Psychological Considerations, Growth, and Transcendence at the End of Life
The Art of the Possible

Susan D. Block, MD

THE PATIENT’S STORY
Mr N is a 77-year-old retired systems theorist and educator with pancreatic cancer metastatic to his liver and lungs. Two years after diagnosis, he has outlived his physicians’ (and his own) expectations about prognosis. Treatment with capecitabine (Xeloda) has successfully controlled his disease. He has had several episodes of sepsis from biliary obstruction and has an external biliary stent. Chronic medical problems—back pain, gastrointestinal tract bleeding, dyspepsia, malabsorption, diarrhea, and urinary retention—are controlled with celecoxib, ursodeoxycholic acid, ferrous gluconate, morphine, omeprazole, vitamin K, pancreatic enzymes, loperamide, and terazosin.

Mr N is divorced, with a son who lives 2000 miles away. He and his son enjoy a close relationship, although the frequency of their visits is limited by distance. Mr N maintains a cordial relationship with his ex-wife, enjoys many friendships, and has strong connections with his family and physicians. His economic circumstances are secure.

PERSPECTIVES
Mr N: At 77 any time I have left is frosting . . . . This term “life-threatening illness” isn’t any more life threatening than if I didn’t have an illness . . . . it’s part of what goes with living. I’m perfectly content with the thought that it’s the end . . . .

Mr N’s SON: The end of life. There’s nothing good about his eventually dying. There’s no upside to that. There’s certainly a lot of good to my having this time with him. That’s a great thing.

Mr N is an articulate, reflective, and warm man. Several painful losses have served as a stimulus for self-reflection and growth. He has developed an eclectic but firm sense of values and beliefs. Mr N’s unusual equanimity in the face of his death offers a “best possible” scenario for the end of life. It illustrates how his life’s final chapter can be an opportunity for personal growth, development, and even joy, shared by his family and his physician.

Patients with life-threatening illnesses face great psychological challenges and frequently experience emotional distress. Yet, the end of life also offers opportunities for personal growth and the deepening of relationships. When physical symptoms and suffering are controlled, it is easier to address patients’ central concerns—about their families, about their own psychological integrity, and about finding meaning in their lives. Optimal end-of-life care requires a willingness to engage with the patient and family in addressing these distinct domains. In addition to supporting growth of patients and their caregivers, physicians need to recognize the impact of psychiatric disorders such as depression, anxiety, and delirium at the end of life and develop skills in diagnosing and treating these syndromes. Comments of a patient with pancreatic cancer, his son, and his physician help illuminate the potential opportunities presented when coping with life-threatening illness. Enhanced understanding of the common psychological concerns of patients with serious illness can improve not only the clinical care of the patient, but also the physician’s sense of satisfaction and meaning in caring for the dying.

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COPING: THE SPECTRUM OF PSYCHOLOGICAL RESPONSES AT THE END OF LIFE
Virtually all patients nearing the end of life are faced with physical, psychological, social, and spiritual challenges. Personal coping responses may fall anywhere on a continuum, ranging from the exceptional (like Mr N’s), to the

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adaptive (most typical), to the dysfunctional. From an “extraordinary case” like Mr N, clinicians can come to appreciate the opportunities inherent in the dying process—possibilities that we can strive for in our care of other patients.

**Psychosocial and Spiritual Assessment**

Developing an optimal treatment plan for a patient with a life-threatening illness requires not only a thorough physical evaluation, but also a comprehensive psychosocial and spiritual assessment that includes an understanding of what strengths and vulnerabilities the patient brings to the illness experience. Core domains of a psychosocial assessment and screening questions for each domain appear in Table 1. Systematic assessment of these domains allows the clinician to support good coping, identify persons at risk of experiencing unusual difficulties, and proactively attend to vulnerabilities. Mr N’s situation at the onset of his illness demonstrates a mix of assets and weaknesses. Mr N views his illness as a random cellular derangement and does not ascribe meanings to his illness that are likely to have adverse psychological consequences (eg, punishment, retaliation). He has coped with loss effectively in the past, and after his divorce he maintained solid relationships with his ex-wife and his son. He has many friends but he lives alone and his son is far away, so he has no obvious potential caretaker should he need one later. He is experiencing relatively little stress in his daily life. While he has no formal religious affiliation, he does have a spiritual philosophy that guides his life. Mr N has had 2 episodes of depression, one after his divorce and the other in association with severe back pain, suggesting a potential for recurrence under the stress of illness. His adequate financial resources and good health insurance free him of economic concerns. He describes a close relationship with his physician that offers him a sense of security as he faces what is ahead. These fortuitous circumstances allow Mr N and his physician to focus on growth that might be achieved in the dying process. Nonetheless, like all patients with a life-threatening illness, Mr N confronts several emotional challenges.

