid) to maintain a respiratory rate of about 10 to 15 breaths per minute. Morphine alters the patient's perception of breathlessness and reduces anxiety, dilating the pulmonary vessels and thereby reducing oxygen consumption and decreasing pulmonary congestion. Symptom relief occurs before sedation, and sedation occurs before vital signs become depressed.¹⁰

Ordinarily, excess carbon dioxide in the blood stimulates respiration, but during the final 48 hours of life, as pulmonary congestion and poor gas exchange lead to a rise in carbon dioxide levels, the brain becomes less responsive to this signal. Breathing becomes irregular and periods of shallow breathing alternate with periods of apnea lasting five to 30 seconds; the full cycle lasts from 30 seconds to two minutes. Families should be made aware that this breathing pattern, called Cheyne–Stokes respiration, is another sign of imminent death.

Musculoskeletal system. As nutritional status declines (over a period that depends on the underly-



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ing disease), severe muscle weakness develops. The mouth droops, and difficulty in swallowing makes oral intake impossible. This sign of dying is usually one of the most distressing. In most cultures, food and drink are associated with health, love, and comfort, and they figure prominently in various traditions and rituals. Therefore, any discussion of the benefits and disadvantages of artificial nutrition and hydration should be undertaken with great sensitivity. Viewing them as treatments allows a more objective appraisal of their value in end-of-life care. The same standards used to judge other treatment decisions should be applied.

Difficult decisions about artificial hydration must often be made. For example, if a terminally ill patient exhibits agitated delirium or renal failure secondary to dehydration, artificial hydration is warranted.¹¹ Dehydration can be the underlying cause of delirium; in such a case, hydration may be appropriate. And in terminally ill patients, dehydration can cause renal failure. If the patient is taking opioids and has renal failure, opioid metabolites can accumulate, resulting in confusion, myoclonus, and seizures; opioids should be decreased and hydration may be appropriate.

Families often ask to feed the patient or to have fluids administered intravenously, but IV fluids add to the physiologic burden in patients who are actively dying, moving into the extracellular spaces (“third-spacing”) and causing signs and symptoms such as edema, nausea, and pain. If a tumor is present, such edema can increase pressure on surrounding organs and aggravate symptoms, particularly pain.¹² Families may be willing to consider withdrawal of food and fluids as a comfort measure. Despite lack of intake, patients who are actively dying aren’t usually hungry.¹³ Sullivan noted that the absence of hydration and nutrition may even induce an analgesic euphoria, as metabolic processes shift to adipose tissue, producing ketonemia.¹³ But providing even small amounts of carbohydrate interferes with ketone production and stimulates hunger. Therefore, continuing to supply intravenous glucose at even a slow infusion rate may inadvertently cause discomfort by preventing ketonemia.¹³ Good mouth care is vital, though, as many patients experience dry mouth. (For more on the benefits and drawbacks of artificial nutrition and hydration, see “Ethical Concerns in End-of-Life Care,” *AJN*, January.)

As death approaches, the muscles of the tongue and the tissues of the soft palate sag, the gag reflex and reflexive clearing of the oropharynx decline, and secretions accumulate in the oropharynx or bronchi or both. Air passing through these secretions can cause a loud gurgling sound—the “death rattle”—which can be quite distressing to families and clinicians. But in most cases, these secretions should not be suctioned: they’re hard to reach, and the procedure can cause unnecessary discomfort.^{9,14} The simple repositioning of the patient, turning him on his side, and elevating the head of the bed may interrupt the rattle. Also, anticholinergic and antispasmodic agents that decrease secretions (such as atropine, methscopolamine, and hyoscyamine [Levsin]) are often administered during the last hours of life.

Renal system. The decreased cardiac function results in reduced kidney function and decreased urine production. In the final hours of life, sphincters relax and incontinence can occur, but most patients don’t require catheterization at this stage. Good absorbent padding usually suffices. In some cases, however, catheterization eases the stress involved with unnecessary movement such as turning the patient in order to change linen.

