

# Palliative Care: Prognostication and the Chronically Ill

Methods you need to know as chronic disease progresses in older adults.

By Marianne L. Matzo, PhD, APRN, BC, GNP, FAAN

The well-documented aging of the U.S. population has many consequences, among them a growing incidence of chronic illness. Chronic illnesses—no longer accidents and infections—are the most common causes of death among older adults.<sup>1</sup> “End of life” has changed from a period of overwhelming illness, typically lasting minutes or days, to a period of slow deterioration caused by chronic illnesses that may last months or years. Nurses, therefore, have to be prepared to address the problems associated with chronic medical conditions as well as the issues related to their patients’ dying and deaths.

According to the Federal Interagency Forum on Aging-Related Statistics, the six leading causes of death among Americans ages 65 years or older are heart disease (44% of deaths from these six causes), cancer (29%), stroke (11%), chronic obstructive pulmonary disease (COPD) (8%), influenza and pneumonia (4%), and diabetes (4%).<sup>1</sup> Five of the six are chronic illnesses that are often protracted and frequently involve chronic disabilities that may be both financially burdensome to the patient and her family as well as taxing to the health care system. And the prevalence of each illness among the same age group has increased between 1984 and 1995: stroke increased by 1%, diabetes by 2%, heart disease by 5%, and cancer by 7%.<sup>1</sup> Older adults are also at an increased risk for

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# Palliative Nursing



▲ *Gifts*, by Deidre Scherer, fabric and thread, 32" × 54", 1999; photo by Jeff Baird. From the collection of St. Mary's Foundation, Rochester, NY.

Says Scherer, "Dignity is expressed in the lift of a chin, a gentle glance, the warm support of a hand."

For more on the artist and her work, go to [www.dscherer.com](http://www.dscherer.com).

developing multiple chronic, life-threatening diseases, including heart disease, cancer, stroke, and respiratory diseases, and other terminal illnesses, such as Alzheimer disease.

Hospice care is available to any dying person regardless of age or underlying diagnosis, yet these services are primarily used for people with cancer diagnoses. Adults with terminal, nonmalignant lung diseases are less likely to receive hospice or palliative care.<sup>2</sup> In one study of Medicare patients enrolled in hospice programs, 80% of the patients had a cancer diagnosis and only 3% had COPD, even though it's the fourth-leading cause of death.<sup>3</sup>

Excellent palliative care begins with an understanding of disease processes and trajectories, end-stage disease indicators, and the nursing skills needed at each stage of the dying process.

## CASE STUDY

When she was admitted to a nursing home seven years ago, Rose Gendron was 85 years old and had a diagnosis of Alzheimer disease. At that time, she was sociable, ambulatory, and could complete most of her activities of daily living with supervision. Her children saw that she was becoming increasingly confused, and they worried for her safety if she had continued to live alone at home. She was in extremely good physical condition, except for chronic back pain that had plagued her for as long as her family could remember. This pain was treated over the years with various antiinflammatory agents including, most recently, celecoxib (Celebrex).

Ms. Gendron developed close relationships with staff members at the nursing home and participated in all of the activities on her Alzheimer unit. The

## FIGURE 1. Using Flacker and Kiely's Assessment Tool and the Resident Assessment Instrument to Identify Residents at High Risk for Dying Within One Year

Complete the chart below and tabulate a total score.

Resident Characteristic	Scoring Chart
Functional ability score* . . . . .	If the summary scale score (using Minimum Data Set data) is greater than 4, score 2.5. If the summary scale score is 4 or less, score 0.
Weight loss . . . . .	If patient has lost 5 or more pounds in the last 30 days or 10 or more pounds in the last 180 days, score 2.26. If not, score 0.
Shortness of breath . . . . .	If patient has shortness of breath, score 2.08. If not, score 0.
Swallowing problems . . . . .	If patient has swallowing problems, score 1.81. If not, score 0.
Sex . . . . .	If male, score 1.76. If female, score 0.
Body mass index (BMI) . . . . .	If BMI is less than 22 kg/m <sup>2</sup> , score 1.75. If BMI is greater than 22 kg/m <sup>2</sup> , score 0.
Congestive heart failure (CHF) . . . . .	If patient has CHF, score 1.57. If not, score 0.
Age . . . . .	If patient is older than 88 years, score 1.48. If 88 years old or younger, score 0.

