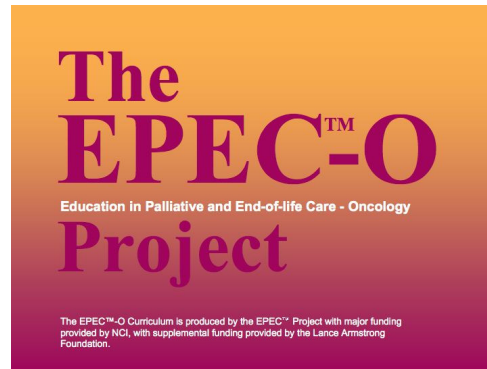
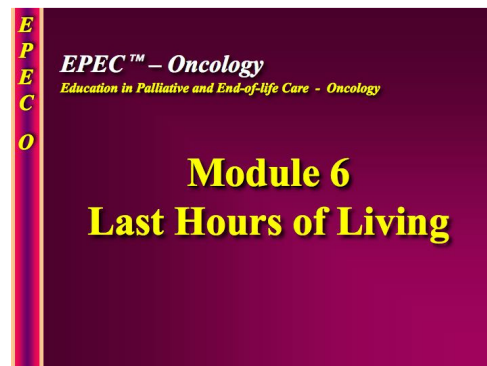


Slide 1



Slide 2



Abstract

Slide 3



Clinical competence, willingness to educate and calm, and empathic reassurance are critical to helping patients and families in the last hours of living. Clinical issues that commonly arise in the last hours of living include the management of feeding and hydration, changes in consciousness, delirium, pain, breathlessness, and secretions. 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, inform the family and other professionals about what to do and what to expect. Care does not end

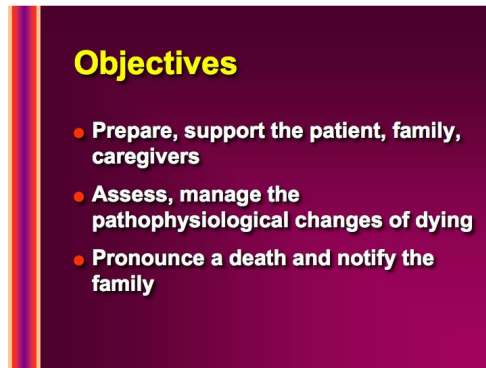
until the family has been supported with their grief reactions and those with complicated grief have been helped to get care.

Key Words

Bereavement, breathing changes, complicated grief, coroner, decreased appetite, decreased mobility, decreased perfusion, decreased thirst, delirium, expectations, eyes, fatigue, imminent death, moving the body, neurological dysfunction, normal grief, pain, rigor mortis, sphincter control, swallowing, tasks of caring

Objectives

Slide 4

A presentation slide with a dark purple background and a vertical rainbow-colored bar on the left. The title 'Objectives' is in yellow. Below it are three bullet points in white text.

Objectives

- Prepare, support the patient, family, caregivers
- Assess, manage the pathophysiological changes of dying
- Pronounce a death and notify the family

After reviewing this module, oncologists and other members of the cancer care team will be able to:

- Assist families to prepare for the last hours of life.
- Assess and manage the pathophysiologic changes of dying.
- Pronounce a death and notify the family.

Case Study Vignette

Slide 5

A presentation slide with a dark purple background and a vertical rainbow-colored bar on the left. The title 'Video' is in yellow.

Video

A.F. is a 79-year-old woman with metastatic breast cancer who is in her own home, cared for by her daughter with the help of the home hospice program. She developed aspiration pneumonia, and it was treated with oral antibiotics. Advance care planning indicates she does not want to go to the hospital under any circumstances, and oral antibiotics were an intermediate level of care. The patient and daughter agree that if she gets better, she may have some quality of time left. But if she doesn't, A.F. says she is ready to go. Her physician makes a joint home visit with the home hospice nurse in order to assess changes in mental status and because it sounds like her daughter panicked and considered calling 911.

Introduction

Slide 6

Last hours of living

- Everyone will die
 - <10% suddenly
 - >90% prolonged illness
- Unique opportunities and risks
- Little experience with death
 - Exaggerated sense of dying process

Virtually all oncologists participate in the care of dying patients and their families during 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 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 will first summarize the physiologic changes that occur as patients are dying and approaches to the management of associated symptoms. Then, we will discuss care at the time of death. Loss, grief, and bereavement are covered in **EPEC™-O Module 4: Loss, Grief, and Bereavement**.

Most oncologists have little or no formal training in managing the dying process or death. Most have neither watched someone die nor provided direct care during the last hours of life.

Families usually have even less experience or knowledge. Based on media dramatization and vivid imaginations, most people have developed an exaggerated sense of what dying and death are like. However, with appropriate management, it is possible to provide smooth passage and comfort for the patient and all those who watch.

Preparing for the Last Hours of Life

Slide 7

Preparing for the last hours of life . . .

- Time course unpredictable
- Any setting that permits privacy, intimacy
- Anticipate need for medications, equipment, supplies
- Regularly review the plan of care

During the last hours of their lives, most patients require skilled care around the clock. This can be provided in any setting as long as the professional, family, and volunteer caregivers are appropriately prepared and supported throughout the process. The environment must allow family and friends access to their loved one around the clock without disturbing others and should be conducive to privacy and intimacy. Medications, equipment, and supplies need to be available in anticipation of problems, whether the patient is at home or in a health care institution. As the patient's condition and the family's ability to cope can change frequently, both must be reassessed regularly and the plan of care modified as needed. Changes in the patient's condition can occur suddenly and unexpectedly, so caregivers must be able to respond quickly. This is particularly important when the patient is at home, if unnecessary readmission is to be avoided.

Slide 8

. . . Preparing for the last hours of life

- Caregivers
 - Awareness of patient choices
 - Knowledgeable, skilled, confident
 - Rapid response
- Likely events, signs, symptoms of the dying process

If the last hours of a person's life are to be as rewarding as possible, advance preparation and education of professional, family, and volunteer caregivers are essential, whether the patient is at home, in an acute care or skilled nursing facility, a hospice or palliative care unit, prison, etc. Everyone who participates must be aware of the patient's health status, his or her goals for care and the parents' goals if the patient is a child, advance directives,

and proxy for decision making. They should also be knowledgeable about the potential time course, signs, and symptoms of the dying process, and their potential management. Help families to understand that what they see may be very different from the patient's experience. If family members and caregivers feel confident, the experience can be a time of final gift giving. When parents feel confident about providing for the needs of their dying child, their sense that they are practicing good parenting skills is reinforced. If left unprepared and unsupported, they may spend excessive energy worrying about how to handle the next event. If things do not go as hoped for, family members may live with frustration, worry, fear, or guilt that they did something wrong or caused the patient's death.

Establish in advance whether potential caregivers, including professionals who work in institutions, are skilled in caring for patients in the last hours of life. Do not assume that anyone, even a professional, knows how to perform basic tasks. Those who are inexperienced in this particular area will need specific training including, for instance, knowledge about body fluid precautions. Written materials can provide additional support to caregivers when experts are not present.

Although we often sense that death will either come quickly over minutes or be protracted over days to weeks, it is not possible to predict when death will occur with precision. Some patients may appear to wait for someone to visit, or for an important event such as a birthday or a special holiday, and then die soon afterward. Others experience unexplained improvements and live longer than expected. A few seem to decide to die and do so very quickly, sometimes within minutes. While it is possible to give families or professional caregivers a general idea of how long the patient might live, always advise them about the inherent unpredictability of the moment of death.

