

Palliative Care in the Final Days of Life

"They Were Expecting It at Any Time"

James Hallenbeck, MD

The Patient's Story

Mr R was a 74-year-old widower diagnosed with cholangiocarcinoma. Three months later, a stent was placed to prevent biliary obstruction. He was reportedly in good health for 6 months, but thereafter, Mr R became progressively jaundiced and weaker. Within 9 months of his diagnosis, he was using a wheelchair. In clinic, his oncologist referred him to home hospice. Two days after hospice admission, Mr R became acutely ill with a fever (temperature to 39°C) and gasping respirations. His family brought him to the hospital. He was intubated, admitted to the intensive care unit (ICU), and given antibiotics and vigorous hydration. Blood cultures grew *Escherichia coli*. A palliative care consultation was obtained. A family conference was held, and the team recommended a transition to comfort care. The family agreed. Mr R was transferred to a palliative care unit bed. Although the family thought that Mr R's death was imminent, he lived for a week. He initially rallied and was able to recognize and greet visitors. Over the next days, he became less alert and eventually was unresponsive. By day 7 of his hospitalization, he was receiving 2 mg of morphine every 4 hours intravenously for possible pain and dyspnea and lorazepam for agitation. Atropine eye drops were administered sublingually for retained respiratory secretions. His family remained at his bedside during his final days. On the day of his death, his morphine dose was doubled because of an increased respiratory rate, suggestive of possible underlying pain or dyspnea. At 10 PM, he was given a continuous morphine infusion and his family went home. He died at 11:47 PM. His family was called and returned to the hospital. They stayed with Mr R until 6:30 AM. A week later, the palliative care consulting attending physician made a follow-up telephone call to the patient's daughter to offer condolences.

PERSPECTIVES

In August 2004, shortly after Mr R's death, a *Perspectives* editor separately interviewed Mr R's daughter and the attending physician on the palliative care consultation team.

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Providing care to actively dying patients presents unique challenges for the clinician. Patients in their final days require careful symptom management. Families need support and coaching as death approaches. Care does not end with the death of the patient but continues through death pronouncement, family notification of the death, discussion of autopsy, and immediate bereavement support. Skills in these and related areas are discussed in the context of one man's death, as illuminated by comments made after death by his daughter and his physician. This case also highlights the often differing perspectives of families and clinicians as they work to deal with a patient's death. A goal of mastering the palliative skills necessary to competently care for an actively dying patient is to enable a patient to die peacefully and relatively free of discomfort. Achieving such competency should also help to relieve clinician stress attendant to caring for dying patients.

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This case may remind clinicians of many dying patients for whom they have provided care. Still, there is much that can be learned. This article addresses issues that commonly arise in the care of actively dying patients—prognostication, physical changes at the end of life and related treatment, family coaching, death pronouncement, inquiries about autopsy, and postdeath follow-up. Consideration of the very different perspectives of the daughter and the physician, as they struggle to understand Mr R's death, is also instructive. For most patients, active dying, a rapidly evolving process just preceding death, will be recognized hours to days earlier; sudden deaths by trauma or illness are the exceptions, not the rule. With each death, families and friends grieve the loss of

Author Affiliation: Stanford University School of Medicine, Palo Alto, Calif.
Corresponding Author: James Hallenbeck, MD, Stanford University School of Medicine, VA Palo Alto HCS (1002C), 3801 Miranda Ave, Palo Alto, CA 94304 (james.hallenbeck@med.va.gov).

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Table. Signs of Active Dying in 100 Cancer Patients

Sign	Hours Prior to Death, Mean/Median (SD)
Retained respiratory secretions audible (death rattle)	57/23 (82)
Respirations with mandibular movement (jaw movement increases with breathing)	7.6/2.5 (18)
Cyanosis of extremities	5.1/1.0 (11)
No radial pulse	2.6/1.0 (4.2)

Adapted from Morita et al.⁷

their loved one. Clinicians come to recognize limitations in their powers to cure illness and must also grieve. We all are reminded of our own mortality.