**Total Score:** \_\_\_\_\_

\*The functional ability score is derived from the Minimum Data Set data for the following seven items: bed mobility, transferring, eating, toileting, hygiene, locomotion, and dressing. Each item is scored on a scale of 0 (no impairment) to 4 (high impairment), yielding a summary scale score ranging from 0 to 28.

If total score is:	The probability of death within one year is:
0 to 2 . . . . .	7.1%
3 to 6 . . . . .	19.2%
7 to 10 . . . . .	50.5%
11 or more . . . . .	85.7%

Adapted with permission from Flacker JM, Kiely DK. *J Am Geriatr Soc* 1998;46(8):1012-5.

nurses documented slow and gradual cognitive decline, no major illnesses, but no improvement in her back pain, which continued to be managed with medication. Six months ago they noted that Ms. Gendron was eating less and clutching her abdomen, and that her stools were black and tarry. She was diagnosed with gastrointestinal bleeding, and her family opted to have her treated with surgery.

### PERIDEATH NURSING CARE

Dying and death should be viewed as a process, just as pregnancy and birth are a process. The perinatal period comprises a series of biologic changes, symptoms, and signs, and evokes many beliefs and responses at each of its different stages. So, too, does the process of dying and death. The last hours of life—including the symptoms and experiences of the patient and her caregivers right before death occurs—as well as death itself, the pronouncement

of death by an RN or a physician, and the care of the body after death, can be considered the *perideath period*, during which intensive holistic nursing care is necessary. Thinking about the process of death in terms of specific themes (such as denial, fear, anger, and spiritual concerns), clinical issues (such as pain, fatigue, and depression), and patient and caregiver needs (such as home care, spiritual care, and caregiver support) helps the nurse to recognize and address such developments as they arise in the course of illness and dying.<sup>4,5</sup>

The first phase of the perideath period occurs when death is imminent, at which time comfort care should be provided and life-preserving interventions withdrawn. Any, all, or none of the following symptoms may occur during the final stages of the dying process: pain, weakness, fatigue, immobility, a lack of interest in eating or drinking, drowsiness, dyspnea, and delirium. (Palliative care nursing interven-

**FIGURE 2.** Risk of Death Within One Year of Discharge in Hospitalized Older Adults

Risk Factors for Postdischarge Death	Points	Patient's Score
Male sex	1	
Number of limitations in the performance of activities of daily living: 1 to 4	2	
All 5	5	
Congestive heart failure	2	
Cancer		
Solitary	3	
Metastatic	8	
Serum creatinine level > 3.0 mg/dL (indicative of renal dysfunction)	2	
Low serum albumin level: 3.0 to 3.4 g/dL	1	
< 3.0 g/dL (marker for both malnutrition and general disease severity)	2	
<b>Total Risk Score</b>		
<b>0–1 Point = lowest risk of death in one year (13% chance of death)</b>		
<b>2–3 Points = low risk (20% chance of death)</b>		
<b>4–6 Points = moderate risk (37% chance of death)</b>		
<b>&gt; 6 points = high risk of death (68% chance of death)</b>		
Adapted with permission from Walter LC, et al. JAMA 2001;285(23):2987-94.		

tions for these symptoms are detailed in previous articles in this series.)

When a nurse provides end-of-life care during the dying process, the focus of care is both the dying adult and her family. When the death occurs, the work of the nurse is not finished, because the deceased person's family is still in need of nursing care and interventions. Postdeath nursing care begins with preparing the body for the morgue or funeral home and helping the family make decisions regarding autopsy and burial. The goals of post-death nursing care are to promote optimal adjustment and to help the family and significant others with the tasks of bereavement.<sup>4</sup>

### DYING TRAJECTORIES

A report by the Institute of Medicine, *Approaching Death: Improving Care at the End of Life*, identified three trajectories of illness and dying.<sup>6</sup> The first trajectory is that of a sudden and unexpected death (for example, a fatal automobile accident). The second trajectory applies to those patients who are terminally ill and experience a steady decline in their physical health and a relatively short terminal phase.