Physiologic Changes and Symptom Management

Slide 9

Physiological changes during the dying process

- Increasing weakness, fatigue
- Cutaneous ischemia
- Decreasing appetite/fluid intake
- Cardiac, renal dysfunction
- Neurological dysfunction
- Pain
- Loss of ability to close eyes

There are a variety of physiologic changes that occur in the last hours and days of life, and when the patient is actually dying. Each can be alarming if it is not understood. The most common issues are summarized here. To effectively manage each syndrome or

symptom, oncologists need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.

Fatigue/weakness

Slide 10



Weakness / fatigue

- Decreased ability to move
- Joint position fatigue
- Increased risk of pressure ulcers
- Increased need for care
 - Activities of daily living
 - Turning, movement, massage

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

Table 1: Changes During the Dying Process

Change	Manifest by/Signs
Fatigue, weakness	Decreasing function, hygiene Inability to move around bed Inability to lift head off pillow
Cutaneous ischemia	Erythema over bony prominences Skin breakdown, wounds
Decreasing appetite/ food intake, wasting	Anorexia Poor intake Aspiration, asphyxiation Weight loss (muscle & fat), notable in temples
Decreasing fluid intake, dehydration	Poor intake Aspiration Peripheral edema due to hypoalbuminemia Dehydration, dry mucous membranes/conjunctiva
Cardiac dysfunction, renal failure	Tachycardia Hypertension followed by hypotension Peripheral cooling Peripheral and central cyanosis (bluing of extremities) Mottling of the skin (livedo reticularis) Venous pooling along dependent skin surfaces Dark urine Oliguria, anuria
Neurological dysfunction, including:	
Decreasing level of consciousness	Increasing drowsiness Difficulty awakening Unresponsive to verbal or tactile stimuli
Decreasing ability to communicate	Difficulty finding words Monosyllabic words, short sentences Delayed or inappropriate responses Verbally unresponsive
Terminal delirium	Early signs of cognitive failure (e.g., day-night reversal) Agitation, restlessness Purposeless, repetitious movements Moaning, groaning
Respiratory dysfunction	Change in ventilatory rate—increasing first, then slowing Decreasing tidal volume Abnormal breathing patterns—apnea, Cheyne-Stokes respirations, agonal breaths
Loss of ability to swallow	Dysphagia Coughing, choking Loss of gag reflex Buildup of oral and tracheal secretions Gurgling
Loss of sphincter control	Incontinence of urine or bowels Maceration of skin Perineal candidiasis
Pain	Facial grimacing Tension in forehead; between eyebrows
Loss of ability to close eyes	Eyelids not closed Whites of eyes showing (with or without pupils visible)
Rare, unexpected events:	
Bursts of energy just before death occurs, the “golden glow” Aspiration, asphyxiation	

Cutaneous ischemia

At the end of life, fatigue need not be resisted and most treatment to alleviate it can be discontinued (see **EPEC™-O Module 3: Symptoms**). Patients who are too fatigued to move and have joint position fatigue may require passive movement of their joints every 1 to 2 hours. To minimize the risk of pressure ulcer formation, turn the patient from side to side every 1 to 1.5 hours and protect areas of bony prominence with hydrocolloid dressings and special supports. Do not use “donuts” as they paradoxically worsen areas of breakdown by compressing blood flow circumferentially around the compromised area. A draw sheet can assist caregivers to turn the patient and minimize pain and shearing forces to the skin. If turning is painful, consider a pressure-reducing surface (e.g., air mattress or airbed). As the patient approaches death, the need for turning lessens as the risk of skin breakdown becomes less important.

Intermittent massage before and after turning, particularly to areas of contact, can both be comforting and reduce the risk of skin breakdown by improving circulation and shifting edema. Avoid massaging areas of nonblanching erythema or actual skin breakdown.

Decreasing appetite/food intake, wasting

Slide 11



Decreasing appetite / food intake

- Fears: “giving in,” starvation
- Reminders
 - Food may be nauseating
 - Anorexia may be protective
 - Risk of aspiration
 - Clenched teeth express desires, control
- Help family find alternative ways to care

Most dying 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.^{6,7,8,9,10} Anorexia may be helpful as the resulting ketosis can lead to a sense of well-being and diminish discomfort.

Physicians can help families understand that loss of appetite is normal at this stage. Remind them that the patient is not hungry, that food either is not appealing or may be nauseating, that the patient would likely eat if he or she could, that the patient’s body is unable to absorb and use nutrients, and that clenching of teeth may be the only way for the patient to express his/her desire not to eat.

Whatever the degree of acceptance of these facts, it is important for physicians to help families and caregivers realize that food pushed upon the unwilling patient may cause

problems such as aspiration and increased tension (see **EPEC™-O Module 11: Withdrawing Nutrition, Hydration**). Above all, help them to find alternate ways to nurture the patient so that they can continue to participate and feel valued during the dying process.

Decreasing fluid intake, dehydration

Slide 12

Decreasing fluid intake . . .

- Oral rehydrating fluids
- Fears: dehydration, thirst
- Remind families, caregivers
 - Dehydration does not cause distress
 - Dehydration may be protective

Most dying patients stop drinking.¹¹ This may heighten onlookers' distress as 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.^{12,13,14} 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 light-headed or dizzy. Patients with peripheral edema or ascites have excess body water and salt and are not dehydrated.

Slide 13

. . . Decreasing fluid intake

- Parenteral fluids may be harmful
 - Fluid overload, breathlessness, cough, secretions
- Mucosa / conjunctiva care

Parenteral fluids, given 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 painful, 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.

Mucosal/conjunctival care

To maintain patient comfort and minimize the sense of thirst, even in the face of dehydration, maintain moisture on mucosal membrane surfaces with meticulous oral, nasal, and conjunctival hygiene.¹⁶ Moisten and clean oral mucosa every 15 to 30 minutes with either baking soda mouthwash (1 teaspoon salt, 1 teaspoon baking soda, 1 quart tepid water) or an artificial saliva preparation to minimize the sense of thirst and avoid bad odors or tastes and painful cracking. Treat oral candidiasis with topical nystatin or systemic fluconazole if the patient is able to swallow. Coat the lips and anterior nasal mucosa hourly with a thin layer of petroleum jelly to reduce evaporation. If the patient is using oxygen, use an alternative nonpetroleum-based lubricant. Avoid perfumed lip balms and swabs containing lemon and glycerin, as these can be both desiccating and irritating, particularly on open sores. If eyelids are not closed, moisten conjunctiva with an ophthalmic lubricating gel every 3 to 4 hours, or artificial tears or physiologic saline solution every 15 to 30 minutes to avoid painful dry eyes.

Cardiac dysfunction, renal failure

Slide 14

Cardiac, renal dysfunction

- Tachycardia, hypotension
- Peripheral cooling, cyanosis
- Mottling of skin
- Diminished urine output
- Parenteral fluids will not reverse

As cardiac output and intravascular volume decrease at the end of life, there will be evidence of diminished peripheral blood perfusion. Tachycardia, hypotension, peripheral cooling, peripheral and central cyanosis, and mottling of the skin (livedo reticularis) are expected. Venous blood may pool along dependent skin surfaces. Urine output falls as perfusion of the kidneys diminishes. Oliguria or anuria usually ensue. Parenteral fluids will not reverse this circulatory shut down.¹⁷