When Dying Becomes Apparent

MR R'S DAUGHTER: *When we saw the cancer specialist, he gave us the results of the CAT scan and said that there wasn't much we could do. The cancer was growing, and there was a blockage on the stent, and [he said] we should probably call hospice and get home comfort care for him. That was devastating for us. We thought there was still hope. So, we got hospice going. We were not at the point where we were ready for him to die.*

The focus of this article is on the last hours of life and the time just following death. However, each person's death must be understood in the context of his or her preceding story. Mr R's path, his dying trajectory, was a typical one for cancer.¹ Despite having metastatic cancer, his functional level remained high until just weeks before his death. As is often the case, the family seemed shocked by his rapid decline. How the oncologist discussed his prognosis or what was done to prepare them for this almost inevitable decline² is not known, but some additional coaching on what could be expected might have softened the shock of this bad news.^{3,4} Certainly, clinicians must be careful not to frame referral to hospice in terms of "nothing more that can be done" or in terms of a lack of hope.⁵

Although the family accepted the referral to hospice, family members were not yet accepting of the fact that Mr R was dying. Unfortunately, he took a turn for the worse shortly after hospice admission. Had there been more time for the family to accept his dying and more time to establish a trusting relationship with the hospice agency, his admission to the hospital might have been averted.

Expecting It at Any Time

MR R'S DAUGHTER: *When we went into the emergency department and they said he had an infection, we thought that maybe . . . they [could] do something . . . to get rid of it. They [could] feed him intravenously so he [could] gain the strength to go home, and then we [could] have hospice at home with him. But they were saying that the situation was pretty grave. When they said it was grave, and there was a good chance he couldn't come home, we said that we wanted comfort care.*

DR N: *She knew that her father was dying. They were expecting it at any time. [Later] His feet were now mottled even*

above the ankle and were cool to the touch. His pulse was thready. He had open-mouth breathing, though I didn't see his jaw moving. I talked to the family and told them that these things that I observed made me think that he was closer to the end of his life. I told them that I wouldn't be surprised if something happened that day. They still seemed to appreciate the information. It seems to be helpful to know that it could happen at any moment. And it could happen when they were out of the room. It might be that the patient is waiting for them to leave, because it's hard and they don't want to burden their loved one with having to be there at the time that they die.

MR R'S DAUGHTER: *I felt he was very good about trying to explain to us where my dad was in this process.*

Prognostication involves both acts of prediction and the art of communication.^{2,6} In this case, Dr N demonstrated a keen awareness of prognostic signs of the last 48 hours of life—signs that Morita et al⁷ identified as commonly preceding death (TABLE). Dr N also demonstrated the importance of communication by acknowledging uncertainty. Prognosis should be provided in terms of ranges, not dates (eg, minutes to hours, hours to days, days to weeks, weeks to months). Prognostic uncertainty helps family members who wish to conduct a death vigil understand that it is difficult to know the exact timing of death. Finally, the clinician should emphasize that the trend of how the patient is doing is the most important prognostic tool and that the prognosis will be updated with the family as the patient's condition changes. If death occurs when the family is away, family members may experience guilt, anger, or great regret. Suggesting a positive framing for such an event ("perhaps he found it difficult to leave with you present . . .") may provide solace.

Symptom Management

DR N: *He was [receiving morphine], 2 mg every 4 hours [intravenously]. I think that by the end of his life it was up to every 2 hours. Because there was some concern that he had gotten a little uncomfortable and his respiratory rate had increased, they increased the frequency.*

MR R'S DAUGHTER: *We didn't want him to suffer; we wanted him to be peaceful.*

In a survey of 310 patients with serious, life-limiting illnesses, freedom from pain was ranked first in importance.⁸ Yet the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) found that fully half of bereaved family members thought that their loved ones were in moderate to severe pain 50% of the time in the last 72 hours of life.⁹ With good palliative care, most deaths can indeed be peaceful and relatively free of discomfort although symptom management remains challenging.^{10,11}

