

Competency in End-of-Life Care: Last Hours of Life

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ABSTRACT

Clinical competence, willingness to educate, and calm and empathic reassurance are critical to helping patients and families in the last hours of living. This review adapted from the Education for Physicians on End-of-Life Care (EPEC) Curriculum describes the predictable course that occurs as well as approaches to management. Management principles are the same at home or in a health care institution. However, death in an institution requires accommodations to assure privacy, cultural observances, and communication that may not be customary. In anticipation of the event, it helps to inform the family and other professionals about what to do and what to expect. Care does not end until the family has been supported with their grief reactions and those with complicated grief helped to get care. Care at the end of life is a core competency.

INTRODUCTION

VIRTUALLY ALL HEALTH CARE PROFESSIONALS participate in the care of dying patients and their families at some point in their careers. Of all patients who die, only a few (<10%) die suddenly and unexpectedly. Most (>90%) die after a long period of illness with gradual deterioration until an active dying phase at the end.¹ The care provided during those last hours and days can have profound effects, not just on the patient, but on all who participate. At the very end of life, there is no second chance to get it right.

We first summarize the physiologic changes that occur as patients are dying, and approaches to the management of associated symptoms. Then, we discuss care at the time of death. Finally, we discuss loss and the assessment and management of normal and complicated grief reactions.

PHYSIOLOGICAL CHANGES AND SYMPTOM MANAGEMENT

There are a variety of physiologic changes that occur in the last hours and days of life. Each can be alarming if it is not understood. The most common issues are summarized here.

Weakness and fatigue

Weakness and fatigue usually increase as the patient approaches the time of death. It is likely that the patient will not be able to move around in the bed or raise his or her head.² Because this is irreversible, weakness and fatigue need not be resisted and most treatment to alleviate it can be discontinued. Joints may become uncomfortable if they are not moved.³ Continuous pressure on the same area of skin, particularly over bony prominences, will increase the risk of skin isch-

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emia and pain.⁴ As the patient approaches death, providing adequate cushioning on the bed will lessen the need for uncomfortable turning.

Decreased oral intake

Most patients lose their appetite.⁵ Unfortunately, families and professional caregivers may interpret cessation of eating as "giving in" or "starving to death." Yet, studies demonstrate that parenteral or enteral feeding of patients near death neither improves symptom control nor lengthens life.⁶⁻¹⁰ Anorexia may be helpful because the resulting ketosis can lead to a sense of well-being and diminish discomfort. Help direct families and caregivers to find alternate ways to express their need to provide appropriate physical care and emotional support to the patient.

Most patients stop drinking.¹¹ This may heighten onlookers' distress because they worry that the dehydrated patient will suffer, particularly if he or she becomes thirsty. Most experts feel that dehydration in the last hours of living does not cause distress and may stimulate endorphin release that promotes the patient's sense of well-being.¹²⁻¹⁴ Low blood pressure or weak pulse is part of the dying process and not an indication of dehydration. Patients who are not able to be upright do not get lightheaded or dizzy. Patients with peripheral edema or ascites have excess body water and salt and are not dehydrated.

Parenteral fluids, either intravenously or subcutaneously using hypodermoclysis, are sometimes considered, particularly when the goal is to reverse delirium.¹⁵ However, parenteral fluids may have adverse effects that are not commonly considered. Intravenous lines can be cumbersome and difficult to maintain. Changing the site of the angiocatheter can be uncomfortable, particularly when the patient is cachectic or has no discernible veins. Excess parenteral fluids can lead to fluid overload with consequent peripheral or pulmonary edema, worsened breathlessness, cough, and orotracheobronchial secretions, particularly if there is significant hypoalbuminemia. Maintain patient comfort and minimize the sense of thirst, even in the face of dehydration, with meticulous oral, nasal, and conjunctival hygiene.¹⁶

