

## Last hours of living

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The end-of-life and the death of someone close are never easy. No one can escape the experience. Everyone at the bedside will be watching the potential for her or his own future end-of-life experience and death. If symptoms are not well managed, the patient may suffer unnecessarily, the dying process may be prolonged unnecessarily, and the individuals who watch may be left with memories that the death was not good and fear that their own death will be similar.

Because much end-of-life care and dying take place in hospitals and long-term care facilities, most people today have never witnessed death or seen a dead body outside of a funeral home. They have seen only dramatizations on television or in movies. Most observers project their own experiences on what they think the patient is feeling and do not realize that the patient's experience may be different.

Along with end of life and death come many losses for the patient and family, such as loss of functional capabilities, body image, sense of future, independence, control, and dignity. These losses are accompanied by major transitions in roles, responsibilities, and family dynamics. Social support systems also change under stress; some people remain loyal to the patient and family, whereas others abandon them out of fear or other reasons.

As the patient's physical capabilities diminish, the need for care increases, particularly as goals of care and treatment priorities start to shift frequently. Although individual family members may be willing to care for their loved one, they need considerable training and support from the physician and other health care professionals.

Ultimately, as the patient dies, the original family group adjourns. The surviving members need to form a new family group with only the memory of the

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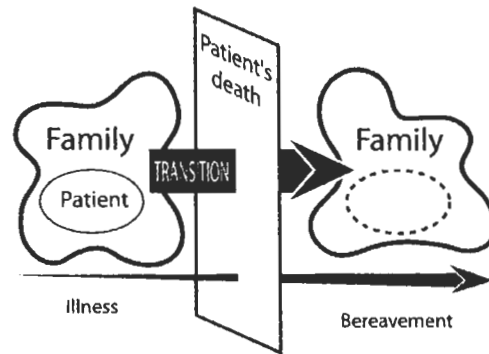


Fig. 1. Family transitions.

patient. Most families need considerable ongoing help from physicians and health care professionals before they once more perform effectively (Fig. 1) [1-3].

### Advance preparation

Care during the last hours of life is a core competency of every physician and health care worker [4-6]. People who know what to expect have a different experience of dying and death than people who are ignorant of the process. Time spent preparing patients, family members, and caregivers for the end of life helps to reduce anxiety and fear; increase competence and confidence to provide care; increase the sense of value and gifting during the process; create good memories of the experience; prepare for impending losses; shift roles, responsibilities, and support systems; and reduce dependence on health care professionals (eg, frequency of visits and urgent phone calls). Health care professionals can help people prepare for end of life and dying by conducting one or more family meetings to convey information, facilitate the development of an effective care team, facilitate life closure, help arrange for rites and rituals, and encourage planning for funeral or memorial services.

#### *Conduct a family meeting*

The process for conducting a family meeting is another application of the six steps of effective communication. One must be sensitive to personal and cultural differences related to information sharing and decision making. The following guidelines are suggested:

1. Set the stage carefully, and ensure that everyone who wants to be there is present and comfortable.
2. Start by asking what is known about the patient's illness and prognosis.
3. Ask how they would like to receive information.

4. When the family has made it clear that they would like to know, tell them the facts about the patient's illness and the prognosis (ie, that the patient is dying), then stop talking.
5. Wait for the emotional response, then offer support.
6. When they understand the situation, ask if they have any questions and determine whether they are prepared to receive more information. If emotions have been intense and family members seem to be unsettled, it may be better to schedule a follow-up meeting.

If the family is prepared for further discussions, provide an overview of changes and events that are likely to occur during the dying process (Table 1). Ask who the caregivers might be. Ask about their care-giving skills and experience. Facilitate decision making in terms of goals of care and treatment priorities. Develop a plan of care that includes personal activities that the patient may wish to complete before dying. Clarify who the surrogate decision maker will be when the patient loses capacity to make decisions and review advance directives. Discuss the appropriateness and comfort level of the family with the current setting of care (eg, the home) as the place for the patient's end-of-life care and death. If the family is not prepared for the patient to die at home, plan far enough in advance of the patient's death for a change in setting of care to ensure that it is safe for the patient, family, and all caregivers. Try to minimize the risk of sudden changes in the care setting when death is near. Transfers from a nursing home to hospital can be disruptive and distressing to everyone.