**Grief and Loss**

Mr N: I regret losing my friendships and connection with the world when the time comes . . . the feeling of the loss for some friends and for my son, particularly. . . . So, it’s that sadness for his sadness, for his sense of loss. That clearly is the most intense aspect of dying.

The preeminent coping task faced by a dying patient is dealing with loss. Grief is an intensely painful, but normal, psychological response to loss. Dying is associated with grief over both current and anticipated losses of health, the future, physical abilities, and roles and relationships.

It can be challenging to differentiate the distress of normal grieving from pathologic responses, particularly depression, that require intervention. Table 2 compares the clinical features of grief and depression. Mr N’s distress clearly lies within the spectrum of normal grief.

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<th>Table 1. Psychosocial and Spiritual Assessment of the Patient With a Life-Threatening Illness: Sample Screening Questions</th>
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Clinicians use various constructs to describe and understand the grieving process and the psychological pathway toward death. Kübler-Ross’s 5-stage model of the response to impending death (denial, anger, bargaining, depression, and acceptance) represents one conceptual model. Although most individuals do not move sequentially through each of these phases, Kübler-Ross’s schema describes many of the normal emotional responses that characterize coping during terminal illness.

Grieving patients generally benefit from the opportunity to express their emotions. Understandably, patients and family members frequently try to shield each other from their grief. Yet, avoidance may lead to isolation and disconnection for both patients and family members. By speaking openly about grief, by asking, for example, “Have you told your son how hard it is for you to think of leaving him?” the physician can help the patient and family find a way to share their feelings.

**Coping and Defending: Acceptance and Denial**

Weisman has described two modes of confronting illness and preserving psychological equilibrium. In one mode the patient copes, using active problem-solving approaches to deal with problems. In the other, the patient defends, avoiding difficult new realities and maintaining psychological balance. These defenses can be either adaptive (reducing stress and allowing time for fuller psychological adjustment) or maladaptive (preventing necessary adjustments).
Denial is a common defense in life-threatening illness. It may impair adjustment and distort care and can be a marker for depression. Patients may refuse to accept the possibility of death, disbelieve their physicians about their prognosis, focus on unrealistic treatment goals, or fail to make necessary legal, financial, and health care arrangements. Recent research suggests that severe denial occurs in 10% of hospitalized patients with advanced cancer, with more moderate levels of denial occurring in an additional 18% of patients.

When confronted with a patient manifesting denial, the physician should consider whether the denial is helping the patient deal with the illness. When the denial is indeed helping the patient cope, it need not be addressed, but when it is causing problems or is likely to lead to them, the physician may need to challenge the patient’s denial to achieve a greater good. An example might be: “I know that making a decision about who will have custody of your children is extremely painful, yet I want to help you have as much control as possible over this important decision. If we only plan for your survival, we may lose that chance.” Clinicians agree that denial generally should not be challenged when a patient is in the midst of a crisis because doing so risks undermining the patient’s psychological equilibrium.

Requests for Hastened Death

Thoughts and appeals for hastened death arise regularly but should be viewed as a request to open a dialogue about dying and perhaps as a sign of depression or concerns about losing control. Most wishes for hastened death are transient. Exploration of fears, concerns, and wishes for end-of-life care, and an assurance that the physician is willing to discuss these issues, may provide enough security that the desire diminishes. Comprehensive psychosocial assessment, including referral to a psychiatrist to assess depression, is essential for all patients who express a sustained desire for hastened death. Such exploration usually, but not always, points to ameliorable suffering. Depression, anxiety, and delirium, all common among dying patients, are discussed in the Box.