Diminished blood perfusion

As cardiac output and intravascular volume decrease at the end of life, there will be evidence of diminished peripheral blood perfusion. Tachy-

cardia, hypotension, peripheral cooling, peripheral and central cyanosis, and mottling of the skin (livedo reticularis) are normal. Venous blood may pool along dependent skin surfaces. Urine output falls as perfusion of the kidney diminishes. Oliguria or anuria is normal. Parenteral fluids will not reverse this circulatory shut down.¹⁷

Neurologic changes

The neurologic changes associated with the dying process are the result of multiple concurrent irreversible factors. These changes may manifest themselves in two different patterns that have been described as the "two roads to death" (Fig. 1).¹⁸ Most patients follow the "usual road" that presents as decreasing level of consciousness that leads to coma and death.

Terminal delirium

An agitated delirium may be the first sign to herald the "difficult road to death." It frequently presents as confusion, restlessness, and/or agitation, with or without day-night reversal.¹⁹ To the family and professional caregivers who do not understand it, agitated terminal delirium can be distressing. Although previous care may have been excellent, if the delirium goes misdiagnosed or unmanaged, family members will likely remember a horrible death "in terrible pain" and cognitive impairment "because of the drugs" and may worry that their own death will be the same.

If the patient is not assessed to be imminently dying, it may be appropriate to evaluate and try to reverse treatable contributing factors. However, if the patient is in the last hours of his or her life, the condition is by definition irreversible. Management appropriately focuses on the management of the symptoms associated with the terminal delirium in order to settle the patient and the family.²⁰

When moaning, groaning, and grimacing accompany the agitation and restlessness, they are frequently misinterpreted as physical pain.²¹ However, it is a myth that uncontrollable pain suddenly develops during the last hours of life when it has not previously been a problem. While a trial of opioids may be beneficial in the unconscious patient who is difficult to assess, physicians must remember that opioids may accumulate and add to delirium when renal clearance is poor.^{22,23} If the trial of increased opioids does not relieve the agitation or makes the delirium worse

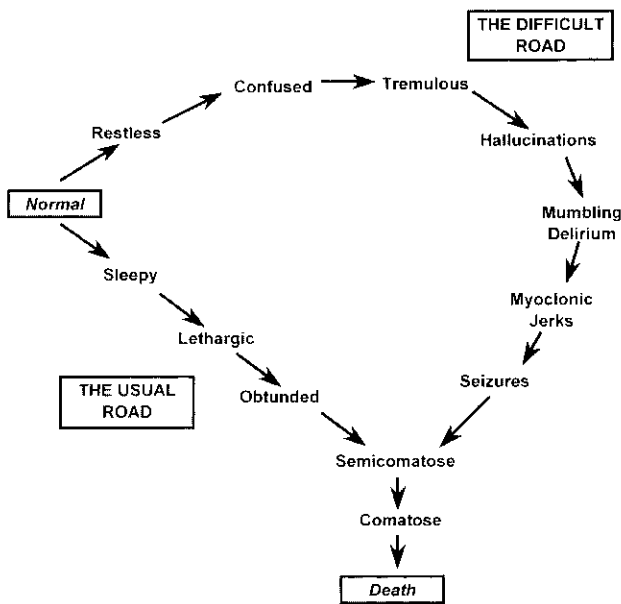


FIG. 1. Two roads to death.

by increasing agitation or precipitating myoclonic jerks or seizures (rare), then pursue alternate therapies directed at suppressing the symptoms associated with delirium.

Benzodiazepines are used widely to treat terminal delirium as they are anxiolytics, amnestics, skeletal muscle relaxants, and antiepileptics (Table 1).²⁴ Oral lorazepam can be administered against the buccal mucosa and dose escalated to effect. Infusional benzodiazepines may be a rapidly effective alternative.