Of major physical symptoms, pain and dyspnea are both prevalent and distressing if they are not skillfully addressed.^{9,12,13} Among actively dying cancer patients, prevalence rates for pain have been reported to range from 51% to 100% and for dyspnea, from 22% to 46%.^{10,14-16} Studies

of patients without cancer are limited but suggest that such patients may have more difficulty with dyspnea than do cancer patients. In a chart audit of 238 deceased nursing home patients of whom only 14% had cancer, 42% were noted to have pain and 62% experienced dyspnea in the last 48 hours.¹² Many patients and families fear worsening of symptoms as death approaches and may need reassurance that such is not necessarily the case. Good medical management can usually provide reasonable palliation. In a study of 200 patients with cancer enrolled in a home and inpatient hospice program, Lichter and Hunt¹⁰ judged 91.5% of deaths to be peaceful. Ellershaw et al¹¹ found that 85% of 168 patients with cancer had good symptom control in the last 48 hours.¹¹ Two separate studies both found that the prevalence of pain in treated cancer patients tended to decrease over the last few days and hours of life,^{11,17} but 1 of these studies also found that some symptoms increased in frequency over the final 2 weeks of life, including asthenia (76.7% increasing to 81.8%), anorexia (68.2% to 80.1%), and dry mouth (61.4% to 69.9%). The symptom with the greatest increase in prevalence was mental confusion (30.1% to 68.2%).¹⁷ In the terminal phase, as many as 85% of people may experience some altered mental status or delirium, which often is not reversible^{18,19} even with best efforts.²⁰ Although not all such altered states are distressing,⁶ Ellershaw et al¹¹ found that the 13.4% rate of agitation 48 hours before death could be reduced with therapy. Many dying patients display signs of retained respiratory secretions, sometimes called the *death rattle*.¹¹ Although this is often disturbing to family members, it is unclear whether patients themselves find it distressing.

Comprehensive reviews of treatment options for symptoms observed in the last 48 hours are readily available,^{21,22} but few standardized clinical pathways for care of the actively dying have emerged.^{11,23} Opioids are commonly administered for pain and dyspnea, but for nonverbal patients, such as Mr R, it is not always clear if tachypnea reflects discomfort. Mr R's increased respiratory rate may have been a sign of increasing dyspnea, pain, or underlying agitation or may simply have reflected a compensatory respiratory alkalosis in response to a metabolic acidosis. Generally, once started, opioids should be continued in the last 48 hours. Commonly, when increased pain or dyspnea is a concern, the dose may be increased by 25% to 50%. In nonhospital settings, patients who are no longer able to take medications orally may need subcutaneous infusions, transdermal preparations, nebulizations, or concentrated oral solutions.²⁴⁻²⁶ Relief of dyspnea best correlates with steady state blood levels of opioids, as does pain relief, whereas suppression of respiratory drive results from rapid increases in opioid blood levels, not steady state levels. Furthermore, dyspnea relief is not a function of respiratory drive suppression.²⁷⁻³⁰ Thus, opioids, when reasonably and properly administered at the end of life, should not hasten death.³¹ Although it may be appropriate to treat pain or dyspnea pre-

sumptively, the goal of such therapy should not be simply to reduce the respiratory rate per se, which is just one of a number of possible markers of distress. Oxygen administration may also relieve dyspnea via mechanisms other than by raising oxygen saturation.³²

Traditionally, care for agitated delirium emphasizes attempting to clear the sensorium, but this is not possible for most patients in the last few days of life.²⁰ The clinician should search for and treat correctable causes of agitation, such as medication adverse effects, pain, bladder distention, or other physical discomforts, but in nonverbal patients, it is not always possible to determine whether physical discomfort is causing agitation. Often palliative therapies are attempted in an iterative fashion to determine whether agitation is reduced. If no such conditions are identified, sedating agents, such as benzodiazepines; neuroleptics, such as chlorpromazine; or even barbiturates may be used, following consultation and informed consent from the patient, family member, or proxy. In most cases, small doses of these agents suffice to relieve agitation. Administration of high doses of sedating agents, so-called terminal or palliative sedation, for symptoms is seldom needed.^{33,34} There is no evidence that the use of sedating agents at the end of life, when properly administered, hastens death.³⁵ Because families are understandably distressed at witnessing delirium in the dying person, they may benefit from emotional support from clinicians.^{36,37}

Retained respiratory secretions can be treated with anticholinergic agents, such as atropine, scopolamine, or glycopyrrolate, and by turning the patient to the side.^{38,39} In this case, atropine eye drops were given sublingually, as is common practice in many hospices and palliative care units. Although there is anecdotal concern that atropine may be a less desirable agent to use because it may cause agitation, there are no good clinical trials comparing atropine with other drugs. Deep suctioning is uncomfortable and should be avoided.