The third trajectory is that most often experienced by older adults, as a consequence of

longevity: a prolonged decline in health, punctuated by periodic crises, that lasts an unpredictable length of time, perhaps years, and ultimately ends in death. Patients in this group perform their activities of daily living while coping with uncertainty and the increasing imminence of death.

The symptom burden related to chronic illness—measured in terms of the number of symptoms and the length of time they're experienced, the degree to which activity is restricted, and the amount of time lost from work—is much higher in adults than in younger people. Looking at all symptoms common at the end of life, the number of symptoms experienced increased with age from 5.7 in those younger than 65 to 7.4 in those older than 85. The symptoms most commonly seen in older adults at the end of their lives were mental confusion, incontinence, difficulty hearing and seeing, and dizziness.<sup>7</sup> Dying at an older age also means that the symptom burden is carried for a much longer period. Of those people younger than 65, 39% were reported to have had their symptoms for a year or more; of those between 65 and 84 years old, 52% were symptomatic for a year or more; and of those older than 85, 69% had had their symptoms for a year or more.<sup>7</sup> The quality of the patient's life and independence may dimin-

**FIGURE 3.** Predicting 6-Month Mortality in Nursing Home Residents with Advanced Dementia

Risk Factor from Minimum Data Set	Points	Score
Activities of daily living score of 28*	1.9	
Male sex	1.9	
Cancer	1.7	
Congestive heart failure	1.6	
Oxygen therapy needed in prior 14 days	1.6	
Shortness of breath	1.5	
< 25% of food eaten at most meals	1.5	
Unstable medical condition	1.5	
Bowel incontinence	1.5	
Bedfast	1.5	
Age > 83 years	1.4	
Not awake most of the day	1.4	
<b>Total Risk Score</b> , rounded to the nearest whole number (possible range, 0 to 19)		
<b>If total risk score is:</b>		<b>The estimated risk of death within 6 months is:</b>
0 . . . . .		8.9%
1 or 2 . . . . .		10.8%
3, 4, or 5 . . . . .		23.2%
6, 7, or 8 . . . . .		40.4%
9, 10, or 11 . . . . .		57.0%
12 or greater . . . . .		70.0%
<p><i>*The activities of daily living score is obtained by adding ratings of the resident's performance ratings from the Minimum Data Set (MDS) for the following seven functional activities: bed mobility, dressing, toileting, transfer, eating, grooming, and locomotion. In the MDS, functional ability is rated on a 5-point scale for each activity (0, independent; 1, supervision; 2, limited assistance; 3, extensive assistance; and 4, total dependence). A total score of 28 represents complete functional dependence.</i></p>		
Adapted with permission from Mitchell SL, et al. JAMA 2004;291(22):2734-40.		

ish in the terminally ill adult because of weakness, falls, delirium, dementia, urinary incontinence, sleep disturbances, and serious depression.

For example, when Ms. Gendron returned to her nursing home after abdominal surgery, the nursing staff noted a significant change in her behavior and cognition. Ms. Gendron was combative and would throw her meal tray onto the floor. She remembered none of the nurses' names, even though many of them had cared for her during her entire seven-year stay, and she became increasingly confused. During the next few months she was unable to recognize her children, stopped walking and eating, and became incontinent of bowel and bladder. When sitting up in a chair, she moaned in pain, which was related to her chronic back condition, according to nurses' assessments.

### PROGNOSTICATION

The inability to determine prognosis—that is, the course that disease will take and, ultimately, when death will occur—is a significant barrier to the pro-

vision of excellent end-of-life care. For example, consider Ms. Gendron's case. When she was diagnosed with gastrointestinal bleeding, her physician apparently saw no reason not to suggest major surgery as an intervention, and her family saw no reason not to give their consent. Even though she had been diagnosed with Alzheimer disease, she was not perceived to have a terminal illness, and consideration wasn't given to a palliative model of care.