Neurologic dysfunction

Slide 15

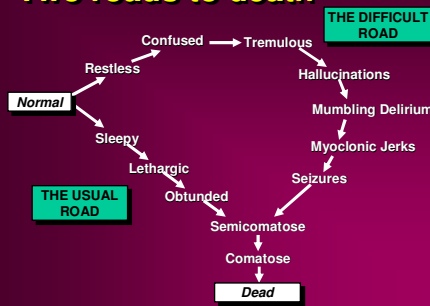
Neurological dysfunction

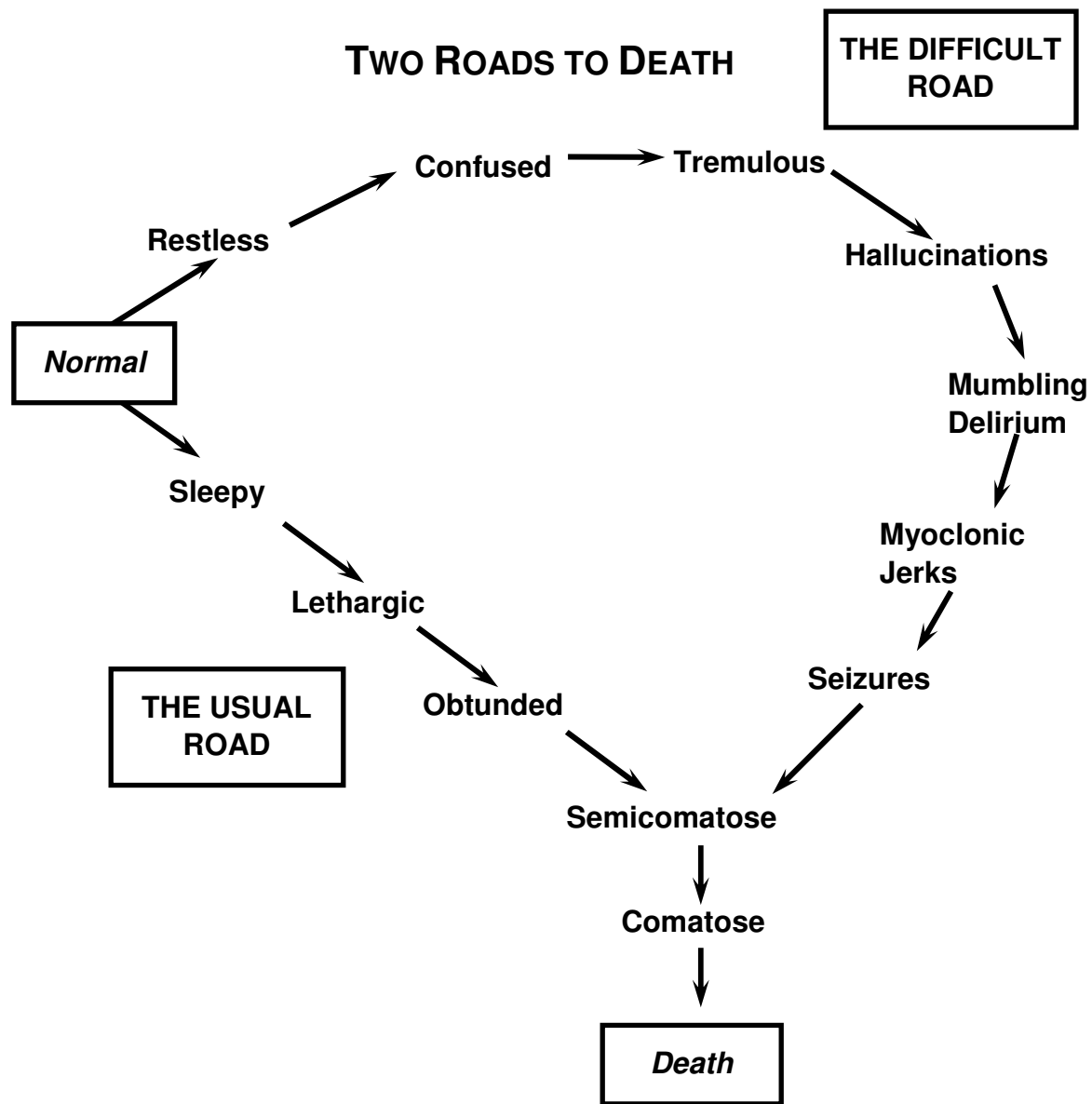
- Decreasing level of consciousness
- Communication with the unconscious patient
- Terminal delirium
- Changes in respiration
- Loss of ability to swallow, sphincter control

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” (see Figure 1).¹⁸ Most patients follow the “usual road” that presents as a decreasing level of consciousness that leads to coma and death.

Slide 16

Two roads to death

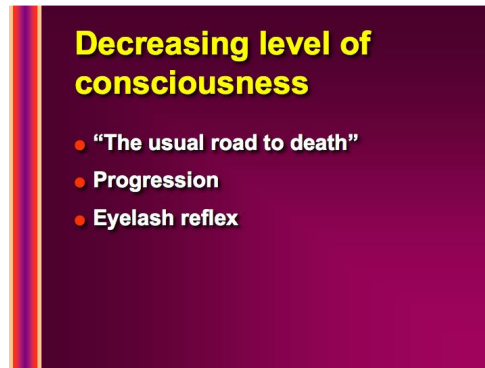




As reprinted in: Advance planning. In: Ferris FD, Flannery JS, McNeal HB, Morissette MR, Cameron R, Bally GA, eds. Module 4: Palliative care. In: *A Comprehensive Guide for the Care of Persons with HIV Disease*. Toronto, Ontario: Mount Sinai Hospital and Casey House Hospice, Inc.; 1995:118-120. Originally published in: Freeman FR. Delirium and organic psychosis. In: *Organic Mental Disease*. Jamaica, NY: SP Medical and Scientific Books; 1981:81-94.

Decreasing level of consciousness

Slide 17



Decreasing level of consciousness

- “The usual road to death”
- Progression
- Eyelash reflex

The majority of patients traverse the “usual road to death.” They experience increasing drowsiness, sleep most if not all of the time, and eventually become unarousable. Absence of eyelash reflexes on physical examination indicates a profound level of coma equivalent to full anesthesia.

Communication with the unconscious patient

Slide 18



Communication with the unconscious patient . . .

- Distressing to family
- Awareness > ability to respond
- Assume patient hears everything

Families will frequently find that their decreasing ability to communicate is distressing. The last hours of life are the time when they most want to communicate with their loved one. As many clinicians have observed, the degree of family distress seems to be inversely related to the extent to which advance planning and preparation occurred. The time spent preparing families is likely to be very worthwhile.

While we do not know what unconscious patients can actually hear, extrapolation from data from the operating room and “near death” experiences suggests that at times their awareness may be greater than their ability to respond. Given our inability to assess a dying patient’s comprehension and the distress that talking “over” the patient may cause, it is prudent to presume that the unconscious patient hears everything. Advise families and professional caregivers to talk to the patient as if he or she were conscious.



. . . Communication with the unconscious patient

- Create familiar environment
- Include in conversations
 - Assure of presence, safety
- Give permission to die
- Touch

Encourage families to create an environment that is familiar and pleasant. Surround the patient with the people, children, pets, objects, music, and sounds that he or she would like. Include the patient in everyday conversations. Encourage family members to say the things they need to say. 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. The physician or other caregivers might suggest to family members other words like:

- “I know that you are dying; please do so when you are ready.”
- “I love you. I will miss you. I will never forget you. Please do what you need to do when you are ready.”
- “Mommy and Daddy love you. We will miss you, but we will be okay.”

As touch can heighten communication, encourage family members to show affection in ways they are used to. Let them know that it is okay to lie beside the patient in privacy to maintain as much intimacy as they feel comfortable with.

Terminal delirium



Terminal delirium

- “The difficult road to death”
- Medical management
 - Benzodiazepines
 - Lorazepam, midazolam
 - Neuroleptics
 - Haloperidol, chlorpromazine
- Seizures
- Family needs support, education

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 very 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 cognitively impaired “because of the drugs” and may worry that their own death will be the same.

In anticipation of the possibility of terminal delirium, educate and support family and professional caregivers to understand its causes, the finality and irreversibility of the situation, and approaches to its management. It is particularly important that all onlookers understand that what the patient experiences may be very different from what they see.