Benzodiazepines may paradoxically excite some patients.²⁵ These patients require neuroleptic medications to control their delirium. Haloperidol given intravenously, subcutaneously, or rectally may be effective.²⁶ A more sedating alternative is chlorpromazine given intravenously or rectally.²⁷ Barbiturates or propofol have been suggested as alternatives.^{28,29}

Decreased communication

Families frequently find their decreasing ability to communicate with a dying patient to be distressing. As many clinicians have observed, the degree of family distress sometimes seems to be inversely related to the extent to which advance planning and preparation occurred. The family report of having "said what they needed to say" before neurologic dysfunction occurs is an important outcome. In addition, experience from other unconscious patients suggests that their awareness may be greater than their ability to respond. Therefore, it is prudent to advise families and professional caregivers to talk to the patient as if he or she was conscious.

Families may need permission to create a familiar environment that includes children, pets, things, music, and sounds. At times, it may seem that a patient may be waiting for permission to die. If this is the case, encourage family members to give the patient permission to "let go" and die in a manner that feels most comfortable to them. As touch can heighten communication, encour-

TABLE 1. SOME COMMON PHARMACOLOGIC AGENTS USED IN THE LAST HOURS

Drug	Dosing	Notes
Lorazepam	1-2 mg pr, sl, sc, iv q1h to titrate then q4-6h to maintain	If paradoxical agitation observed, choose a non benzodiazepine for sedation.
Haloperidol	2-5 mg pr, sc, iv q1h to titrate then q6h to maintain	Relatively nonsedating at low doses. May require 10-30 mg daily to sedate.
Chlorpromazine	10-25 mg pr, iv q4-6h	Parenteral route may require special exemptions from standard nursing policy in some settings.
Scopolamine (hyoscine hydrobromide)	10-100 µg/hr sc/iv continuous infusion or 0.1-0.4 mg sc q6h or 1-10 patches q72h	Transdermal preparation only delivers approximately 10 µg/hr and takes many hours to reach therapeutic levels.
Glycopyrrolate	0.2-0.4 mg sc q2-4h and titrate	Does not cross blood-brain barrier.

age family members to show affection in ways to which they are accustomed. Permission may be required for the family member to lie beside the patient in privacy and intimacy.

Changes in breathing patterns

Changes in a dying patient's breathing pattern may be indicative of significant neurological compromise.³⁰⁻³² Breaths may become shallow and frequent with a diminishing tidal volume. Periods of apnea and/or Cheyne-Stokes pattern respirations may develop. Accessory respiratory muscle use may become prominent. A few (or many) last reflex breaths may signal death.

Families and professional caregivers frequently find changes in breathing patterns to be one of the most distressing signs of impending death. Many fear that the comatose patient will experience a sense of suffocation. Knowledge that the unresponsive patient may not be experiencing breathlessness or "suffocating," and may not benefit from oxygen may be comforting. Low doses of opioids or benzodiazepines are appropriate to manage any perception of breathlessness.

Loss of ability to swallow

Weakness and decreased neurological function frequently combine to impair the patient's ability to swallow. The gag reflex and reflexive clearing of the oropharynx decline and secretions from the tracheobronchial tree accumulate. These conditions may become more prominent as the patient loses consciousness. Build up of saliva and oropharyngeal secretions may lead to gurgling, crackling or rattling sounds with each breath.³³ Some have called this the "death rattle" (a term frequently disconcerting to families and caregivers).

Once the patient is unable to swallow, cease oral intake. Warn families and professional caregivers of the risk of aspiration. Scopolamine or glycopyrrolate will effectively reduce the production of saliva and other secretions (Table 1).³⁴⁻³⁵ They will minimize or eliminate the gurgling and crackling sounds, and may be used prophylactically in the unconscious dying patient. Anecdote suggests that the earlier treatment is initiated, the better it works, as larger amounts of secretions in the upper aerodigestive tract are more difficult to eliminate. However, premature use in the patient who is still alert may lead to

unacceptable drying of oral and pharyngeal mucosa. While atropine may be equally effective, it has an increased risk of producing undesired cardiac and/or central nervous system (CNS) excitation.³⁶

If excessive fluid accumulates in the back of the throat and upper airways, it may need to be cleared by repositioning or postural drainage. Oropharyngeal suctioning is likely to be ineffective if fluids are beyond the reach of the catheter. Continued efforts to suction may only stimulate an otherwise peaceful patient and distress family members who are watching.