Other signs and symptoms. The fear of dying in pain is one of the fears most commonly expressed in our society.¹⁵ Pain assessment should continue to be

performed frequently, even during the patient’s final hours, as opioid requirements can vary greatly. A recent study retrospectively analyzed opioid use patterns during the last week of life in 238 patients who died in palliative care units.¹⁶ In a majority of these patients, the opioid requirement remained low during the last 24 hours of life, but among those who required significantly increased dosing, length of survival was no different than it was among patients who remained on stable dosing. Even in an unresponsive patient, opioids should never be abruptly discontinued, as that can precipitate withdrawal reaction and a pain crisis. And even a dose as low as one-quarter the prior daily dose prevents withdrawal symptoms.¹⁷ If the patient is taking opioids orally and becomes unable to swallow, the nurse should be prepared to administer them sublingually, parenterally, or rectally, keeping in mind that doses may differ. (See “Difficulties in Managing Pain at the End of Life,” *AJN*, July 2002.)

It’s not uncommon for patients near death to moan or grunt as they breathe, and families often assume that this indicates pain. Our experience suggests that that is not so. The nurse should explain this to family members and make sure they know that pain assessment and management are an ongoing part of care.

Agitation in the final hours of life is common, and the patient may become very restless and try to disrobe or get out of bed. This may be caused by drugs (especially psychotropics), electrolyte or glucose abnormality, liver failure, ischemia or hypoxia, renal failure, impaction of stool, urinary tract (or other) infections, and metastases to the brain.¹⁸ Other possible causes are a distended bladder or unresolved emotional or spiritual issues. All members of the interdisciplinary team should be involved in identifying the cause. An agitated delirium at the end of life should be treated pharmacologically with an agent such as haloperidol (Haldol). Palliative sedation should be considered only after nonpharmacologic and all other pharmacologic interventions have been tried.

Many patients conserve their energy during their final days and hours, and when they have come to terms with dying and are at peace, they become less communicative. This “transitional withdrawal” seems not to be the social withdrawal associated with depression. As Paice has noted, the patient becomes weak, increasingly drowsy, and less interested in food.¹⁹ It’s important to explain to families that people who are dying often withdraw in this way and that it doesn’t mean that the patient is rejecting them.

Final Days

A Cleveland hospice offers advice.

The staff of Hospice of the Western Reserve supports you in the provision of care to your loved one during the last stage of life. As each person's life is unique, so is each one's journey toward death; but it is always a difficult time and people may not know what to expect.

We hope this information will help you to be better informed and prepared, but remember that it is natural to feel confused and upset anyway. Do not reproach yourself for that.

It is common for the dying to focus inward, beginning about one to three months before death. This withdrawal from the exterior world does not reflect unfavorably on anyone. Rather, it reflects the patient's need to turn his attention inward in thought and contemplation. Dying is hard. Your presence during the process is very important.

Signs and Symptoms of Imminent Death

As the patient enters the final stage of life, you may notice physical changes. They do not all occur at the same time and some may not occur at all. Your hospice team will help you to identify and understand them in the effort to support you through this trying period.

Call when you observe the following signs of impending death:

- The patient has a **decreasing need for food and drink** as body functions slow down gradually. There may be **difficulty in swallowing**. The mouth may become dry and should be kept moist. The patient is not hungry—the body has its own sense of what it needs. Gradually, the patient spends more time sleeping during the day and at times is **difficult to arouse**. This symptom is a result of a change in the body's metabolism. Try to spend more time with the patient at points of greatest consciousness.
- It is common for the dying patient to become **restless** and to pull at the bed linen. The patient may become increasingly **confused** about time, place, and the identity of familiar people. Reminders as to what day it is, what time it is, and who is in the room will be comforting. The lights should be dim rather than bright, but sufficient for the patient to see faces. Soft music may be calming. Keep the side rails of the bed up for safety.
- The patient may have **visions** of people and things not visible to others. They are not necessarily frightening and often are comforting.
- **Incontinence** may become a problem. Your nurse or hospice nursing assistant can help

you get pads to place under the patient for comfort and cleanliness. You may notice a **decrease in the amount of urine and it may also be darker than usual**.