#### *Develop an effective care team*

Most family members are not skilled at caring for someone who is dying. Family members frequently volunteer to provide care, but they need considerable training and support from the health care team. As the care team forms, determine who would like to provide personal care versus who wants to help with other activities, such as cleaning, shopping, and scheduling visitors. Clinicians must explicitly give everyone permission to be family members first and to be bedside caregivers only if they are prepared for the role. The assignment of appropriate tasks helps minimize guilt and makes each person feel that he or she is helping. Identify who the coordinators of the care team would be (ie, which clinician will lead the health care team and who will coordinate family, friends, and caregivers).

When the care team has been selected, it is necessary to educate family and caregivers about expected and unexpected changes and signs during the dying process (see Table 1), how to communicate during the dying process, signs that death has occurred (Box 1), and what to do when death occurs (Box 2). Family members and caregivers also must be familiar with specific caregiving skills: how to change a bed with a patient in it; turning; massage; passive movement of joints; management of urine and stool; mouth, nose, lip, and eye care; and how to

Table 1  
Changes during the dying process

Change during the dying process	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
Pain	Facial grimacing Tension in forehead, between eyebrows
Decreasing food intake, wasting	Anorexia Poor intake Aspiration, asphyxiation Weight loss, muscle and fat, notable in temples
Loss of ability to close eyes	Eyelids not closed Whites of eyes showing (with or without pupils visible)
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 Nonresponsive to verbal or tactile stimuli
Decreasing ability to communicate	Difficulty word finding Monosyllabic words, short sentences Delayed or inappropriate responses Not verbally responsive
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

(continued on next page)

Table 1 (continued)

Change during the dying process	Manifest by/signs
Loss of sphincter control	Incontinence of urine or bowels Maceration of skin Perineal candidiasis
Terminal delirium	Early signs of cognitive failure, eg, day-night reversal Agitation, restlessness Purposeless, repetitious movements Moaning, groaning
Rare, unexpected events	
	Bursts of energy just before death occurs, the “golden glow”
	Aspiration, asphyxiation

deliver medications when the patient is unable to swallow. Ensure that all caregivers know how to practice universal body fluid precautions.

Too many visitors can be fatiguing for the patient and the family. For this reason, have a care team member take the task of scheduling visitation so that everyone gets to spend an appropriate amount of time with the patient.

The use of a logbook can facilitate communication between caregivers and minimize repetitious questioning of patients and families. The logbook could include categories such as goals of care; active treatments; patient preferences (eg, food, conversation, turning); summaries of conversations, care provided, and fluid and nutritional intake; contact information for all professional and informal caregivers; emergency instructions; and information on what to do when death occurs and whom to call.

#### Box 1. Signs that death has occurred

- Heart stops beating
- Breathing stops
- Pupils become fixed and dilated
- Body color becomes pale and waxy as blood settles
- Body temperature decreases
- 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
- Jaw can fall open
- Observers may hear the trickling of fluids internally, even after death

**Box 2. What to do when death occurs**

Always be sensitive to and respect personal, cultural, and religious values, beliefs, and practices.

Ensure family, caregivers, and health care professionals know what to do when death occurs:

- There are no rules or regulations governing what happens after the patient dies.
- There is no need to call 911.
- There is no need to rush to call a physician or other health care professional; invite the family and caregivers to call whenever they want support.

Encourage everyone:

- To spend the time they need to witness and realize what has happened and say their goodbyes
- To touch, hold, and kiss the person's body, as they feel most comfortable
- To complete the desired rites and rituals at the appropriate time

Sufficient time spent at the bedside beginning to "realize" that their loved one has died benefits everyone as they start to adapt to the changes in their lives.

When family members are ready for or need support, ensure they know who to call (eg, the physician, the hospice).

*Discuss communication with the dying patient*

During the last hours of life, families frequently want "just a little more time" to communicate with their loved one and become distressed when they are not able to have that time. The degree of distress seems inversely related to the extent to which advance planning and preparation occurred.