Communication and Coaching the Family

MR R'S DAUGHTER: *It was to the point where, even though he was not in pain, they had increased the morphine from [every] 4 hours to 2 hours. I have a girlfriend who is a nurse and she was honest with me in telling me that as the morphine is increasing, the morphine is sort of killing him, too. [A]bout the morphine, they didn't tell us what that was really doing to him. I didn't relay what I knew about the morphine to any other member of the family.*

DR N: *We've been there before and we know what to expect, and we know what's normal, and by extension, we know what's not normal . . . [so we are able to say] "If anything comes up, we're going to treat him, so let us know if you have any questions or concerns, because there's a lot we can do for your dad."*

These 2 comments illustrate that families and clinicians often have very different perspectives of the same event, in this case the escalation of the morphine dose. Excellent communication is required to avoid misunderstandings. In-

Box 1. Counseling About Palliative Care Interventions

Be clear about intent of intervention

“We would like to increase his morphine dose because we are concerned that he might be experiencing some pain (or shortness of breath).”

Inquire as to understanding of action and concerns

“What is your understanding of (the proposed action)? Do you have any concerns?”

Address spoken (and commonly unspoken) concerns

“We do not believe this action will hasten death, nor is this our intent.”

“Our goal is to enable him to die a natural and peaceful death, letting it unfold at its own pace.”

Box 2. Clinician Checklist for Actively Dying Patients

Evaluate for and treat new symptoms

Pain

Dyspnea

Dry mouth

Agitation

Retained respiratory secretions

Review current medications and therapies

Switch essential medications to nonoral route

Stop unnecessary medications, procedures, monitoring, such as blood pressure, oxygen saturation, continuous cardiac monitoring

Connect with family: engage, coach, and console

Enlist additional support from

Other clinicians, such as social workers, psychologists, chaplains

Friends, community, or spiritual leaders

creasing the patient’s morphine for possible discomfort was a reasonable intervention, and there is no indication that the intent was for a hastened death or that death was, in fact, hastened. Nevertheless, the daughter’s interpretation of the increase, reinforced by incorrect counsel from a nurse friend, was that death was hastened. Uncertainty regarding this haunted the daughter following her father’s death. In an otherwise well-managed case, this lack of understanding suggests that communication about the dosage change was inadequate and that better coaching was needed. Approaches to explaining the intent behind dose escalation and inquiring about family concerns appear in **BOX 1**.

Coaching builds on a foundation of mutual understanding developed through good communication. The clinician-coach facilitates new relationships between the family and

the dying person, whose condition is changing rapidly and radically. For example, when patients stop eating and drinking, families may interpret this to mean that their loved one is starving to death. Pointing out how different these changes are from starvation or “dying of thirst” can help alleviate these concerns.⁴⁰ However, simply stating this is often not enough. Families wish to nurture their loved ones, even in their dying. Although usual food may not be tolerated, the clinician may suggest that families help by using ice chips or mouth swabs for dry mouth. When patients become nonverbal or unresponsive, many family members grieve the loss of 2-way communication and may believe that the patient is unconscious or in a coma, which may not be the case. Counseling that hearing and touch are the last senses to go and suggesting that their presence, their loving words, and their touch may comfort the dying encourages a continuing relationship. So doing also offers family and loved ones an opportunity for any parting words, such as asking for (and giving) forgiveness, expressing love and thanks, and bidding farewell.^{41,42} Additional coaching and support may best be provided by other members of the health care team. **BOX 2** presents a summary checklist of interventions to consider in caring for the actively dying patient.

Death Enters the Room

MR R’S DAUGHTER: *They set the morphine drip at 10 o’clock that night, and we got the call that he had passed away at quarter to midnight. I had just gotten home about half an hour prior to the call. We got up, picked everyone up, and went back to the hospital.*

Although the details of Mr R’s passing are not available, hopefully it was peaceful. Yet, one wonders, who pronounced his death and how was this done? Who called the family and how was the family informed of this on the telephone? Did someone greet the family when they came into the hospital? How were condolences offered, and how was the family consoled and counseled? It would be a mistake to view these as bureaucratic details. How these issues are addressed may leave lasting impressions on the bereaved. Sadly, this important and sensitive work is too often relegated to the most junior clinicians such as interns, who have had little or no training as to how to do it skillfully.^{43,44} Suggestions for telephone notification of death are presented in **BOX 3**.