Loss of sphincter control

Fatigue and loss of sphincter control in the last hours of life may lead to incontinence of urine and/or stool. Both can be distressing to patients and family members, particularly if people are not warned in advance that these problems may arise. If they occur, attention needs to be paid to cleaning and skin care. A urinary catheter may minimize the need for frequent changing and cleaning, prevent skin breakdown, and reduce the demand on caregivers. However, it is not always necessary if urine flow is minimal and can be managed with absorbent pads or surfaces. If diarrhea is considerable and relentless, a rectal tube may be similarly effective.

Inability to close eyes

Eyes that remain open can be distressing to on-lookers unless the condition is understood. Advanced wasting leads to loss of the retro-orbital fat pad, and the orbit falls posteriorly within the orbital socket.³⁷ Because eyelids are of insufficient length to both extend the additional distance backward and cover the conjunctiva, they may not be able to fully appose. This may leave some conjunctiva exposed even when the patient is sleeping. If conjunctiva remains exposed, maintain moisture by using ophthalmic lubricants, artificial tears, or physiologic saline.³⁸

Reassess the need for each medication and minimize the number that the patient is taking. Leave only those medications to manage symptoms such as pain, breathlessness, excess secretions, and terminal delirium and reduce the risk of seizures. Choose the least invasive route of administration: the buccal mucosa or oral routes first, the subcutaneous or intravenous routes only if necessary, and the intramuscular route almost never.

WHEN DEATH OCCURS

No matter how well families and professional caregivers are prepared, they may find the time of death to be challenging. Families, including children, and caregivers may have specific questions for the physician. Basic information about death may be appropriate (Table 2).^{39,40}

There are no universally applicable "rules" that govern what happens when the patient dies (in any setting). If the patient dies an expected death at home there is no need to call for emergency assistance. If a hospice program is involved, have the family call the hospice. If a hospice program is not involved, determine in advance who should be notified. Unless death is unexpected, or malice is suspected, involvement of the coroner's office is usually not required (local regulations may vary).

When expected death occurs, the focus of care shifts from the patient to the family and those who provided care. Even though the loss has been anticipated for some time, no one will know what it feels like until it actually occurs, and indeed it may take hours to days to weeks or even months for each person to realize the full effect.

Many experts assert that the time spent with the body immediately after the death will help people with acute grief.⁴¹⁻⁴³ Those present, including caregivers, may need the physician's permission to spend the time to come to terms with the event and say their good-byes. There is no need to rush, even in the hospital or other care facility. Encourage those who need to touch, hold, and even kiss the person's body as they feel most comfortable (while maintaining universal body fluid precautions). As a visually peaceful and accessible environment may facilitate the acute grieving process, a few moments spent alone in the room positioning the patient's body, discon-

necting any lines and machinery, removing catheters, and cleaning up any mess will allow the family closer access to the patient's body.⁴⁴⁻⁴⁵

Spiritual advisors or other interdisciplinary team members may be instrumental in orchestrating events to facilitate the experience of those present. Those who have not been present for the death may benefit from listening to a recounting of how things went leading up to the death and afterward. Grief reactions beyond cultural norms suggest a risk of significant ongoing or delayed grief reactions.

When letting people know about the death, follow the guidelines for communicating bad news. Try to avoid breaking unexpected news by telephone, because communicating in person provides much greater opportunity for assessment and support. If additional visitors arrive, spend a few moments to prepare them for what they are likely to see.

Once family members have had the time they need to deal with their acute grief reactions and observe their customs and traditions, then preparations for burial or cremation and a funeral or memorial service(s) can begin. Some family members may find it therapeutic to help bathe and prepare the person's body for transfer to the funeral home or the hospital morgue. For many, such rituals will be their final act of direct caring.