Although it is not known what unconscious patients can hear, experience suggests that their awareness may be greater than their ability to respond. It is prudent to *presume that an unconscious patient hears everything*. Advise families and caregivers to talk to the patient as if the patient were conscious. Surround the patient with things such as people, children, pets, music, and sounds that the patient would like. Encourage the family to say the things they need to say. Keep difficult conversations and bad news away from the bedside. Encourage family members to give the patient permission to "let go and die" by using words that are comfortable for them. Some suggested phrases are: "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."

Touch can heighten communication. Encourage everyone to show affection in ways they are used to, including touching and lying beside the patient. Maintain privacy. Encourage the family to engage in as much intimacy as they are comfortable with.

#### *Facilitate life closure*

Given the opportunity, many patients who are approaching the end of life want to finish their business, organize their financial and legal affairs, and reconcile close and estranged relationships. The care team can help patients engage in activities to create memories, including reminiscence and life review, in many ways: stories and photos, family reunions and celebrations, letter writing and the creation of audio or video tapes, gift giving (eg, thoughts, personal treasure, family heirlooms, money, organ donation), and saying goodbye. Some patients may want to have a party before their death to give gifts and say goodbye to close family and friends.

#### *Rites and rituals, funerals, memorial services*

The care team should ensure that everyone involved is aware of 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 or how the body can be moved. The team also can help the patient and family plan funeral and memorial services and burials or cremations.

#### *Provide ongoing support*

Throughout the last hours of life, families benefit from repeated contact with the physicians and health care team. Review the status of the patient, the family, and caregivers regularly. Repeat and clarify the goals of care, the futility of life-prolonging therapies, and the irreversibility of unfolding events. Modify the care plan as needed to address the changing situation and goals of care. The care team should assess the potential for an intense, acute grief reaction and identify persons at high risk for a complicated grief reaction. Because delays in communication heighten anxiety, ensure that knowledgeable clinicians, including a physician, are available by telephone 24 hours per day, 7 days per week. Families and caregivers have the best outcome if their questions and concerns are addressed promptly.

#### *Dying in institutions*

Many patients now die in hospitals and nursing homes, and there are particular challenges of ensuring a comfortable death in an institution where the culture is not focused on end-of-life care (eg, acute and long-term care facilities, prisons and jails) [7]. Tradeoffs that were acceptable because the patient would recover

(loss of privacy, no opportunity for intimacy) are no longer acceptable because this is the last chance for the patient and family to be together. Provide a private environment where confidential conversations are possible and where the family can be present at any time, day or night. This may involve moving other patients out of a multibed room. Encourage the family to surround the patient with a few favorite personal belongings and photos.

Because this is the last chance for the patient and family members to be close, encourage intimacy. Teach families how to pillow side-rails and curl up safely in the hospital bed beside their loved one. Provide privacy signs for family members to hang on closed doors, and teach staff to respect these signs.

Ensure that the staff is knowledgeable about and skilled in care during the last hours of life and that they collaborate to provide a single plan of care across nursing shifts and changes in house staff. If providing an environment conducive to end-of-life care is difficult on the general medical/surgical unit, establish a specialized palliative care unit where patients and families can be assured of the environment and the skilled care they need [8,9].

### Managing the dying process

As the last hours of life evolve, the many common, irreversible signs and symptoms can be alarming if not understood by the family (see Box 1). Reassess the need for every therapeutic intervention. Stop medications and therapies that are inconsistent with the patient's goals of care. Give only medications needed to manage symptoms (eg, pain, breathlessness, terminal delirium, secretions, seizures) (Table 2). Base pharmacologic and nonpharmacologic management

Table 2  
Medications used during the last hours of life

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

Abbreviations: IV, intravenous; PR, per rectum; SC, subcutaneous; SL, sublingual.



on the etiology and underlying pathophysiology of each symptom. Use the least invasive route of administration, usually the oral or buccal mucosa (buccal) routes, occasionally the subcutaneous or intravenous routes, and rarely the intramuscular route.