THE ART OF THE POSSIBLE: PATIENTS’ VIEWS OF A “GOOD” DEATH

When the physician has addressed physical distress and potentially dysfunctional responses to terminal illness, it is then possible to focus on helping patients achieve their unique vision of a “good” death. To be sure, not every patient will seek or be able to invest emotionally in the possibility of discovery and transcendence in the dying process. But it is not rare, and as Mr N’s story reveals, his physician’s care and his own emotional strengths have enabled him to focus on the goals that many patients identify as central to a “good” death:

- Optimizing physical comfort
- Maintaining a sense of continuity with one’s self
- Maintaining and enhancing relationships
- Making meaning of one’s life and death
- Achieving a sense of control
- Confronting and preparing for death

Optimizing Physical Comfort

Mr N: Fundamentally, I’m in good shape. I don’t have any real claims that I’m not. The edges are sort of murky now and then from the [chemotherapy’s] side effects, but otherwise, I’m fine.
Patients anticipating death are concerned with minimizing physical distress. Pain and other symptoms, as well as the prospect of future suffering, represent a threat to the integrity of the self and undermine coping. In a study of patients diagnosed as having advanced cancer, inpatients had an average of 13.5 symptoms and outpatients an average of 9.7 symptoms. Psychological distress commonly contributes to physical symptoms such as pain, lack of energy, and dyspnea. Assiduous attention to pain and symptom management can lessen psychological distress and enhance coping. Education and reassurance for the patient and family are also essential.

### Box. Common Psychiatric Disorders in Dying Patients

Psychiatric disorders represent abnormal responses to the stress of terminal illness and are distinct from the normal sadness, grief, and worry that characterize the dying process. In one large study, 47% of cancer patients in varying stages of illness fulfilled diagnostic criteria for psychiatric disorders, 68%, had adjustment disorders with depressed or anxious mood, 13% had major depression, and 9% had organic mental disorders (delirium). Patients with other terminal illnesses demonstrate similarly elevated rates of psychiatric disorders relative to healthy populations.

Frequent reassessment of psychological symptoms is essential because psychological state fluctuates during terminal illness. Symptoms should be treated actively. Finally, physicians should be aware of their own therapeutic nihilism (“I’d be depressed, too, if I were dying,” or “What is the point of trying a new drug? She probably only has a week left”) that may keep them from offering potentially helpful treatments and that conveys a sense of psychological, if not physical, abandonment.

### Depression

Depression is not normal in the terminally ill and is both underdiagnosed and undertreated. Experts estimate that about one quarter of cancer patients experience major depression during their illness, with increased rates in advanced disease. Depression impairs the patient’s capacity for pleasure, meaning, and connection. It erodes quality of life, amplifies pain and other symptoms, causes anguish to family and friends, and is a risk factor for suicide.

Many dying patients have neurovegetative symptoms such as poor appetite, sleep disturbance, lack of energy, and diminished concentration. Thus, emotional symptoms such as hopelessness, helplessness, worthlessness, guilt, and suicidal ideation are better indicators of depression in this setting (Table 2).

Physicians should have a low threshold for initiating treatment. Although no controlled clinical trials evaluate the efficacy of combined interventions in this patient population, most experts recommend an approach that combines supportive psychotherapy, patient and family education, and stimulants and/or antidepressants (Table 2).

### Anxiety

Anxiety and fear surrounding death and dying are common. Significant anxiety symptoms occur in about 25% of patients with life-threatening illness. Anxiety can often be assuaged by direct exploration: “What are you afraid of? What do you imagine dying will be like? Where do these worries come from?” Ongoing exploration and support are the core elements of treatment. Persistently high levels of anxiety often respond to low doses of a benzodiazepine (eg, clonazepam, 0.5 mg orally twice daily). Behavioral treatments (eg, meditation, relaxation training) may also be useful adjuncts. Anxiety and depression often have overlapping symptoms, and both can respond to selective serotonin reuptake inhibitors. Substance abuse and withdrawal, undertreated pain, dyspnea, treatment with corticosteroids, and undiagnosed delirium can also contribute to anxiety symptoms.

