

The Last Hours of Living: Practical Advice for Clinicians

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Clinical competence, willingness to educate, and calm and empathic reassurance are critical to helping patients and families during a loved one's 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. In anticipation of the event, inform the family and other professionals about what to do and what to expect.

Of all people who die, only a few (< 10%) die suddenly and unexpectedly. Most people (> 90%) die after a long period of illness, with gradual deterioration until an active dying phase at the end. 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.**

Most clinicians have little or no formal training in managing the dying process or death. Families usually have even less experience or knowledge about death and dying. 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

During the last hours of their lives, most patients require continuous skilled care. 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.

If the last hours of a person's life are to be as positive as possible, advance preparation and education of professional, family, and volunteer caregivers are essential. Everyone who participates must be aware of the patient's health status, 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. If they are left unprepared and unsupported, family members may live with frustration, worry, fear, or guilt that they did something wrong or caused the patient's death.

It is not possible to predict with precision when death will occur. Although 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

A variety of physiologic changes occur in the last hours and days of life, and when the patient is actually dying, which can be alarming if it is not understood. The most common issues are summarized here. (Table 1).

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 and 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
Neurologic 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 (eg, 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

Fatigue and weakness. Fatigue and weakness increase as the patient approaches the time of death. Joints may become uncomfortable if they are not moved. Continuous pressure on the same area of skin, particularly over bony prominences, will increase the risk for skin ischemia and pain. As the patient approaches death, providing adequate cushioning on the bed will lessen the need for uncomfortable turning. At the end of life, fatigue need not be resisted and most treatment to alleviate it can be discontinued. Patients who are too fatigued to move and have joint position fatigue may require passive movement of their joints every 1 to 2 hours.

Cutaneous ischemia. To minimize the risk for 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. 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 (eg, air mattress or airbed). As the patient approaches death, the need for turning lessens as the risk for skin breakdown becomes less important. Intermittent massage before and after turning, particularly to areas of contact, can both be comforting and reduce the risk for skin breakdown by improving circulation and shifting edema. Avoid massaging areas of nonblanching erythema or actual skin breakdown.

Decreasing appetite and food intake. Most dying patients lose their appetite. Unfortunately, families and professional caregivers may interpret cessation of eating as "giving in" or "starving to death." Studies demonstrate that parenteral or enteral feeding of patients near death neither improves symptom control nor lengthens life. Anorexia may be helpful as the resulting ketosis can lead to a sense of well-being and diminish discomfort.

Clinicians can help families understand that loss of appetite is expected 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 professionals to help families and caregivers realize that food pushed upon the unwilling patient may cause problems such as aspiration and increased tension. Above all, help them to find alternative ways to nurture the patient so that they can continue to participate and feel valued during the dying process.

Decreasing fluid intake and dehydration. Most dying patients stop drinking. 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. Low blood pressure or weak pulse is part of the dying process and not an indication of dehydration. Patients with peripheral edema or ascites have excess body water and salt and are not dehydrated.

Parenteral fluids, given either intravenously or subcutaneously using hypodermoclysis, are sometimes considered. 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 and conjunctival care. To maintain patient comfort and minimize the sense of thirst, maintain moisture on mucosal membrane surfaces with meticulous oral, nasal, and conjunctival hygiene. Moisten and clean oral mucosa every 30 minutes with an artificial saliva preparation to minimize the sense of thirst and avoid bad odors or tastes and painful cracking. Coat the lips and anterior nasal mucosa hourly with a thin layer of petroleum jelly to reduce evaporation. 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 and renal failure. 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 ensues. Parenteral fluids will not reverse this circulatory shut down.

Neurologic dysfunction. The neurologic changes associated with the dying process are the result of multiple concurrent irreversible factors. These changes may follow 2 different patterns that have been described as the "2 roads to death." Most 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. Families will frequently find the inability to communicate with their loved one 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.

Although 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. It is prudent to assume that the unconscious patient hears everything. *Advise families and professional caregivers to talk to the patient as if he or she were conscious.*

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. 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. 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. To the family 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". 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.