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. Focus 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 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.²⁴ Common starting doses are:

- **Lorazepam**, 1-2 mg as an elixir, or a tablet predissolved in 0.5-1.0 ml of water and administered against the buccal mucosa q 1 h PRN will settle most patients with 2 to 10 mg/24 h. It can then be given in divided doses, q 3-4 h, to keep the patient settled. For a few extremely agitated patients, high doses of lorazepam, 20 to 50+ mg/24 h, may be required.
- **Midazolam** 1-5 mg/hr SC or IV continuous infusion, preceded by repeated loading boluses of 0.5 mg q 15 min to effect, may be a rapidly effective alternative.

Benzodiazepines may paradoxically excite some patients.²⁵ These patients require neuroleptic medications to control their delirium.

- **Haloperidol** 0.5-2.0 mg IV, SC, PR q 1 h PRN (titrated to effect, then nightly to q 6 h to maintain) given intravenously, subcutaneously, or rectally may be effective.²⁶

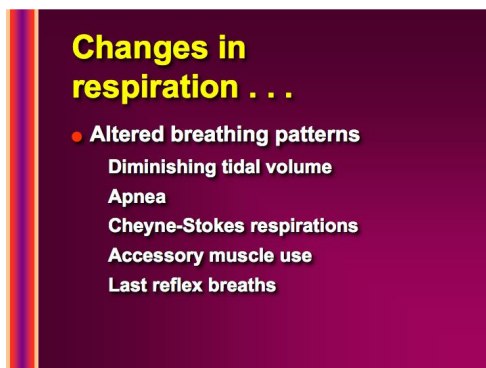
- **Chlorpromazine** 10-25 mg PO, PR, IM nightly to q 6 h and titrated to effect intravenously or rectally is a more sedating alternative.²⁷

Barbiturates or propofol have been suggested as alternatives.^{28,29}

Seizures may be managed with high doses of benzodiazepines. Other antiepileptics such as **phenytoin** IV, **fosphenytoin** SC, or **phenobarbital**, 60 to 120 mg pr, IV, or IM q 10 to 20 min PRN, may become necessary until control is established. Alternatively, **carbamazepine** PR 200 mg tid to qid can be used.

Respiratory dysfunction

Slide 21



Changes in a dying patient's breathing pattern may be indicative of significant neurologic compromise.^{30,31,32} Breaths may become very 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 which may actually prolong the dying process, can be very comforting. Low doses of opioids or benzodiazepines are appropriate to manage any perception of breathlessness (see **EPEC™-O Module 3: Symptoms**).

Slide 22

... Changes in respiration

Fears

Suffocation

Management

Family support

Oxygen may prolong dying process

Breathlessness

Some oncologists express concern that the use of opioids or benzodiazepines for symptom control near the end of life will hasten death. Consequently, they feel they must invoke the ethical principle of double effect to justify treatment. While it is true that patients are more likely to receive higher doses of both opioids and sedatives as they get closer to death, there is no evidence that initiation of treatment or increases in dose of opioids or sedatives is associated with precipitation of death. In fact, the evidence suggests the opposite.³³

Loss of ability to swallow

Slide 23

Loss of ability to swallow

Loss of gag reflex

Build-up of saliva, secretions

Scopolamine to dry secretions

Postural drainage

Positioning

Suctioning

Weakness and decreased neurologic 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. Buildup of saliva and oropharyngeal secretions may lead to gurgling, crackling, or rattling sounds with each breath.³⁴ Some have called this the "death rattle" (a term that frequently is 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.^{35,36} Common starting doses are:

- **Scopolamine**, 0.2-0.4 mg SC q 4 h, or
Scopolamine, 1-3 transdermal patches q 72 h, or
Scopolamine, 0.1-1.0 mg/hr by continuous IV or SC infusion.
- **Glycopyrrolate**, 0.2 mg SC q 4 to 6 h
Glycopyrrolate, 0.4-1.2 mg daily by continuous IV or SC.

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 CNS excitation.³⁷

If excessive fluid accumulates in the back of the throat and upper airways, it may need to be cleared by repositioning of the patient or postural drainage. Turning the patient onto one side or into a semi-prone position may reduce gurgling. Lowering the head of the bed and raising the foot of the bed while the patient is in a semiprone position may cause fluids to move into the oropharynx, from which they can be easily removed. Do not maintain this position for more than a few minutes at a time, as stomach contents may also move unexpectedly.

Oropharyngeal suctioning is not recommended. It is frequently ineffective, as fluids are beyond the reach of the catheter, and may only stimulate an otherwise peaceful patient and distress family members who are watching.

Loss of sphincter control

Slide 24



Loss of sphincter control

- Incontinence of urine, stool
- Family needs knowledge, support
- Cleaning, skin care
- Urinary catheters
- Absorbent pads, surfaces

Fatigue and loss of sphincter control in the last hours of life may lead to incontinence of urine and/or stool. Both can be very distressing to patients and family members, particularly if they 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.

Pain

Slide 25

Pain in the last hours of life . . .

- **Fear of increased pain**
- **Assessment of the unconscious patient**
 - Persistent vs. fleeting expression
 - Grimace or physiologic signs
 - Incident vs. rest pain
 - Distinction from terminal delirium

While many people fear that pain will suddenly increase as the patient dies, there is no evidence to suggest that this occurs.

Though difficult to assess, continuous pain in the semiconscious or obtunded patient may be associated with grimacing and continuous facial tension, particularly across the forehead and between the eyebrows. The possibility of pain must also be considered when physiologic signs occur, such as transitory tachycardia that may signal distress. Do not overdiagnose pain when fleeting forehead tension comes and goes with movement or mental activity (e.g., dreams or hallucinations). Do not confuse pain with the restlessness, agitation, moaning, and groaning that accompany terminal delirium. If the diagnosis is unclear, a trial of a higher dose of opioid may be necessary to judge whether pain is driving the observed behaviors.

Slide 26

. . . Pain in the last hours of life

- **Management when no urine output**
 - Stop routine dosing, infusions of morphine
 - Breakthrough dosing as needed (PRN)
 - Least invasive route of administration

Knowledge of opioid pharmacology becomes critical during the last hours of life. The liver conjugates codeine, morphine, oxycodone, and hydromorphone into glucuronides. Some of their metabolites remain active as analgesics until they are renally cleared, particularly morphine. As dying patients experience diminished hepatic function and renal perfusion, and usually become oliguric or anuric, routine dosing or continuous infusions of morphine may lead to increased serum concentrations of active metabolites, toxicity, and an increased risk of terminal delirium. To minimize this risk, discontinue routine dosing or continuous infusions of morphine when urine output and renal clearance stop. Titrate morphine breakthrough (rescue) doses to manage expressions suggestive of continuous pain. Consider the use of alternative opioids with inactive metabolites such as fentanyl or hydromorphone.

Loss of ability to close eyes

Slide 27



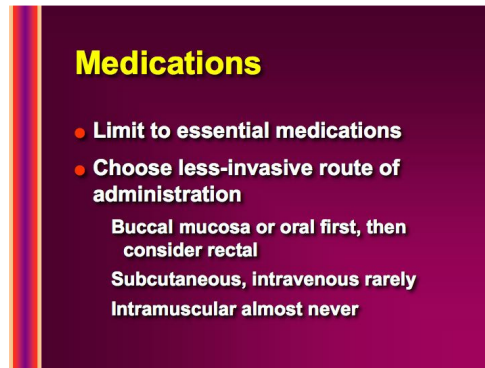
Loss of ability to close eyes

- Loss of retro-orbital fat pad
- Insufficient eyelid length
- Conjunctival exposure
 - Increased risk of dryness, pain
 - Maintain moisture

Eyes that remain open can be distressing to onlookers 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.³⁸ As 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.³⁹

Medications

Slide 28

A purple rectangular box with a vertical rainbow-colored bar on the left side. The title 'Medications' is at the top in yellow. Below it are two bullet points in white: 'Limit to essential medications' and 'Choose less-invasive route of administration'. Under the second bullet point, there are three lines of white text: 'Buccal mucosa or oral first, then consider rectal', 'Subcutaneous, intravenous rarely', and 'Intramuscular almost never'.