- The patient's **respiration may sound moist**. This is caused by sagging of the muscles of the tongue and a decreased ability to clear secretions that collect in the back of the throat. The patient is not discomforted by this and even may not be aware of it. Elevating the head of the bed or turning the patient to one side usually quiets these sounds. Medication can dry the secretions.
 - The acuity of **hearing and vision may deteriorate**. Maintain some soft light in the room. Assume that the patient can hear, since hearing is thought to be the last of the senses to diminish, and explain to him whatever may be happening in the room.
 - The patient's **arms and legs may become cool to the touch and bluish**. You may notice that the underside of the body is much darker. These symptoms are the result of blood circulation slowing down and do not necessarily indicate that the person is too cold. Fevers also are common.
 - You may notice a **change in breathing patterns**. There may be 10- to 30-second periods of apnea, a very common symptom at the final stage of life.
 - Most of the time, the patient will be **unable to respond to touch or sound**. Again, assume that the **sense of hearing** remains, and speak in a comforting tone of voice.
 - **Pain and discomfort** may increase, remain at the same level, or decrease as death approaches. If it appears that pain has increased, as evidenced by greater restlessness or other factors, contact the nurse, and even if it seems to have decreased, continue to give medications as directed by her.
- If there are indications that the patient has died, call the hospice. The hospice nurse always makes a visit to the home at the time of death, unless it is declined. In Ohio, nurses do not pronounce the patient dead—they verify the cessation and absence of vital signs and notify the physician who, by prior arrangement, then signs the death certificate.

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A predictable sequence. Although the period from symptom onset to active dying and then to death varies, a predictable sequence has been reported. Morita and colleagues observed 100 terminally ill cancer patients for five signs of impending death: “clouding of consciousness, death rattle, respiration with mandibular movement, cyanotic extremities, and pulselessness on the radial artery.”²⁰ They found that as death approached, the death rattle (if it developed) occurred first at a mean of 57 hours before death and was followed by respiration with mandibular movement at a mean of 7.6 hours before death. Cyanosis of extremities took place at a mean of 5.1 hours before death, and pulselessness on the radial artery occurred next at a mean of 2.6 hours before death. Consciousness was measured using a categorical scale of awake–drowsy–comatose. At one week before death, 56% of the patients were awake, 44% were drowsy, and none was comatose; in the final six hours of life, 8% were awake, 42% were drowsy, and 50% were comatose, leading the researchers to conclude that it’s essential that providers encourage communication between patients and families *before* the final hours of life.

THE DEATH VIGIL

As the patient nears death, nurses should focus on managing symptoms. Patients very close to death are often aware of it, and if such a patient can communicate, the nurse should ask about immediate concerns: “Are you physically comfortable?” “What are you afraid of right now?” “What can we do to help you die peacefully?” If the patient asks whether he’s dying, it’s best to be honest. If the dying patient isn’t able to communicate, family members and friends should be consulted because they’re likely to know the patient’s wishes best. Talk to the patient (or the patient’s family) about his surroundings. “Do you want anything in particular at your bedside, such as religious items or photographs?” and “Who do you want in the room with you at this time?”

Explain to patients and families that changes in hearing and vision occur as death nears. It’s generally believed that hearing is the last sense to leave the body, so one should never say anything near the patient that one would not want him to hear. Whispering to the patient should also be avoided: patients are likely to have difficulty hearing and concentrating, and trying to follow whispered conversation causes additional strain. Visual changes include loss of acuity and increased sensitivity to bright light.²¹ As vision becomes less clear, patients

will have greater difficulty distinguishing people and objects, especially if the room is dark. Although the room lighting should be dim rather than bright, it should be sufficient for the patient to easily discern the faces of those present.

Reconciliation. If a dying woman and her daughter are estranged, for example, the team’s social worker might counsel them separately and then together, affording an important opportunity for reconciliation, whether or not it happens. Many patients wish to establish or reestablish connection with their religion before they die, and the nurse and the team’s spiritual care coordinator should also discuss how to address this.²² (See “Cultural Considerations in End-of-Life Care,” *AJN*, March.)

The family’s wishes. It’s important to clarify with family members what their specific needs and wishes are concerning the moment of death. Direct questions are best: “Do you want to be present?” and “Do other members of your family want to be present?” Family members almost always want to be present at the moment of death. But to some, this may be neither desirable nor possible and they may find it comforting to have a volunteer take their place. This discussion should take place early in the planning of the death vigil. Young people should be told exactly what to expect.

Through conversation, determine how involved in physical care family members want to be, and when clinicians provide care, invite family members to participate, as appropriate. Teach them simple techniques as assisting in turning, positioning pillows, providing mouth care, or giving gentle massage. Many people are fearful of hurting a loved one; have them perform the techniques under your guidance.