In a study of 343 physicians' estimates of survival of terminally ill patients, researchers found that only 20% of predictions were accurate (an accurate prediction was defined as one that fell between 0.67 and 1.33 times the number of days that the patient survived; the median length of survival was 24 days). Most physicians (63%) were overly optimistic while 17% were overly pessimistic. Prognostic accuracy actually decreased when correlated with longer and closer physician-patient relationships.<sup>8</sup>

Identifying transition points in the patient's condition helps the patient, her family, and health care providers prepare for the final stage of life. (A transi-

**FIGURE 4.** Karnofsky Performance Status

Score	Function
100%	Normal, no evidence of disease
90%	Able to perform normal activity with only minor symptoms
80%	Normal activity with effort, some symptoms
70%	Able to care for self but unable to do normal activities
60%	Requires occasional assistance, cares for most needs
50%	Requires considerable assistance
40%	Disabled, requires special assistance
30%	Severely disabled
20%	Very sick, requires active supportive treatment
10%	Moribund (fatal processes are progressing rapidly)
0%	Dead

Karnofsky D, et al. *Cancer* 1948;1:634-56. Reprinted by permission of Wiley-Liss, Inc., a subsidiary of John Wiley and Sons, Inc.

tion point is an event in the trajectory of an illness that moves the patient closer to death. For example, a patient with COPD may have no change in her condition until she gets influenza and never fully recovers; contracting influenza is a transition point in that patient's condition.<sup>9</sup> In Ms. Gendron's case, a nurse should have discussed with the family the effect that major surgery could have on her already compromised mental status and rehabilitative potential.

#### **Acknowledging the severity of terminal disease.**

Prognostication, with the aid of a risk index or scale, enables nurses working with older adults to plan clinical strategies with the patient and family members and help them consider their needs regarding home care, long-term care, hospice, or other supportive services. But accurate prognostication is important for another reason: health care providers are often unwilling to acknowledge that a patient is entering the perideath period. Prognostication can help nurses overcome the "conspiracy of silence" concerning the severity of disease, especially with regard to chronic illnesses that are not considered terminal.

While it's understandable that bewildered family members of a chronically ill patient express surprise at the sudden death of their loved one—saying, for example, that the patient had been through worse exacerbations of the illness and survived—nurses, also, are too often taken by surprise when such patients are hospitalized for a seemingly simple problem such as fluid volume overload and never return home. As nurses, we cannot provide excellent end-of-life care if we don't recognize and acknowledge that the patient is dying.

Such acknowledgment typically leads to discussions about the goals of care and the appropriateness of interventions, and efforts should be made to help the patient and family begin to say good-bye.

The prognostication tools discussed here may help nurses determine whether a patient's chronic

illness has reached a terminal phase and can help both patients and families make decisions regarding care at the end of life. The patient's care setting determines which tool is used.

**Flacker and Kiely's assessment tool.** Flacker and Kiely developed a model for identifying factors associated with one-year mortality by conducting a retrospective cohort study using Minimum Data Set (MDS) information from residents in a 725-bed long-term care facility.<sup>10</sup> Figure 1, page 42, shows Flacker and Kiely's assessment tool, the risk-assessment scale developed from those findings. It's used in conjunction with MDS data using the standard Resident Assessment Instrument<sup>11</sup> and is applicable to older adults living in long-term care facilities.

On Flacker and Kiely's scale, Ms. Gendron scored 2.5 on functional ability (because her summary scale score using MDS data was greater than 4), 2.26 on weight loss, 0 on shortness of breath, 1.81 on swallowing problems, 0 each on sex, body mass index, and congestive heart failure (CHF), and 1.48 on age. Her total score equaled 8.05, which was indicative of a 50.5% risk of dying within one year. If nurses in long-term care were to complete this type of assessment on patients whenever there's a change of status, it could help to guide family members and physicians in choosing the best options in the care of chronically ill patients.