Medications

- Limit to essential medications
- Choose less-invasive route of administration
 - Buccal mucosa or oral first, then consider rectal
 - Subcutaneous, intravenous rarely
 - Intramuscular almost never

As patients approach death, 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 to 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. Rectal administration can also be considered, especially if the oral route is not possible.

Dying in institutions

Slide 29

A purple rectangular box with a vertical rainbow-colored bar on the left side. The title 'Dying in institutions' is at the top in yellow. Below it are four bullet points in white: 'Home-like environment', 'Continuity of care plans', 'Avoid abrupt changes of settings', and 'Consider a specialized unit'. Under 'Home-like environment', there are two lines of white text: 'Permit privacy, intimacy' and 'Personal items, photos'.

Dying in institutions

- Home-like environment
 - Permit privacy, intimacy
 - Personal items, photos
- Continuity of care plans
- Avoid abrupt changes of settings
- Consider a specialized unit

The preceding discussion is relevant to patients dying in any setting (e.g., at home, in hospitals, 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.⁴⁰

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.^{41,42}

When Death Occurs

Slide 30

Signs that death has occurred . . .

- Absence of heartbeat, respirations
- Pupils fixed
- Color turns to a waxy pallor as blood settles
- Body temperature drops

Slide 31

. . . Signs that death has occurred

- Muscles, sphincters relax
- Release of stool, urine
- Eyes can remain open
- Jaw falls open
- Body fluids may trickle internally

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.

Table 2: Signs that Death Has Occurred

The heart stops beating
Breathing stops
Pupils become fixed and dilated
Body color becomes pale and waxy as blood settles

Body temperature drops
Muscles and sphincters relax (muscles stiffen 4-6 hours after death as rigor mortis sets in)
Urine and stool may be released
Eyes may remain open
The jaw can fall open
Observers may hear the trickling of fluids internally, even after death

Basic information about death may be appropriate (e.g., the heart stops beating; breathing stops; pupils become fixed; body color becomes pale and waxy as blood settles; body temperature drops; muscles and sphincters relax, and urine and stool may be released; eyes may remain open; the jaw can fall open; and observers may hear the trickling of fluids internally).^{43,44}

Slide 32

What to do when death occurs

- Don't call "911"
- Whom to call
- No specific "rules"
- Rarely any need for coroner
- Organ donation
- Traditions, rites, rituals

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 (State and local regulations vary. Health care professionals will need to familiarize themselves with the regulations in the areas where they practice).

When an 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 death will help people deal with acute grief.^{45,46,47} 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, disconnecting any lines and machinery, removing catheters, and cleaning up any mess will allow the family closer access to the patient's body.^{48,49}

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, as communicating in person provides a 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 pick up 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.

Slide 33

Moving the body

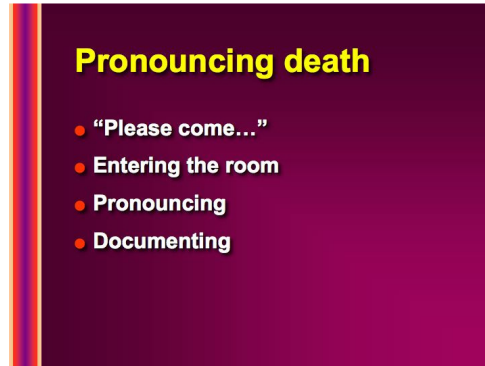
- Prepare the body
- Choice of funeral service providers
- Wrapping, moving the body
 - Family presence
 - Intolerance of closed body bags

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, and then leave them to have some privacy together.

Pronouncing death

Slide 34



In teaching hospitals, medical students and residents are typically called to “pronounce” death.⁵⁰ In non-teaching settings, the attending physician or nursing staff may be the ones to do it. When a patient dies at home with hospice care, it is usually a nurse who confirms the absence of vital signs. Although local regulations differ, if an expected death occurs at home without hospice care and the patient has a physician willing to sign a death certificate, then transportation to a hospital for a physician to confirm death may not be needed.

The phone call: “Please come; I think the patient has died.”

- Find out the circumstances of the death—expected or sudden? Is the family present? What is the patient’s age?

Preparation before you enter the room

- Confirm the details on the circumstances of death. Ask a nurse or other caregiver. Review the chart for important medical (length of illness, cause of death) and family issues (Who is family? What faith? Is there a clergy contact?).
- Find out who has been called. Other physicians? The attending?
- Has an autopsy ever been requested? Do you see a value in requesting an autopsy?
- Has the subject of organ donation been broached? Has the Organ Donor Network been contacted?

In the room

- You may want to ask the nurse or chaplain to accompany you; he/she can give you support and introduce you to the family.

- Introduce yourself (including your relationship to the patient) to the family if they are present. Ask each person their name and relationship to the patient. Shake hands with each.
- Say something empathic: “I’m sorry for your loss...” or “This must be very difficult for you...”
- Explain what you are there to do. Tell the family they are welcome to stay if they wish, while you examine their loved one.
- Ask what questions the family has. If you cannot answer, contact someone who can.

The pronouncement

- Identify the patient. Use the hospital ID tag if available. Note the general appearance of the body.
- Test for response to verbal or tactile stimuli. Overtly painful stimuli are not required. Nipple or testicle twisting, or deep sternal pressure, are inappropriate.
- Listen for the absence of heart sounds; feel for the absence of carotid pulse.
- Look and listen for the absence of spontaneous respirations.
- Record the position of the pupils and the absence of pupillary light reflex.
- Record the time at which your assessment was completed.

Documentation in the medical record

- Called to pronounce (name); chart findings of physical examination.
- Note date and time of death; distinguish time family or others noted death from the time you confirmed the absence of vital signs. Note whether family and attending physician were notified.
- Document whether family declines or accepts autopsy; document whether the coroner was notified.

Telephone notification

Slide 35



Telephone notification

- Sometimes necessary
- Use six steps of good communication

There will be cases where the people who need to know about the death are not present.^{51,52,53,54,55} In some cases, you may choose to tell someone by phone that the patient's condition has "changed," and wait for them to come to the bedside in order to tell the news. Factors to consider in weighing whether or not to break the news over the phone include: whether death was expected, what the anticipated emotional reaction of the person may be, whether the person is alone, whether the person is able to understand, how far away the person is, the availability of transportation for the person, and the time of day (or night). Inevitably, there are times when notification of death by telephone is unavoidable. If this is anticipated, prepare for it. Determine who should be called and in what fashion. Some families will prefer not to be awakened at night if there is an expected death.

1. **Get the setting right.** Determine the facts before you call. Find a quiet or private area with a telephone. Identify yourself and ask the identity of the person to whom you are talking and their relationship to the patient. Ask to speak to the person closest to the patient (ideally the health care proxy or the contact person indicated in the chart). Avoid responding to direct questions until you have verified the identity of the person to whom you are speaking. Ask whether the contact person is alone. Do not give death notification to minor children.
2. **Ask what the person understands** about the patient's condition with a phrase like, "What have the doctors told you about M's condition?"
3. **Provide a "warning shot"** like, "I'm afraid I have some bad news."
4. **Tell the news.** Use clear, direct language without jargon like, "I'm sorry to have to give you this news, but M just died." Avoid words like expired, passed away, and passed on. They are easily misinterpreted.
5. **Respond to emotions** with empathy. Most importantly, listen quietly to the person, and allow enough time for the information to sink in. Elicit questions with a phrase like, "What questions do you have?" Ascertain what support the person has. Ask if you can contact anyone for them. Consider other support through the person's church, Red Cross, local police, or other service agencies if it is needed.
6. **Conclude with a plan.** If the family chooses to come to see the body, arrange to meet them personally. Provide contact information for the physician or official who can meet with them and/or make arrangements.