Signs and implications. Information regarding the signs of imminent death should be discussed with the family, both before and as they occur. Written information, such as pamphlets, can be provided, but should be regarded as supplementary (see *Final Days*, page 47). Family members usually do not understand the implications of some of the observable changes, and these should be explained. For example, a primary nurse may tell the family that mottling is increasing, the patient is becoming less responsive, and his blood pressure is decreasing—and family members who have been sitting vigil continuously might decide to go home to rest, unaware that what they have just been told indicates that their loved one will probably die within the next few hours.

Many clinicians report that patients appear to

have the ability to choose the time of death. It's not unusual for an unresponsive dying patient to awaken when a long-awaited loved one arrives, say goodbye, and then die. It's also not unusual for a patient to die when a family member who has been at the bedside day and night steps away for a short time. Nurses should explain the latter phenomenon to family members to help them avoid reproaching themselves later (if they are absent when death occurs).

Interestingly, many families (and some clinicians) also believe that it's important to give the patient "permission to die." But telling a patient "You can go now" may be less helpful than reassuring him that those left behind will be well. For example, suppose an 80-year-old man who has been married for 60 years is dying and his son tells him, "Dad, as you and Mom wanted, we made arrangements today for her to move into an assisted-living facility." Knowing that his partner will be taken care of could ease his anxiety and ease his death.

Being present. The ability to "be present with" (as opposed to "do something for") someone can be acquired. As Borneman said, "Presence may in fact be our greatest gift to these patients and their families."²³ For both clinicians and family members, ways of simply being present with the patient include sitting at the bedside, allowing there to be comfortable silence, listening, reviewing their lives, and gently touching the patient, as appropriate and in accordance with his wishes. Nurses who are familiar with the concept and practice of this type of presence can teach it to others by explaining and demonstrating it.

Communicating with the dying patient. Even when patients are disoriented their utterances may be significant. Their attempts at communication may be missed or ignored, however, because they are allusive, cast in symbolic language or metaphor.²⁴ According to Callanan and Kelley, patients usually attempt either to describe what they're experiencing or ask for something they need in order to die peacefully.²⁴ Many use travel metaphors. For example, a patient might say, "I keep having a dream that I'm waiting for a train, but it won't stop for me when it arrives." The nurse might ask the patient why he thinks it won't and what needs to be done to make it stop.

In communicating with dying patients, the nurse should convey accessibility through body language and tone of voice, respond in a way that validates and supports rather than denies or questions, speak candidly ("I don't understand but I'll keep trying"),

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ask open-ended questions ("Can you tell me more?"), cast statements as questions ("Is George waiting for you?"), and give information, as appropriate, to the family. If the patient's words and expression are confused, the nurse and family members should work together to determine what it is that he is trying to communicate.²⁴ Unless the nurse explains that what he's saying may be significant, family members may assume that it isn't. And without the family's help, it would very likely be impossible for the nurse to ascertain the meaning of personal content.

Some patients who are very near death may appear to see and hear someone or something neither visible nor audible to others. Visions often are of someone who has died or of benevolent figures such as angels, and their presence is usually comforting. This phenomenon should be differentiated from terminal delirium, which can manifest as con-

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fusion, anxiety, hallucination, agitation, and restlessness, and in which the patient is distressed. In this case, hallucinations that may at first seem benign can become frightening to the patient. Haloperidol, which can be administered by several routes, may be useful in controlling the symptoms.¹⁹

At the moment of the patient's death, it's extremely important not to interrupt or intrude upon family members—the acknowledgment of the lack of vital signs can wait until they appear to be ready for it. Nurses can simply observe the scene. There is usually an indication that final leave has been taken and last good-byes have been said—movement away from the body, for example.

Never be surprised by what family members might do at the point of the patient's death: it is an unusual time—a bereaved husband might climb into the bed with his deceased wife, a family might gather around the deceased's bed for a final photograph.

Immediately after death, it is very important that

the nurse express sympathy for the family, and a simple statement such as “I am sorry for your loss” is all that is necessary. Anecdotal reports of conversations with bereaved families have indicated that clinicians often leave the room without saying anything and that that is very distressing to the family. Nurses should devise rituals to perform with family members in the presence of the patient's body—a moment of silence or of prayer, perhaps, according to the particular circumstance. All members of the interdisciplinary team who had been involved in the care of the patient should be encouraged to be present at that time.