**Determining risk in older adults.** Figure 2, page 43, shows one way of establishing point scores for several risk factors associated with death within one year of hospital discharge and allows a clinician to evaluate a patient's risk of death accordingly. The point system is based on a study of 2,922 patients discharged from an acute care hospital.<sup>12</sup> The researchers concluded that, in predicting one-year mortality, this index performed better than other prognostic scales that focus only on coexisting illnesses or physiologic measures. It takes into consid-

**TABLE 1. Core and Disease-Specific End-Stage Indicators**

**Core end-stage indicators** are physical decline, weight loss, multiple comorbidities, a serum albumin level < 2.5 g/dL, dependence on assistance with most activities of daily living, and a Karnofsky Performance Status score of less than 50%.

**Select disease-specific indicators****HIV or AIDS**

- CD4<sup>+</sup> cell count < 25 cells/mm<sup>3</sup> or persistent viral load > 100,000 copies/mL
- antiretroviral therapy no longer effective or desired
- **Plus** any one of the following:
  - ┆ wasting syndrome
  - ┆ progressive multifocal leukoencephalopathy
  - ┆ cryptosporidiosis
  - ┆ *Mycobacterium avium* complex, unresponsive to treatment
  - ┆ visceral Kaposi sarcoma, unresponsive to treatment
  - ┆ toxoplasmosis, unresponsive to treatment

**Heart disease—congestive heart failure (CHF)**

- New York Heart Association class IV disease
- symptomatic at rest despite optimal diuretic–vasodilator therapy
- patient is not a candidate for or declines revascularization

**Liver disease**

- prothrombin time > 5 sec above control or international normalized ratio > 1.5
- serum albumin level < 2.5 g/dL
- **Plus** any one of the following:
  - ┆ refractory ascites
  - ┆ spontaneous bacterial peritonitis
  - ┆ hepatorenal syndrome
  - ┆ encephalopathy with asterixis, somnolence, or coma
  - ┆ recurrent variceal bleeding

**Dementia**

- patient is unable to walk without assistance
- urinary and fecal incontinence
- an absence of consistently meaningful verbal communication
- patient is unable to dress without assistance
- **Plus** any one of the following:
  - ┆ 10% weight loss in previous six months
  - ┆ serum albumin level < 2.5 g/dL
  - ┆ recurrent fevers
  - ┆ aspiration pneumonia
  - ┆ pyelonephritis or urinary tract infection
  - ┆ multiple stage III or stage IV pressure ulcers

eration a cancer diagnosis and is applicable to hospitalized older adults.

**Mortality Risk Index.** A recent study by Mitchell and colleagues identified factors associated with the six-month mortality of nursing home residents diagnosed with advanced dementia.<sup>13</sup> The retrospective study of MDS data from 11,430 patients with advanced dementia admitted to nursing homes in New York and Michigan generated risk scores based on 12 MDS variables. The researchers concluded that these risk scores provided more accurate estimates of six-month mortality than those derived from existing prognostic guidelines.

Using the tool shown in Figure 3, page 44, Ms. Gendron scored 1.9 for activities of daily living, 1.5 for eating less than 25% of her food at most meals, 1.5 for bowel incontinence, 1.5 for being bedfast, 1.4 for being older than 83, and 1.4 for not being awake most of the day. Her total risk score (rounded to the nearest whole number) is 9, indicating an estimated 57% risk of death within six months. This prognostication score is consistent with her score on other tools. The researchers demonstrated that certain characteristics, such as older age, male sex, greater functional impairment, diabetes mellitus, poor nutritional status, and car-

**TABLE 1, contd.** Core and Disease-Specific End-Stage Indicators

Select disease-specific indicators

**Amyotrophic lateral sclerosis**

- rapid progression of disease
- intake is insufficient to sustain life
- significant dyspnea, on oxygen at rest
- patient declines artificial ventilation
- medical complications, such as pneumonia or sepsis