Slide 36

Bereavement care

- Bereavement care
- Attendance at funeral
- Follow up to assess grief reactions, provide support
- Assistance with practical matters
 - Redeem insurance
 - Will, financial obligations, estate closure

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.⁵⁶ Many physicians and members of the professional team consider it a part of their professional duty of care to encourage follow-up visits from bereaved family members in order to assess the severity of their grief reactions and the effectiveness of their coping strategies, and to provide emotional support. Professional members of the interdisciplinary team can also offer to assist family members in dealing with outstanding practical matters, such as helping to secure documents necessary to redeem insurance, find legal counsel to execute the will and close the estate, find resources to meet financial obligations, etc. Bereavement care for the family is a standard part of hospice care in the United States.

Summary

Slide 37

Summary

Care in last hours is as important as at any other time in cancer care.

Clinical competence, willingness to educate and calm, and 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 that include 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, and 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 an important responsibility for every oncologist, and there is a body of knowledge to guide care.^{2,57,58}

Key Take-Home Points

1. There is only one chance to get management of the last hours right.
2. Patients in the last hours of life usually need skilled care around the clock. The environment must allow family and friends ready access to their loved one in a setting that is conducive to privacy and intimacy.
3. Advance preparation and education of professional, family, and volunteer caregivers are essential. They should also be knowledgeable about the potential time course, signs and symptoms of the dying process, and their potential management. The physician needs to help family members understand that what they see may be very different from what the patient is experiencing.
4. The physiologic changes of dying are complex. To control each symptom effectively, physicians need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.
5. When death is imminent, fatigue is an expected part of the dying process and should not be treated medically in most cases.
6. Most patients lose their appetite and reduce food intake long before they reach the last hours of their lives. Anorexia may be protective, and the resulting ketosis can lead to a greater sense of well-being and diminish pain.
7. Most patients also reduce their fluid intake, or stop drinking entirely, long before they die. Dehydration in the last hours of living does not cause distress and may stimulate endorphin release that adds to the patient's sense of well-being.
8. Moisture should be maintained in mucosal membranes with meticulous oral, lip, nasal, and conjunctival hygiene and lubrication.
9. The majority of patients experience increasing drowsiness, sleep most if not all of the time, and eventually become unarousable. Absence of eyelash reflexes indicates a profound level of coma equivalent to full anesthesia.
10. It should be presumed that the unconscious patient hears everything.
11. Moaning, groaning, and grimacing accompanying agitation and restlessness are frequently misinterpreted as pain. Terminal delirium may be occurring. While a trial of opioids may be beneficial in the unconscious patient who is difficult to assess, benzodiazepines or sedating neuroleptics may be needed to manage terminal

delirium. Benzodiazepines may cause paradoxical exciting effects; these patients require neuroleptic medications to control their delirium.

12. Diminished hepatic function and renal perfusion may change the pharmacology of chronically administered medications.
13. Secretions from the tracheobronchial tree frequently accumulate. Scopolamine or glycopyrrolate will effectively reduce the production of saliva and other secretions.
14. Institutional dying presents particular challenges. Priorities and care plans at the very end of life differ from those for life prolongation and cure.
15. Planning discussions should cover personal, cultural, and religious traditions, rites, and rituals that may dictate how prayers are to be conducted, how a person's body is to be handled after death, and when/how the body can be moved.
16. When an expected death occurs, the focus of care shifts to the family and those who provided care.
17. Acute grief reactions should be addressed, especially when the body is moved.

Pearls

1. Use only essential medications. Stop routine dosing and continue to offer opioids as needed. Accumulating serum concentrations of active drug and metabolites may lead to toxicity and terminal delirium.
2. Know the signs of the dying process.
3. Make a partnership with your patient and the family caregiver; draw them into the interdisciplinary team and foster their active participation in the care plan.

Pitfalls

1. Maintaining parenteral fluids. They may have adverse effects that are not commonly considered.
2. Oropharyngeal suctioning. It is likely to be ineffective at clearing secretions, yet very effective at stimulating a gag, cough, or vomiting.
3. Removing the body insensitively or too soon. This can be more distressing for families than the moment of death.

Patient Resources

Hospice Net

- Website: www.hospicenet.org
- Useful Resources:
 - [A Dying Person's Guide to Dying.](#)
 - [What Does Someone Dying Need?](#)
 - [Helping Yourself When You Are Dying.](#)

National Cancer Institute (NCI)

- Website: www.cancer.gov
- Phone: 1-800-4-CANCER (1-800-422-6237)
- Useful Resource:
 - CIS fact sheet: End of Life: Questions and Answers

References

- ¹ Field MJ, Cassel CK, eds. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press. 1997;28-30. ISBN: 0309063728; [full text](#).
- ² Twycross R, Lichter I. The terminal phase. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. Oxford, England: Oxford University Press; 1998:977-992. ISBN: 0192625667.
- ³ Fulton CL, Else R. Physiotherapy. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. Oxford, England: Oxford University Press; 1998:821-822. ISBN: 0192625667.
- ⁴ Walker P. The pathophysiology and management of pressure ulcers. In: Portenoy RK, Bruera E, eds. *Topics in Palliative Care, vol. 3*. New York: Oxford University Press; 1998:253-270. ISBN: 0195102452.
- ⁵ Bruera E, Fainsinger RL. Clinical management of cachexia and anorexia. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. Oxford, England: Oxford University Press; 1998:548. ISBN: 0192625667.
- ⁶ Ferris FD, Flannery JS, McNeal HB, Morissette MR, Cameron R, Bally GA, eds. Module 4: Palliative care. In: *A Comprehensive Guide for the Care of Persons with HIV Disease*. Toronto, Ontario: Mount Sinai Hospital and Casey House Hospice, Inc.; 1995; [full text](#).

Throughout its trajectory, palliative care can relieve the intense, broad suffering of persons living with HIV disease.
- ⁷ Ahronheim JC, Gasner MR. The sloganism of starvation. *Lancet*. 1990;335:278-279. PMID: 1967733.

Patients in a persistent vegetative state or coma, or suffering from dementia, do not experience pain and suffering when food and water are withdrawn.

- ⁸ Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: A review of the evidence. *JAMA*. 1999;282:1365-1370. [PMID: 10527184](#); [full text](#).

In patients with advanced dementia, there are no data to suggest that tube feeding prevents aspiration pneumonia, prolongs survival, reduces the risk of pressure sores or infections, improves function, or provides palliation. Risks are substantial. For severely demented patients the practice should be discouraged on clinical grounds.

- ⁹ McCann RM, Hall WJ, Groth-Juncker A. Comfort care for terminally ill patients: The appropriate use of nutrition and hydration. *JAMA*. 1994;272:1263-1266. [PMID: 7523740](#).

Of the 32 terminally ill cancer patients monitored during the 12 months of study, 20 patients (63%) never experienced any hunger, while 11 patients (34%) had symptoms only initially. Similarly, 20 patients (62%) experienced either no thirst or thirst only initially during their terminal illness. In all patients, symptoms of hunger, thirst, and dry mouth could be alleviated, usually with small amounts of food, fluids, and/or by the application of ice chips and lubrication to the lips.

- ¹⁰ American College of Physicians. Parenteral nutrition in patients receiving cancer chemotherapy. *Ann Int Med*. 1989;110:734-735. [PMID: 2494922](#); [full text](#).