Depending on local regulations and arrangements, some funeral directors will insist on the completed death certificate being present before they pickup the body. All will require a completed death certificate to proceed with any body preparation and registration of the death. To avoid delaying the process, ensure that the physician who will complete the certificate has ample warning that one will be required.

For many, moving the body is a major confrontation with the reality of the death. Some family members will wish to witness the removal. Others will find it very difficult and will prefer to be elsewhere. Once the body has been removed and family members are settled, professional caregivers can offer to assist them with some of their immediate tasks. They may notify other physicians and caregivers that the death has occurred so that services can be stopped and equipment removed. Local regulations governing the handling of medications and waste disposal after a death vary. When family members are ready, professional caregivers can let the family know how to reach them, then leave them to have some privacy together.

TABLE 2. SIGNS OF DEATH

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1. The heart stops beating.
 2. Breathing stops.
 3. Pupils become fixed and dilated.
 4. Body color becomes pale and waxy as blood settles.
 5. Body temperature drops.
 6. Muscles and sphincters relax.
 7. Urine and stool may be released.
 8. Eyes may remain open.
 9. The jaw can fall open.
 10. The trickling of fluids internally can be heard.
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Immediately after the death, those who survive will need time to recover. A bereavement card from the physician and attendance at the patient's funeral may be appropriate.⁴⁶ For many physicians and members of the professional team, encouraging follow-up visits from family members to assess the severity of their grief reactions to their recent loss, coping strategies, and provide support is a part of their professional duty of care. Professional members of the interdisciplinary team can also offer to assist family members to deal with outstanding practical matters, secure documents to redeem insurance, find legal counsel to execute the will, meet financial obligations, close the estate, etc. Bereavement care for the family is a standard part of hospice care in the United States.

DYING IN INSTITUTIONS

The preceding discussion is relevant to patients dying in any setting (e.g., at home, in hospital, in nursing homes, other extended care facilities, jails, etc.). However, a few remarks are warranted regarding the particular challenges of ensuring a comfortable death in an institution whose culture is not focused on end-of-life care.⁴⁷

When death is imminent, it is appropriate that patients remain with caregivers they know, rather than be transferred to another facility. Institutions can help by making the environment as home-like as possible. It is appropriate for the physician to order a private room where family can be present continuously and be undisturbed with the patient if they so choose. The physician will want to cue the professional staff and encourage continuity of care plans across nursing shifts and changes in house staff.

Priorities and care plans at the end of life differ considerably from those for life-prolongation and cure. It is frequently challenging for physicians and other health care professionals to incorporate both into a busy hospital or skilled nursing facility. For this reason, specialized units where patients and families can be assured of the environment and the skilled care they need have been developed in many institutions.^{48,49}

LOSS AND GRIEF DURING LIFE-THREATENING ILLNESS

To be effective in end-of-life care, health professionals need to be able to recognize grief and

assist with appropriate interventions for patients, their family caregivers, and themselves. Grief is the response to loss.⁵⁰ Throughout the course of a life-threatening illness, patients and families confront many different anticipated, if not actual, losses (e.g., loss of functional capabilities, control, independence, body image, dignity, relationships, sense of future, etc.). As illness progresses, the loss of control over fundamentally important aspects of their lives increases, at times dramatically. Grief reactions (i.e., the emotional reactions to loss) may be pronounced.⁵¹⁻⁵³

Normal grief reactions include a whole range of physical, emotional, and cognitive behaviors (Table 3).^{54,55} Some people will make a conscious effort to deal with the loss. Others will deny what is happening and avoid dealing with the loss. Some coping strategies (e.g., increased smoking/alcohol/medication intake, overworking and suicidal ideation) may accelerate and even become destructive, especially in the face of seemingly insurmountable loss. Patients experiencing grief may seek assistance from their physicians for these symptoms. Recognition of the cause is important if useless or misleading investigations or medication trials are to be avoided.