The main goals of care immediately after a patient's death are the bathing and handling of the body according to the family's wishes and a peaceful environment. Families also should be asked whether they have preferences in clothing the deceased. In some cultures there are mandates about how the body should be treated after death. It's the nurse's responsibility to advocate cultural practices even when they are not customary at the facility. In families that have chosen cremation or decided not to hold an open-casket funeral or viewing of the body, this is the last time that members will be able to touch or see the patient.

It's also important to review the experience with the patient's family members, describing what occurred during the dying process and at death. This helps to minimize lingering doubt and misunderstanding. Topics to discuss include pain and pain management (morphine), artificial nutrition and hydration, and decisions regarding both in which the family may have participated.

Final good-byes are difficult, of course, and families vary greatly in how they say them and in how much time they take to do so. It's important to grant them permission to take as much time as needed.²¹ Nurses can inquire of the family whether each member wants to spend time alone with the deceased patient. The body should never be removed until the family is ready and, of course, under all circumstances, it is vital that staff members treat it respectfully.

PROFESSIONAL REVIEW

Nurses may become anxious caring for the patient, the family, or the body after death and it is strongly recommended that they seek the assistance of the interdisciplinary team. No one should feel obligated to work alone in these circumstances.

Professional review after a patient's death entails summarizing the course of events and expressing

grief. Nurses may feel debilitated by the cumulative loss of patients. A question nurses can ask themselves after each death is “What did I learn professionally and personally from taking care of this patient and family?” This also allows for the identification of questionable decisions and mistakes made, to ensure that they are not repeated. Such review can be accomplished in different forums, but it’s important that all providers participate. Too often, nursing assistants and others who may have formed close bonds with the patient and family and who may not understand exactly what happened at the time of death aren’t included.

THE CASE REVISITED

Ms. Jessup, her husband and daughter, the primary nurse, the social worker, the spiritual care coordinator, and the physician meet to discuss her care. The clinicians present the benefits and disadvantages associated with continuing TPN. Although the family members fear that withdrawing TPN will hasten death, they’re convinced that the third-spacing of fluids is causing edema and pain. A decision is made to discontinue TPN, and edema of the extremities soon decreases.

Ms. Jessup has reported severe lumbar pain, rating it at 8 on a 0-to-10 scale, and medication is changed from meperidine to an equianalgesic dose of iv hydromorphone (Dilaudid) with breakthrough doses available via pump. (Meperidine isn’t an appropriate opioid for ongoing pain management because the active metabolite normeperidine that it produces is neurotoxic and can accumulate, increasing the risk of seizure.) Within 24 hours, Ms. Jessup’s pain rating decreases from 8 to 2. (When, days later, she becomes unresponsive, the opioid is continued, although at a lower dose.)

Ms. Jessup also begins to withdraw emotionally, losing interest in conversation with family members and seeming instead to focus on private thoughts. Although such withdrawal was discussed as a sign of imminent death earlier, Ms. Jessup’s daughter, in particular, finds it deeply upsetting. Mr. Jessup remains concerned that his wife will be denied salvation. The spiritual care coordinator visits frequently, asks how he can help, and encourages them to continue expressing themselves. As the family members hold the vigil around Ms. Jessup, the nursing staff encourages them to review her life with her, discuss memories, and recall what has given her life meaning. This seems to ease everyone’s distress.

During her final days, Ms. Jessup talks to herself and frequently reaches out. She says the name

“Anna” repeatedly. At first this distresses the family until, with the team’s help, and the husband’s recollection, they realize that Ms. Jessup is comforted by this “interaction” with her dead sister.

With the team’s support, the patient’s daughter tells her children of their grandmother’s impending death and asks if they want to see her. The children say that they do, and when they enter the room they climb onto the bed to kiss and hug her.

Throughout the week, the team’s clinicians continued to talk with the family as the signs and symptoms of imminent death arose—decreasing consciousness, the death rattle, mandibular movement on taking breath, and skin mottling. Now her husband suggests that everyone go home for a good night’s rest and reconvene at the hospital the next morning. But because the nurse explains that the signs indicate that Ms. Jessup will probably die that night, the family decides to stay at the bedside, and all are present when she does die at 1 AM. ▼



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