### Delirium

As many as 85% of patients with far-advanced disease experience delirium as a terminal event. It requires early diagnosis and aggressive treatment because it is intensely distressing to the patient and family. The cardinal symptoms are disorientation, waxing and waning levels of consciousness and attention, disorders of perception, memory, emotion, and behavior, as well as disturbances of the sleep-wake cycle. Delirium is regularly misdiagnosed as anxiety, depression, or psychosis. Common etiologies include medications, organ failure, infection, metabolic derangements, and the effects of disease on the central nervous system. Delirium is often multifactorial and may be irreversible; opioids, benzodiazepines, and steroids often contribute to the clinical picture. Having family members present and ensuring that the room is well lit and contains familiar objects sometimes help settle the delirious patient. When these measures alone do not provide effective symptom relief, neuroleptic agents should be considered. Haloperidol, olanzapine, risperidone, and chlorpromazine are all useful agents. Chlorpromazine may be especially useful for bedbound patients because of its relative lack of parkinsonian effects and because it can be administered orally, intravenously, and rectally. Furthermore, its sedating and antipsychotic effects, and its tendency to cause orthostatic hypotension are less of a disadvantage in bedbound patients. Benzo- diazepines alone are generally ineffective in treating delirium and may actually contribute to worsening cognitive impairment. However, their use as an adjunct to neuroleptics may speed the resolution of agitated delirium and reduce extrapyramidal adverse effects.

### Indications for Referral

Comprehensive end-of-life care is best provided by an interdisciplinary team that includes medical, nursing, psychosocial, and spiritual expertise, because patients and their families have a broad array of needs and no single clinician is likely to be able to meet all of them. However, patients with persistent pain, unusually intense grief, depression, anxiety that is unassuaged by exploration and reassurance, delirium, substance abuse, and requests for hastened death require the expertise of a psychiatrist.
PERSPECTIVES ON CARE AT THE CLOSE OF LIFE

Table 3. Useful Questions for Clinicians

A. Mobilizing patients’ coping strengths and inner resources

- “What will help you feel that you have lived up to your own ideals in the way you’ve dealt with your illness/your death?”
- “What could you do that would help you feel that this has been a meaningful time for you and the people you care about?”
- “How do you want to be remembered by the people you care about?”
- “What are some of the ways you have found yourself growing or changing, or hoped that you could grow or change in this last phase of your life?”
- “What are some of the moments when you’ve felt most discouraged and downhearted as you’ve faced your illness?”
- “What are the biggest barriers you find to feeling secure and in reasonable control as you go through this experience with your illness?”
- “What are the resources and strengths within you that can help you cope?”

B. Eliciting a patient’s goals for healing and strengthening relationships

- “Are there important relationships in your life, including relationships from the past, that need healing or strengthening?”
- “Are there relationships in which you feel something important has been left unsaid?”
- “Do the important people in your life know what they mean to you?”
- “Are there stories, values, or ideas that you want to transmit to people as part of your legacy?”
- “Are there ways that you can help your family now to prepare for and deal with your death?”
- “How might you be able to continue to be a presence in the lives of people you love after you are gone?”
- “How would you like to say goodbye to the people who have been important to you?”

Unlike most patients with advanced cancer, Mr N’s symptom burden is low. Proactive care has allowed him to focus his energies on psychological, social, and spiritual concerns. In contrast to the “total pain” sometimes experienced by patients with unresolved psychological and spiritual issues, depression, and anxiety, Mr N’s psychological equanimity may also be playing a role in minimizing distress associated with physical symptoms.84

Maintaining a Sense of Continuity With One’s Self

Mr N: I haven’t had any occasion to significantly change my sense of where I am and what’s going on. From very early on, I’ve had to appreciate life as problematic. Tomorrow isn’t promised by today at all.

Mr N’s son: I don’t think it’s changed him a lot, actually. He’s always been somebody that’s felt he’s really lucky and he really appreciates life and day-to-day things.

Dr S: I help manage his biomedical concerns, but in turn he’s teaching me a lot about how people can transform and grow at the end of their lives.

The physical and psychosocial losses that often accompany fatal illness can shatter one’s sense of wholeness and integrity, which are key components of emotional health.83 Death, of course, represents the end of the self as we know it. A dying person may feel that his or her identity as “dying” overwhelms any appreciation of living today and in the future. Mr N’s ability to feel like himself, even in the face of his illness, both reflects and enables his good coping.