Death is usually an easy diagnosis. Certifying death does not require any particular examinations. If death is uncertain, lack of pulse, breath sounds, and heartbeat will usually suffice. Occasionally, the clinician may be fooled by a prolonged respiratory pause, as occurs in Cheyne-Stokes respirations. If in doubt, observation of respirations for several minutes is advised. Such common practices as shining a bright light into the pupils or assessing for pain with a sternal rub are unnecessary and strongly discouraged.

Death pronouncement is a solemn ritual, the importance of which transcends the business of certification. If family is present, pronouncement may formally give permission for loved ones to grieve. As a rule, families should not be asked to leave during pronouncement although some may wish to do so. In the process of pronouncement, condolences can be offered and the bereaved consoled. Even if no one else is present, pronouncement provides an opportunity for clinicians to say good-bye, to reflect on care delivered, and to bear witness to the passing of another human being.⁴⁵ Suggestions for death pronouncement are presented in BOX 4.

After Death Care and Cultural Sensitivity

MR R'S DAUGHTER: *They had already cleaned him up in the bed. We cried and said our good-byes. The nurse was really great and told us we could take our time. We went through our grieving and cried and held each other.*

DR N: *[T]hey basically just spent the night with him, sitting there with him. Then, at 7 in the morning, at shift change, they left. I thought that was really lovely. The daughter didn't describe it as a particularly religious or cultural ritual but just something that they wanted to do, just to be there with him.*

The time of death is often heavily invested with cultural and religious ritual.⁴⁶ Such rituals frequently give rise to cross-cultural misunderstandings or frank conflict with standard hospital procedures. For example, in some cultures only same-sex workers should touch the body.^{43,47} When dealing with a family from an unfamiliar ethnic group or religion, the clinician should inquire, ideally in advance, if any special accommodations need to be made for cultural or religious reasons.⁴⁸ If not done previously, the clinician should ask if the family wishes to speak with a chaplain or other spiritual advisor. When in doubt, seek assistance from someone familiar with that culture or religion.^{49,50} Pulchalski⁵¹ has suggested several ways to address spirituality with patients or families, including asking them, "Are you part of a religious or spiritual community?" and "Can we be of assistance to you in the practice of your spirituality at this time?"

Autopsy, Organ or Body Donation, and Funeral Arrangements

If possible, inquiries about autopsy, organ or body donation, and funeral arrangements are best discussed prior to death, because acutely bereaved families may be too distraught to address them rationally soon after a death. In raising the questions before death, the clinician may suggest that discussing them might lessen the stress that usually follows death. In certain situations, an autopsy will be required by law, as in cases in which a coroner determines that death might have resulted from foul play.⁵² Otherwise, inquiries about autopsy or organ donation, where appropriate, should be presented as options.⁵³⁻⁵⁵ Suggestions for inquiring about autopsy and organ donation are outlined in BOX 5.

Box 3. Telephone Notification of Death

Inquire as to where the person is and whether alone (if driving while on a cell phone, advise the person to pull over and park)

Identify self, relationship to the deceased (physician on-call), give brief advanced alert ("I'm sorry I have some bad news"), and then give the news

Listen more than you speak; if questions arise, answer them briefly; for more detailed inquiries, reassure the caller that these can be answered later

Do NOT say that the person must come in right away—give permission to let feelings settle; suggest coming in with a family member or friend

Give clear instructions as to where to go and whom to contact (the caller or charge nurse) when arriving at the hospital
Finish with an empathetic statement, such as, "This must be very hard for you. Please let me know if there is anything else I can do to help."

Box 4. Death Pronouncement

If called to pronounce someone unknown to you

Inquire as to the circumstances of the death (anticipated or not)

Inquire as to whether family is present and, if present, their condition (quietly grieving, dazed, angry, etc)

On entering the room of the deceased:

First, calm yourself

If family are present

Assess their initial reaction (actively grieving or anxiously waiting for your evaluation)

Do NOT ask them to leave—you should be able to do a brief examination with family present—pulse, respirations, and heartbeat

Clearly communicate that the person has died and offer condolences

Pause for their acute grief reaction; remain quiet, yet available; do not speak too much

Respond simply to immediate reactions and questions

Console as you feel is appropriate to your relationship

Give permission for them to take some time prior to next steps such as autopsy requests or notification of others