**Renal disease**

- patient is not seeking dialysis
- patient is not a candidate for renal transplant
- **Plus** any of the following:
  - ▮ creatinine clearance < 10 mL/min (without comorbid conditions)
  - ▮ creatinine clearance < 15 mL/min (with comorbid diabetes or CHF)
  - ▮ creatinine clearance < 20 mL/min (with comorbid diabetes and CHF)
  - ▮ serum creatinine > 8 mg/dL (> 6 for patients with diabetes)

**Pulmonary disease**

- documented disease progression
- disabling dyspnea at rest
- pulmonary infections
- **Plus** any one of the following:
  - ▮ partial pressure of oxygen < 55 mmHg on room air
  - ▮ partial pressure of carbon dioxide > 50 mmHg
  - ▮ oxygen saturation < 88% (on supplemental oxygen)

**Stroke**

- poor nutritional status
- poor functional status
- persistent vegetative state
- poststroke dementia
- medical complications

**Coma (any etiology)**

- abnormal brain stem response
- absence of verbal response
- absence of withdrawal response to pain
- serum creatinine > 1.5 mg/dL

Adapted with permission from the National Hospice and Palliative Care Organization. *Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases*. 1996.

diovascular disease, are associated with poor survival in older adults with advanced dementia.

**Karnofsky Performance Status.** The Karnofsky Performance Status instrument, originally developed in 1948 and still in use in both original and modified forms, was designed to rate a patient's functional status according to descriptors with associated percentage scores (see Figure 4, page 45). The scale consists of 11 descriptors of functional status ranging from "normal, no evidence of disease" (100%) to "dead" (0%); a clinician simply chooses the descriptor that best describes the patient's functional status. A person rated "moribund (fatal processes are progressing rapidly)" (10%) is entering the perideath period. The Karnofsky scale can be used in any care setting to

follow the course of the illness in terms of progressive deficits, and can also be used as a prognostication tool. The lower the score, the shorter the period that the patient would be expected to survive and the lower the quality of life available to the patient for the rest of the illness.<sup>14</sup>

**End-stage indicators.** Once the patient's Karnofsky Performance Status has been determined, general and disease-specific end-stage indicators should be considered to determine when the patient has entered the terminal phase of a chronic illness. Core end-stage indicators are physical decline, weight loss, multiple comorbidities, a serum albumin level of less than 2.5 g/dL, dependence on assistance to complete most activities of daily living, and a Karnofsky score of less than 50% (see Table 1, above)

Ms. Gendron's Karnofsky Performance Status score was 20%, indicating that she was extremely ill and required active supportive treatment, including bathing, feeding, and incontinence management. She exhibited core end-stage indicators, including physical decline, weight loss, and dependence on assistance in all daily activities. She also exhibited all indicators specific to dementia that would indicate an accelerated dying process and imminent death.

Whereas some nurses might surmise that the additional symptoms reflect neglectful care, such a conclusion would be inaccurate in Ms. Gendron's case. Given her scores on the prognostication scales and the presence of end-stage indicators, it was clear that Ms. Gendron had entered the final stage of her illness. Therefore, a reassessment of nursing interventions was necessary. Care at the end of life is intended to offer the patient the greatest benefit with the least burden. One could see that, given Ms. Gendron's long history of back pain, moving her would have been a tremendous burden. Given her altered nutritional status and incontinence, it was easy for pressure ulcers to form relatively quickly. All of these findings strongly suggest that her family and her physician should have opted for palliative care instead of surgery.

### NURSING ASSESSMENT

Ongoing nursing assessment is the cornerstone of planning care for chronically ill patients. In developing a care plan, nurses must first evaluate functional ability in daily activities and correlated physical signs and symptoms. The prognostication tools discussed in this article take the nursing assessment one step further by providing scores that can help the nurse determine when functional and physical decline signal that the patient has entered the terminal phase.