Like Mr N, many dying patients strive to be valued in the present, and are gratified to have the opportunity to contribute to others through sharing their wisdom, modeling a meaningful path through the dying process, or teaching.86 Mr N’s participation in the interview on which this article is based is an example of one form of teaching. In addition, Dr S’s appreciation of Mr N’s outlook helps the patient feel valued and connected to others. The physician can also help the patient connect with his or her inner strengths by reviewing past experience of strength and mastery and by offering a vision of how the patient can be his or her “best self,” thereby maintaining a sense of personal integrity and value. Questions designed to elicit patient reflection on these issues are presented in Table 3, part A.

Maintaining and Enhancing Relationships

Mr N: I have wonderful friends who are really loving and caring and look after me and it’s genuine. And I have my beloved son and my daughter-in-law and my former wife. I’m surrounded by people who enjoy me and care about me, that I’ve been important to and who are important to me. What this last year has provided me with is the occasion to be deliberately open to receiving other people’s love and care . . . and I’m delighted when it happens.

Relationships are changed by serious illness. Often, there is an enhanced appreciation of the importance of loved ones and a wish to connect more deeply. At the same time, physical dependency can foster fears of being abandoned and of being a burden.

Concerns about family members are central to patients. In one study of terminally ill cancer patients, between 92% and 97% rated the following domains as extremely or very important: “feeling appreciated by my family,” “saying goodbye to people closest to me,” “expressing my feelings to my family,” and “knowing that my family will be all right without me.”87 Patients and family members are occasionally at a loss as to what to talk about as the patient enters the terminal phase of illness. Physicians may encourage the patient and/or the family to consider saying explicit goodbyes, further strengthening connections at the end of life. Questions to open such explorations are presented in Table 3, part B.

Mr N’s experience illustrates a comfortable adaptation to his increased dependency. He frames receiving from others as a new opportunity to learn about himself, allowing him to cope without feeling diminished. Patients often need reassurance that this kind of dependency is not only acceptable but allows family members to feel a sense of purpose and empowerment by providing care.88 Nonetheless, recent literature demonstrates that the strains of caregiving include an adverse impact on caregivers’ work and finances89 and elevated rates of depression associated with the heavy burden of caregiving.90 Helping the family cope with these potentially devastating stressors is not only a humane component of end-of-life care but is also an important step in facilitating a good death for the patient. One
study\textsuperscript{90} demonstrated that caregivers whose physicians listened to their needs and opinions about the patient’s illness were significantly less likely to be depressed and to report that caregiving compromised their personal lives. Regrettably, physicians often do not attend to these issues.\textsuperscript{91–93}

**Making Meaning**

Mr N: I want to be remembered as a human being who’s cared more about caring for people . . . and what happens in society . . . than about becoming rich and famous.

Dr S: [The lesson for me has been] that while life is transient and full of suffering, it’s the meaning you make of the suffering that counts.

**Legacy and Leave-Taking.** Patients frequently question whether they have accomplished something worthwhile, and what kind of legacy they will leave.\textsuperscript{94} The process of leave-taking provides an opportunity for summing up a life. Memories, values, and wisdom are shared, bringing meaning and ensuring continuity to those who are left behind. Because our society generally shies away from direct confrontation with death, the physician often must gently raise these issues, explore patient resistance to addressing them, and support risk-taking.

**Transcendence.** Mr N: I know that as with everything else there is creation and destruction which makes for creation which makes for destruction and I’m part of that process.

Mr N relies on his scientific understanding of the universe to make sense of and to accept death. Finding a sense of meaning or transcendence ameliorates the experience of suffering.\textsuperscript{95} Many patients find this sense of meaning and transcendence within a religious context. Others, like Mr N, experience a broader humanistic or spiritual connection with the human condition.

The physician can help focus these issues by asking questions such as: “How do you understand what is happening to you?” “What would allow you to feel that going through this has a purpose?” “Do you have traditions or beliefs that can help you deal with your illness?” Chaplains, psychiatrists, psychologists, and social workers have special expertise in exploring these concerns.

**Achieving a Sense of Control**

Dr S: We’ve talked about the setting for his death. He’s actually visited the hospice . . . and the inpatient palliative care unit. We’ve talked about his most desired scenario, which is to die at home with his family, hospice, and me taking care of him.