When moaning, groaning, and grimacing accompany the agitation and restlessness, these symptoms are frequently misinterpreted as physical pain. However, it is a myth that uncontrollable pain suddenly develops during the last hours of life when it has not previously been a problem. A trial of opioids may be beneficial in the unconscious patient who is difficult to assess. If the trial of opioids does not relieve agitation or makes the delirium worse or precipitates myoclonic jerks, pursue alternative therapies directed at suppressing the symptoms associated with delirium.

Respiratory dysfunction. Changes in a dying patient's breathing pattern may be indicative of significant neurologic compromise. Breaths may become very shallow and frequent with a diminishing tidal volume. Periods of apnea and/or Cheyne-Stokes pattern respirations may develop. (Cheyne-Stokes is a disorder characterized by recurrent central apneas during sleep, alternating with a crescendo-decrescendo pattern of tidal volume.) Accessory respiratory muscle use may also become prominent. A few (or many) last reflex breaths may signal death.

Families 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 and methotrimeprazine are appropriate to manage any perception of breathlessness. If the patient is already on opioids the dose can be increased.

Although 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.

Loss of ability to swallow. Weakness and decreased neurologic function frequently combine to impair the patient's ability to swallow. Buildup of saliva and oropharyngeal secretions may lead to gurgling, crackling, or rattling sounds with each breath. Some have called this the "death rattle" (a term that should be avoided, as it is frequently disconcerting to families and caregivers).

Once the patient is unable to swallow, cease oral intake. Warn families and professional caregivers of the risk for aspiration. Muscarinic receptor blockers (anticholinergics) are commonly used agents to control respiratory secretions when death is imminent. Some evidence 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.

If excessive fluid accumulates in the back of the throat and upper airways, it can be cleared by repositioning the patient or performing postural drainage. Oropharyngeal suctioning is not recommended. Suctioning 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. 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. Although many people fear that pain will suddenly increase as the patient dies, there is no evidence to suggest that this occurs. Although 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 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.

Loss of ability to close eyes. 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. Because the 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.

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 health professionals.

Basic information about death may be appropriate (eg, 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) (Table 2).

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

When an expected death occurs, the focus of care should shift 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 experience the full effect.

Many experts assert that the time spent with the body immediately after death will help people deal with acute grief. Those present, including caregivers, may need the clinician'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).

Because a visually peaceful and accessible environment may facilitate the acute grieving process, a health professional, usually the nurse, should spend a few moments alone in the room positioning the patient's body, disconnecting any lines and machinery, removing catheters, and cleaning up any mess, to allow the family closer access to the patient's body.

Notifying Others of the Death

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 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.

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.

Telephone Notification

There will be situations in which the people who need to know about the death are not present. In some cases, you may choose to tell someone by telephone 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 to break the news over the telephone 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. Use the same plan as you would for breaking bad news. See Communication section.

Summary of Take-Home Lessons

In summary, keep these key points in mind:

- There is only one chance to get management of the last hours right.
- 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.
- 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 or nurse needs to help family members understand that what they see may be very different from what the patient is experiencing.

- The physiologic changes of dying are complex. To control each symptom effectively, clinicians need to have an understanding of its cause, underlying pathophysiology, and the appropriate pharmacology to use.
- When death is imminent, fatigue is an expected part of the dying process and should not be treated medically in most cases.
- 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.
- 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.
- Moisture should be maintained in mucosal membranes with meticulous oral, lip, nasal, and conjunctival hygiene and lubrication.
- Most patients experience increasing drowsiness and sleep much of the time, eventually becoming unarousable.
- It should be assumed that the unconscious patient hears everything.
- Moaning, groaning, and grimacing accompanying agitation and restlessness are frequently misinterpreted as pain. Terminal delirium may be occurring.
- Diminished hepatic function and renal perfusion may change the pharmacology of chronically administered medications.
- Scopolamine or glycopyrrolate will effectively reduce the production of saliva and other tracheobronchial tree.
- 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 and how the body can be moved.
- When an expected death occurs, the focus of care shifts to the family and those who provided care.