The addition of prognostication tools to the nursing assessment offers the nurse additional data to help the patient and family members decide about care. The uncertainty associated with chronic illness makes it extremely difficult to make other important decisions, such as whether a patient should undergo surgery, move from her home into a long-term care facility, or travel. For example, a 70-year-old woman with COPD may also be diagnosed with breast cancer and have to decide whether to have chemotherapy or radiation therapy. According to the tool shown in Figure 2, if this patient has limitations in three activities of daily living (2 points), CHF (2 points), and a primary cancer diagnosis (3 points), she has a 37% chance of death within one year of discharge. If her cancer had metastasized, her risk of death in the next year would increase to 68%. Given these data, she might look at the risks and benefits of the cancer treatment and, taking into consid-

eration the progressive pulmonary disease, decide that the best course would be to forgo chemotherapy. Another person looking at these same odds might decide to go forward with it.

### THE MOVE TO HOSPICE CARE

As Ms. Gendron's condition deteriorated after abdominal surgery, her son and daughter began to doubt the wisdom of consenting to the surgery. It pained them to visit their mother and see her wasting away in bed, unaware of who they were. The nurse manager, who had cared for Ms. Gendron for the past seven years, and her physician spoke to her son several times. The following dialogue is an example of the kind of conversation that nurses might have with family members.

"Mr. Gendron," the nurse manager said, "because you've been given durable power of attorney for your mother, it's time for you to think about what the goals of care are for your mom."

"I don't know what the options are," he replied. "I just wish she'd never had the surgery."

"I know it's hard to look back and question the decisions that were made in the past. But as you look forward, to the future, what do you think your mother would want for herself, given her current situation?"

"I don't think she would want to live the way she's living now," the son said.

"We can ask her physician for a hospice referral, and people with expertise in end-of-life care will help us care for your mom. We can also ask the doctor for a do-not-resuscitate order, which means that if your mom's heart stops beating, we'll just let it stop, without taking any extraordinary measures to revive her. What do you think of a plan like that?"

"I think we probably should have done this in the first place, but since we didn't, let's do it now."

And so they decided that the physician would refer Ms. Gendron to the hospice service and write a do-not-resuscitate order.

The nurse completing the hospice admission had several issues to consider. Two priorities were the management of Ms. Gendron's pain and working with the long-term care nurses to establish a plan of care that they could implement. A fentanyl (Duragesic) patch was started, and morphine (Roxanol and others) would be given around the clock.

In addition, the nurses were grieving for the person they had known for the past seven years. They shared stories of her likes and dislikes, as well as many of her comments. They also clearly needed support in their grief over the loss of a beloved long-term resident.

Chronic illness can be very stressful for family members as they watch their loved one lose functional ability. In Alzheimer disease, the older adult's

personality is altered, and the ability to interact in meaningful ways may be lost. For the family, wishing for the patient's death may be much more than simply wanting relief from the pain of watching a loved one's decline; it may in fact be the ultimate expression of love.<sup>15</sup> ▼



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## CE 1.5 HOURS

Continuing Education

**GENERAL PURPOSE:** To provide registered professional nurses with the latest information on chronic disease progression, prognostication methods, and indicators that the dying process is accelerating and death is imminent.

**LEARNING OBJECTIVES:** After reading this article and taking the test on the next page, you will be able to

- describe the concept, stages, and goals of end-of-life care.
- outline the typical symptom profile, trajectories, and indicators of the end of life.
- discuss and apply the various prognostication tools detailed in this article.

**To earn continuing education (CE) credit, follow these instructions:**

**1.** After reading this article, darken the appropriate boxes (numbers 1–15) on the answer card between pages 48 and 49 (or a photocopy). Each question has only one correct answer.

**2.** Complete the registration information (Box A) and help us evaluate this offering (Box C).\*

**3.** Send the card with your registration fee to: Continuing Education Department, Lippincott Williams & Wilkins, 333 Seventh Avenue, 19th Floor, New York, NY 10001.

**4. Your registration fee for this offering is \$11.95.** If you take two or more tests in any nursing journal published by Lippincott Williams & Wilkins and send in your answers to all tests together, you may deduct \$0.75 from the price of each test.

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