In departing, model saying good-bye to the deceased, as seems appropriate to the circumstances

Following Up

DR N: *I called Mr R's daughter about a week later to see how she was doing. [I] just asked her how it went and listened to her tell the story. She seemed like she was doing*

Box 5. Inquiries About Autopsy or Organ Donation

Present autopsy or donation as an option

Inquire regarding prior discussions, understandings, and plans

Indicate that autopsy can be limited to certain parts of the body

State that the person's remains will be treated with respect

Identify potential benefits of autopsy

For family—better understanding of what led to death, possibly resolve lingering questions about therapeutic choices or underlying illness, and learning about diseases with possible genetic implications for family, such as dementia, heart disease, and cancer

For society and other individuals—benefits of organ donation and expansion of medical knowledge

For clinicians—better understanding of patient's illness, resolution of lingering questions, and furtherance of clinician education

Anticipate and address possible family concerns

Personal or cultural objections

Disfigurement of body and disposition of remains

Delay of funeral or burial services (problematic in some cultures)

Expense (if autopsy must be paid for)

Potential impact of the autopsy results on the family (if findings might be surprising or disturbing, such as identification of a genetic disease)

Explain plan for communicating autopsy (or organ donation) results following its performance, indicating when and how family will be informed

okay . . . sad . . . good days, bad days, not horribly distraught, but appropriately sad and philosophical about it.

MR R'S DAUGHTER: *I trusted the doctors and felt that they knew what they were doing. I wondered how they knew that we had to increase the morphine that much . . .*

Follow-up calls, as made by Dr N, are not routine in the hospital setting. All health care institutions should establish standards that require condolence calls to be made if someone dies in their facility.⁶ Clinicians may also wish to send a condolence letter.⁵⁹ Here, the family seemed to be adjusting well although the daughter did have second thoughts about the use of morphine. Some questions, like this one, can only be answered by physicians. Clinicians should be prepared to provide referrals to counselors for more intensive follow-up for family members at risk of complicated bereavement.⁵⁷⁻⁵⁹

Clinicians also grieve the loss of their patients. The loss of some patients will be felt more acutely than others. Clinicians are advised to enlist formal and informal networks of support, as are available. To not do so is to risk burnout and aversion to the care of the dying.^{60,61}

CONCLUSION

Excellent care for actively dying patients requires a number of core competencies from symptom management to prognostication and communication. These skills should be included in core curricula for all clinicians caring for dying patients. It is an honor to care for people at the end of life, helping them to write their final chapters. Most deaths, like this one, are accompanied by sadness. Yet, there is much that clinicians can do to help dying patients and those they leave behind. In competently and compassionately providing care, we can achieve a level of job satisfaction that can be profound and sustaining. As in this case, families and loved ones will long remember the work we do. We have a vested interest in improving the quality of care delivered at the end of life. For we, our families, and our friends will all be recipients of care from those who follow in our footsteps.

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Other Sources: For a list of relevant Web sites, see the article on the JAMA Web site at <http://www.jama.com>.

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WEB SITES FOR END-OF-LIFE CARE RESOURCES

End-of-Life Palliative Education Center (EPERC)

<http://www.eperc.mcw.edu>

A wealth of peer-reviewed educational material. Home of the "Fast Facts" series, including a series on treating terminal delirium, the syndrome of imminent death, death pronouncement in the hospital, delivering bad news, morphine and hastened death, taking a spiritual history, opioid dose escalation, writing a condolence letter, prognostication, grief and bereavement, discussing hospice, telephone notification of death, death rattle and oral secretions, and discussing organ donation.

The Inter-Institutional Collaborating Network on End of Life Care (IICN)

<http://www.growthhouse.org/iicn.html>

The Inter-Institutional Collaborating Network on End of Life

Care is a partnership effort by many educational organizations using technology provided by Growth House Inc. The IICN MegaSearch service provides access to more than 4000 pages of high-quality educational content on care at the end of life.

The EPEC (Education on Palliative and End-of-Life Care) Project

<http://epec.net>

Training opportunities through conferences and an online course with CME are available.

The Stanford Faculty Development Center Curriculum on End-of-life Care

<http://www.growthhouse.org/stanford>

A 16-hour curriculum is available for downloading, including an extensive teaching manual.