When grief reactions occur over long periods of time, are very intense, or interfere with the survivor's physical or emotional well-being, they become symptoms of complicated grief.^{56,57} There are four categories of complicated grief reactions. Chronic grief is characterized by normal grief reactions that do not subside and continue over long periods of time. Delayed grief is characterized by normal grief reactions that are suppressed or postponed. In exaggerated grief, the survivor may resort to self-destructive behaviors such as

TABLE 3. NORMAL GRIEF REACTIONS

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1. Feelings of hollowness in the stomach.
 2. Tightness in the chest.
 3. Heart palpitations.
 4. Lack of energy.
 5. Gastrointestinal disturbances.
 6. Weight gain or loss.
 7. Emotional numbness.
 8. Emotional feelings (e.g., relief, sadness, fear, anger, guilt, loneliness, abandonment, despair, or ambivalence).
 9. Cognitive symptoms (e.g., disbelief, confusion, inability to concentrate, and preoccupation with, or dreams of, the deceased).
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suicide. Finally, in masked grief, the survivor is not aware that the behaviors that interfere with normal functioning are a result of the loss.

Be attuned to behaviors that might indicate complicated grief, especially if these continue beyond 6 to 12 months.⁵⁸ The survivor may not be able to speak of the deceased without experiencing intense sadness. Themes of loss may continue to occur in every topic during a clinical interview. Minor events may unexpectedly trigger intense grief and sadness. The survivor may be unwilling to move possessions belonging to the deceased. Sometimes the survivor will develop symptoms similar to those of the deceased. When complicated grief is suspected, referral for specialized help is warranted.

After a major loss, there are typically four tasks to complete before the bereaved will effectively deal with their loss. These tasks apply to the many losses that precede the death, as well as to the death itself. While the tasks are interdependent, they are not necessarily completed in sequence.

First, the bereaved must realize and accept that the loss or death has actually occurred. Second, they need to experience the pain caused by the loss. Because this can be distressing, many who are bereaved try to avoid the pain, and physicians frequently try to blunt it with medication. Third, they need to recognize the significance of their losses and the changes to their lives. Finally, as grief proceeds, the bereaved need to reinvest their energy into new activities and relationships.

These four tasks may seem relatively straightforward. However, for the person who is emotionally distraught and now feels very lonely and abandoned, each task may seem insurmountable and the degree of suffering may be experienced as extreme. While support from family and caregivers may be intense for the first few days or weeks after the death, the degree of support inevitably diminishes as others less affected get on with their lives.

Survivors may seek health care feeling like they are "going crazy" or "losing their minds." Yet, if grief reactions and coping strategies appear to be appropriate and effective, the situation can merely be monitored. In general, most people who are bereaved are able to resume usual activities after 1 to 3 weeks. However, grief can go on for a year or more. Sadness can continue for much longer but typically does not intrude on or prevent satisfying activities.

If grief reactions and coping strategies appear to be inappropriate or ineffective and/or they

have the potential to cause harm (e.g., destructive behaviors or suicide), they will need to be assessed and managed quickly. Consult someone who is skilled in loss, grief, and bereavement care so that therapy can be instigated quickly to reduce the risk of harmful/destructive activities.

SUMMARY

Clinical competence, willingness to educate and calm, empathic reassurance are critical to helping patients and families in the last hours of living. For the majority of dying patients, predictable physiologic changes occur. Management principles are the same at home or in a health care institution. However, death in an institution requires accommodations such as ensuring privacy, cultural observances, and communication that may not be customary. In anticipation of the event, it helps to inform the family and other professionals about what to do and what to expect, including matters such as when rigor mortis sets in, how to call the funeral home, say goodbye, and move the body. Care does not end until the physician has helped the family with their grief reactions and helped those with complicated grief to get care. Care at the end of life is part of the core competency of every physician⁵⁹ and evidence-based guidelines can guide care.⁶⁰

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