Most patients have definite ideas about the care they desire at the end of life. Comprehensive clinical information about the illness and its range of reasonable treatment (or nontreatment) options can provide an important sense of security and control.\textsuperscript{96,97} As is true for Mr N, this wish for control can extend to the details of dying and may include attention to rituals after the death. The physician’s equanimity in the face of approaching death and the assurance of continuing care lessens the patient’s fear.

Often, patients want to engage in broader discussions about the various management options and how well these options meet their values and goals.\textsuperscript{98} Yet some prefer to shield their families, or even themselves, from difficult decisions. Physicians should be guided by explicit discussions with patients about their preferences for information and participation in the decision-making process.

**Confronting and Preparing for Death**

Mr N: Maybe in some profound sense I’m denying fear. I’ve built this elaborate rationale. What happens after I die is part of the mystery. I’m an agnostic. . . . I’m perfectly content with the thought that it’s the end of whatever. What is nice to have in mind is that it’s not the end of what happens to the molecules that make me up. They go back into the soil.

Mr N’s Son: It [the idea of his dying] went from being something horrible to being something that’s just there. I try to see it the way he sees it: that at some age it’s what’s going to happen to everybody.

Dr S: I’ve been interested that he really is not fearful. He’s very accepting . . . and equally intrigued by this next journey.

Patients and their families (and often their physicians) usually confront death episodically. Even when patients are speaking optimistically about their illnesses, there are often clues that darker thoughts or fears are also present. Although physicians may be reluctant to explore these thoughts for fear of taking away hope or causing the patient emotional distress, patients value the opportunity to achieve “completion” of their lives through preparing for death.\textsuperscript{74} For some patients, addressing practical issues such as putting financial affairs in order or planning a funeral or memorial service represent ways of taking care of survivors. Mr N has completed a durable power of attorney for health care, visited 2 inpatient hospice units, and made plans for care he may need in the future.

Preparing for death also often entails a patient’s desire to understand what is likely to happen as death approaches, as well as the ability to speak frankly with his or her physician about prognosis.\textsuperscript{80} Mr N’s calm acceptance of what is ahead has likely been shaped by the relatively comforting images his physicians have offered him about what dying will be like.

Mr N: According to my doctors, if it’s the pancreatic cancer that does me in I’ll go on with a good quality of life until maybe a month before, and then there’s a quick fall off . . . . That is an incredible way to go.

Reassurance that the physician is committed to being with the patient throughout the dying process reduces anxiety about what lies ahead.\textsuperscript{99}

**REWARDS FOR THE PHYSICIAN**

Dr S: I really like seeing him because no matter how distraught I am about that particular day or feeling overwhelmed . . . I feel so much better after each visit with him. It’s almost like he’s a doctor to me.
Caring for the dying is emotionally trying, challenging the physician to be present in the face of suffering, to find ways of using one's self therapeutically when medicine's technical and curative limits have been exhausted, to remain a calm presence in the face of profound human crises, and to grieve repeated losses. At the same time, this work offers deep professional satisfaction. It provides a singular experience of being of service to people at the most difficult moments of their lives. The gratitude expressed by patients and families ameliorates the frustrations and sadness that are sometimes inherent in this work. When patients have “good” deaths, physicians can feel a sense of accomplishment and pride. Finally, many of the skills that a physician acquires in caring for the dying are highly generalizable to other areas of medical work. They make physicians better communicators and help them to better understand and treat suffering in other realms. In addition to the professional satisfactions of providing good end-of-life care, seeing life from the perspective of someone who has limited time enhances clarity about personal priorities. The intimacy of the experience offers deeper understanding about the nature of life, an appreciation of the gifts of being alive, and constantly renewed inspiration and hopefulness about human resilience.

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Other Resources

Last Acts
http://www.lastacts.org
Provides a broad range of resources related to end-of-life care, including professional precepts, innovative programs, and community-based resources.

Growth House, Inc
http://www.growthhouse.org
The largest resource for end-of-life educational materials on the Web, with links to resources on grief and bereavement, quality of care, general death and dying topics, and family support.

End of Life Physician Education Resource Center
http://www.eperc.mcw.org
Provides peer-reviewed end-of-life educational resources for educators.

Harvard Medical School Center for Palliative Care
http://www.hms.harvard.edu/cdi/pallcare
Provides access to faculty development programs in palliative care and medical student educational resources.