- ¹¹ Billings JA. Comfort measures for the terminally ill: Is dehydration painful? *J Am Geriatr Soc*. 1985;33:808-810. [PMID: 4056276](#).

This editorial supports the contention that administration of fluids to a dehydrated, dying patient should be based on the clinical manifestations of water and electrolyte disorders and of the potential benefits of treatment. Does dehydration cause symptoms? Are these symptoms distressing to the patient? Do fluid and electrolyte administration and other treatments help make dying patients comfortable?

- ¹² Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. *J Pain Symptom Manage*. 1995;10:192-197. [PMID: 7629413](#); [full text](#).

This study evaluated 82 subjects with cancer. All subjects died without artificial fluid therapy after a median of 2 days in study. Over 50% of subjects had a serum osmolality less than 295 mOsm/kg. No statistically significant relationship was demonstrated between the level of hydration and respiratory tract secretions. No statistically significant association was found between level of hydration and thirst or dry mouth.

- ¹³ Musgrave CF, Bartal N, Opstad J. The sensation of thirst in dying patients receiving IV hydration. *J Pall Care*. 1995;11:17-21. [PMID: 8648517](#).

Of 19 dying patients with cancer receiving IV hydration ranging from 500 mL to 3,000 mL, 6 experienced mild thirst; 8, moderate thirst; and 4, severe thirst.

- ¹⁴ Musgrave CF. Terminal dehydration: To give or not to give intravenous fluids? *Cancer Nurs*. 1990;13:62-66. [PMID: 2407341](#).

Health professionals' attitudes to dehydration in dying cancer patients and the special ethical problems associated with the question are analyzed. Guidelines to facilitate the decision-making process related to the initiation of parenteral fluids in dying patients, and a discussion on the law as it pertains to the treatment of dehydration in such patients, are presented.

- ¹⁵ Bruera E, Legris MA, Kuehn N, Miller MJ. Hypodermoclysis for the administration of fluids and narcotic analgesics in patients with advanced cancer. *J Pain Symptom Manage.* 1990;5:218-220. [PMID: 2384700](#).

Fifty-eight consecutive patients with advanced cancer received hypodermoclysis. A solution of two-thirds 5% dextrose and one-third saline was used in all cases at a rate of 20-100 cc/hr, with 750 units of hyaluronidase per liter, and 20-40 mEq KCl/L were administered in all patients. The mean duration of infusion and volume were 14 ± 9 days and 1.3 ± 0.8 L/day, respectively (range, 0.5-3 L/day). Toxicity consisted of local infection in two cases and bruising in two cases.

- ¹⁶ Lethen W. Mouth and skin problems. In: Saunders C, Sykes N. *The Management of Terminal Malignant Disease*, 3rd ed. Boston: Edward Arnold; 1993:139-142. ISBN: 0340563540.

Coeditor Dame Cicely Saunders, OM, DBE, FRCP (St Christopher's Hospice, London) is often regarded as the founder of the modern hospice movement. She provides an excellent overview chapter which includes the history of approaches to management of terminal cancer. Her colleague and coeditor, Nigel Sykes, MA, MRCP (St Christopher's Hospice, London), is also a recognized leader in palliative care.

- ¹⁷ Mount BM. Care of dying patients and their families. In: Bennett JC, Plum F. *Cecil Textbook of Medicine*. 20th ed. Philadelphia: W.B. Saunders Company; 1996:6-9. ISBN: 072163561X.

- ¹⁸ Freeman FR. Delirium and organic psychosis. In: *Organic Mental Disease*. Jamaica, NY: SP Medical and Scientific Books; 1981:81-94. ISBN: 0893351091.

- ¹⁹ Ingham J, Breitbart W. Epidemiology and clinical features of delirium. In: Portenoy RK, Bruera E, eds. *Topics in Palliative Care, vol. 1*. New York: Oxford University Press; 1997:7-19. ISBN: 0195102452.

- ²⁰ Fainsinger RL, Tapper M, Bruera E. A perspective on the management of delirium in terminally ill patients on a palliative care unit. *J Pall Care.* 1993;9:4-8. [PMID: 7903694](#).

Delirium occurs commonly in the terminally ill and is associated with a poor prognosis. Management requires a clear understanding of what delirium is, how to assess it, investigations for reversible causes, and the medical treatments that are most useful.

- ²¹ Shuster JL. Delirium, confusion, and agitation at the end of life. *J Pall Med.* 1998;1:177-186.

- ²² Zaw-tun N, Bruera E. Active metabolites of morphine. *J Pall Care.* 1992;8:48-50. [PMID: 1635007](#).

- ²³ Maddocks I, Somogyi A, Abbott F, Hayball P, Parker D. Attenuation of morphine-induced delirium in palliative care by substitution with infusion of oxycodone. *J Pain Symptom Manage.* 1996;12:182-189. [PMID: 8803381](#); [full text](#).

Statistically significant improvements in mental state and nausea and vomiting occurred following a change from morphine to oxycodone.

- ²⁴ Twycross R, Lichter I. The terminal phase. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. Oxford, England: Oxford University Press; 1998:987-988. ISBN: 0192625667.

- ²⁵ Feldman MD. Paradoxical effects of benzodiazepines. *NC Med J.* 1986;47:311-312. [PMID: 2874505](#).

- ²⁶ Liu MC, Caraceni AT, Ingham JM. Altered mental status in patients with cancer: A delirium update. *Principles and Practice of Supportive Oncology Updates*. Philadelphia: J. B. Lippincott Co.; 1999;2. ISBN: 0781733243.

- ²⁷ McIver B, Walsh D, Nelson K. The use of chlorpromazine for symptom control in dying cancer patients. *J Pain Symptom Manage.* 1994;9:341-345. [PMID: 7963786](#).

The median PR dose of chlorpromazine was 25 mg every 4-12 hr. The median IV dose was 12.5 mg every 4-12 hr. Eighteen patients had complete relief and two had partial relief before death.

- ²⁸ Truog RD, Berde CB, Mitchell C, Grier HE. Barbiturates in the care of the terminally ill. *New Engl J Med*. 1992;337:1678-1682. [PMID: 1279424](#).

Situations in which the nonlethal use of barbiturates may be indicated and situations in which their administration can be morally justified are discussed in this article.

- ²⁹ Moyle J. The use of propofol in palliative medicine. *J Pain Symptom Manage*. 1995;10:643-646. [PMID: 8594126](#); [full text](#).

A low-dose infusion of the anesthetic agent propofol (Diprivan, Zenica), sedates patients who are not sedated by midazolam.

- ³⁰ Lichter I, Hunt E. The last 48 hours of life. *J Pall Care*. 1990;6:7-15. [PMID: 1704917](#).

The incidence of pain, dyspnea, moist breathing, nausea and vomiting, confusion, restlessness, jerking and twitching, difficulty swallowing, incontinence and retention of urine, sweating, moaning and groaning, and loss of consciousness was assessed in 200 patients. Many of the features can be attributed to organic brain disease consequent to metabolic disorder associated with multiorgan failure.

- ³¹ Twycross R, Lichter I. The terminal phase. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. Oxford, England: Oxford University Press; 1998:985-6. ISBN: 0192625667.

- ³² Voltz R, Borasio GD, et al. Palliative therapy in the terminal stage of neurological disease. *J Neurol*. 1997;244(Suppl 4):S2-S10. [PMID: 9402547](#).

Current treatment recommendations for the most important symptoms arising in the end stage of neurological diseases are compiled. These recommendations include treatment of dyspnea, death rattle, restlessness, pain, thirst, depression, and other symptoms. A discussion of difficult decisions is included (e.g., the appropriate extent of fluid substitution or the ethical implications of sedation in the terminal phase).

- ³³ Sykes N, Thorns A. Sedative use in the last week of life and the implications for end-of-life decision making. *Arch Intern Med*. 2003;163(3):341-4. [PMID: 12578515](#); [full text](#).

The article describes a retrospective chart review of 237 consecutive patients who died in a specialist palliative care unit. Of these, 13% received sedatives for 7 days or more, while 56% commenced sedative use only in the last 48 hours of life. The groups receiving no sedation or sedation for less than 48 hours had the shortest survival from admission (mean, 14.3 and 14.2 days), whereas the 7-day sedation group survived for a mean of 36.6 days ($P<.001$).

- ³⁴ Nuland S. *How We Die*. New York: Vintage Books; 1995. ISBN: 0679414614.

This is an award-winning account by a noted surgeon describing in frank yet compassionate detail what most of us are likely to face when the time comes. Dying has become such a taboo subject in modern society that most of us never have the honor of being with someone in their final days and moments.

Chapters cover different types of death, making clear the processes and choices that go along with each one. Both medical and emotional realities of common conditions such as cancer, heart disease, AIDS, Alzheimer's, severe trauma, and just plain wearing out are addressed.

Why read such a book? Removing the fear of the unknown can bring courage and peace in the face of a difficult time. This book presents unpleasant facts in simple language that anyone can understand.

Reading it may lead to strong emotions associated with loved ones.

³⁵ Storey P. Symptom control in dying. In: Berger A, Portenoy RK, Weissman D, eds. *Principles and Practice of Supportive Oncology Updates*. Philadelphia: Lippincott-Raven Publishers;1998;741-748. ISBN: 0397515596.

³⁶ Hughes AC, Wilcock A, Corcoran R. Management of “death rattle.” *J Pain Symptom Manage*. 12:271-272. [PMID: 8942121](#); [full text](#).

In this study using a standardized approach and early intervention, retained secretions were controlled in only 50% of patients, highlighting the importance of explanation in easing relatives’ distress.

³⁷ Twycross RB, Lack SA. *Therapeutics in Terminal Cancer*. 2nd ed. [PUB CITY]: Churchill Livingstone; 1990:134-136. ISBN: 0443041180.

³⁸ Gray H. *Anatomy of the Human Body*, 29th ed. Philadelphia: Lea & Febiger; 1985;1303-1313. ISBN: 081210644X.

³⁹ Smeltzer SC, Bare BG, eds. *Brunner and Suddarth’s Textbook of Medical Surgical Nursing*. 7th ed. Philadelphia: J.B. Lippincott Company; 1992;1657-1602. ISBN: 0397547978.

⁴⁰ Ferris TGG, Hallward JA, Ronan L, Billings JA. When the patient dies: A survey of medical housestaff about care after death. *J Pall Med*. 1998;1:231-239.

⁴¹ Kellar N, Martinez J, Finis N, Bolger A, von Gunten CF. Characterization of an acute inpatient hospice palliative care unit in a US teaching hospital. *J Nurs Admin*. 1996;26:16-20. [PMID: 8618119](#).

One hundred consecutive admissions to an acute palliative care unit were assessed. To characterize family satisfaction, a survey was sent to the families of 240 patients who had been cared for on the inpatient unit.

⁴² Walsh D, Gombeski WR, Goldstein P, Hayes D, Armour M. Managing a palliative oncology program: The role of a business plan. *J Pain Symptom Manage*. 1994;9:109-118. [PMID: 7517428](#).

The business plan and the process followed to develop the Palliative Care Program at the Cleveland Clinic Foundation (CCF) are presented. Benefits generated from this effort and lessons learned that may be helpful to other program managers are described.

⁴³ Aspen Reference Group. *Palliative Care Patient and Family Counseling Manual*. Gaithersburg, MD: Aspen Publishers, Inc.; 1996. ISBN: 0834207621.

⁴⁴ Martinez J, Wagner S. Hospice care. In: Groenwald SL, Frogge M, Goodman M, Yarbrow M, Jones CH, ed. *Cancer Nursing: Principles and Practices*. 4th ed. Boston: Bartlett Publishers; 1997. ISBN: 0763702196.

⁴⁵ Sheldon F. Communication. In: Saunders C, Sykes N, eds. *The Management of Terminal Malignant Disease*. Boston: Edward Arnold 1993:29-31. ISBN: 0340563540.

⁴⁶ The Hospice Institute of the Florida Suncoast, Hospice Training Program. *Care at the Time of Death*. Largo, FL: The Hospice Institute of the Florida Suncoast; 1996.

⁴⁷ Doyle D. Domiciliary palliative care. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine*. 2nd ed. Oxford, England: Oxford University Press; 1998:957-973. ISBN: 0192625667.

⁴⁸ O’Gorman SM. Death and dying in contemporary society. *J Adv Nurs*. 1998;27:1127-1135. [PMID: 9663862](#); [full text](#).

The article discusses the fact that nurses are often the professionals left to deal with dying patients’ grief and anger.

⁴⁹ Weber M, Ochsmann R, Huber C. Laying out and viewing the body at home—a forgotten tradition? *J Pall Care*. 1998;14:34-37. [PMID: 9893396](#).

⁵⁰ Weissman DE, Heidenreich CA. *Fast Facts and Concepts #4: Death Pronouncement in the Hospital*. Milwaukee, WI: End of Life Physician Education Resource Center. Available at http://www.eperc.mcw.edu/ff_index.htm. Accessed March 19, 2005.

This fact sheet reviews the steps of death pronouncement.

⁵¹ Osias RR, Pomerantz DH, Brensilver JM. *Fast Facts and Concepts #76 and 77: Telephone Notification of Death*. Milwaukee, WI: End of Life Physician Education Resource Center. Available at http://www.eperc.mcw.edu/ff_index.htm. Accessed March 19, 2005.

⁵² Marchand LR, Kushner KP. Death pronouncement: Survival tips for residents. *Am Fam Physician*. 1998 July. Available at: www.aafp.org/afp/980700ap/rsvoice.html.

When telephone notification is unavoidable, there are suggested guidelines to follow. Doctors must weigh the benefits of truthfulness against the risk of potential harm resulting from abrupt disclosure of the bad news.

⁵³ Magrane BP, Gilliland MG, King DE. Certification of death by family physicians. *Am Fam Physician*. 1997 October;1433-1438. [PMID: 9337765](#); [full text](#).

The primary care physician needs an explicit understanding of how to determine the cause and manner of death and should use succinct, clear language in completing the death certificate. When doubt exists or an external cause of death is a possibility, the coroner or medical examiner is the appropriate public health official to contact.

⁵⁴ Iserson KV. The gravest words: Sudden death notification and emergency care. *Ann Emerg Med*. 2000;36:75-77. [PMID: 10874244](#); [full text](#).

Survivors require our care that is informed by specific knowledge, educated experience, and a compassionate attitude.

⁵⁵ Iserson KV. The gravest words: Notifying survivors about sudden unexpected deaths. *Resident Staff Physician*. 2001;47:66-72.

⁵⁶ Irvine P. The attending at the funeral. *N Engl J Med*. 1985;312:1704-1705. [PMID: 4000217](#).

This sounding board presents reasons why it is important to families and physicians, for the physician to attend a patient's funeral.

⁵⁷ Ellershaw J, Ward C. Care of the dying patient: The last hours or days of life. *BMJ*. 2003;326:30-34. [PMID: 12511460](#); [full text](#).

The major challenge is to transfer best practice from a hospice setting to other care settings and to noncancer patients.

⁵⁸ Ferris FD, von Gunten CF, Emanuel LL. Competency in end of life care: The last hours of living. *J Pall Med*. 2003;6(4):605-613.

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.