### *Weakness and fatigue*

Fatigue and weakness usually increase as death approaches. Most patients are unable to move around in bed or raise their head [10]. Most therapy to alleviate fatigue can be discontinued at this time. Move joints passively every 1 to 2 hours because joint position fatigue and significant aching can develop if a patient remains in the same position without moving for prolonged periods [11].

### *Skin care*

During the last hours of life focus skin care on hygiene, moisture, protection, pressure reduction, and massage. Bathe the patient routinely using warm water and a gentle skin-cleansing agent to maintain body hygiene, remove dead skin, clean away body fluids (eg, urine, stool), and minimize body odor. Avoid soaps that cause dryness and perfumes that may be irritating or abrasive.

Dry the patient's body thoroughly to minimize the risk of maceration. Moisturize skin routinely to minimize the risk of dry, flaking skin and pruritus and to maintain elasticity and minimize the risk of tears. Avoid rubbing areas where the skin has broken down or that are erythematous. Protect thin, fragile skin to minimize the risk of skin tears. This is particularly important in cachectic patients who have lost the elasticity and resilience previously provided by collagen and subcutaneous fat. Thin transparent membranes reduce shearing forces, and hydrocolloid dressings add a cushioning effect.

Continuous pressure, particularly over bony prominences, increases the risk of ischemia, skin breakdown, and pain [12]. To minimize sacral pressure, keep the head of the bed lower than 30° and raise it for only short periods of social interaction. Avoid resting one limb on another. Keep the legs apart with a pillow or some other cushioning support. Protect bony prominences with hydrocolloid dressings.

Turning the patient helps to maintain comfort; reduce pressure; and minimize the risk of ischemia, skin breakdown, and joint position fatigue. When patients are unable to move themselves, turn them carefully from side to side every 1 to 1.5 hours using a logroll technique to distribute forces evenly across the body and to minimize pain on movement. Use a draw sheet to reduce shearing forces that could lead to skin tears. If turning is painful, turn the patient less frequently or place him/her on a pressure-reducing surface, such as an air mattress or air bed. As death approaches, the need for turning lessens because the risk of skin breakdown becomes less important.

Intermittent massage can stimulate circulation, shift edema, spread moisturizing lotions, and be comforting. It is particularly helpful to stimulate circulation in dependent areas that are subject to increased pressure before and after turning. Avoid skin that is erythematous or has broken down.

#### *Wound care*

During the last hours of life, wound care focuses exclusively on comfort, not healing. Minimize the frequency of dressing changes. Use nonstick, pain-reducing dressings, such as hydrogels and alginates. Control infections with topical antibacterials (eg, iodine, metronidazole, or silver compounds) and antifungals (eg, ketoconazole). Contain exudate flow with foam dressings. Reduce odors by placing a pan filled with kitty litter or activated charcoal under the bed or by burning a candle in the room. Odors also can be masked by alternate smells, such as vanilla or vinegar. Avoid scented deodorizers or perfumes.

#### *Decreasing food intake and wasting*

Most patients lose their appetite and reduce food intake long before they reach the last hours of life [12]. Families and professional caregivers often interpret cessation of eating as giving in and worry that the patient will starve to death. Clinicians can help families understand that loss of appetite is a normal part of the dying process and that most patients are simply not hungry. Food is not appealing for many patients, and some may even find it nauseating. Parenteral or enteral feeding of patients at the end of life does not improve symptom control, and it does not lengthen life [13–18]. Anorexia may be a protective mechanism. The resulting ketosis may have an anesthetic effect that diminishes pain and leads to a greater sense of well-being.

It is important for physicians and health care professionals to help families and caregivers realize that food pushed on an unwilling patient or one who is incapable of eating inadvertently may cause nausea, aspiration, or asphyxiation and increase tensions and bad feelings. Clenched teeth may be the only way for the patient to exert control and should be respected. An alternative is to help family members and caregivers find different ways to provide appropriate physical care and emotional support to the patient.

#### *Loss of ability to close eyes*

Patients frequently leave their eyes open during the last hours of life, although the conjunctiva and iris and pupil are not visible. Emphasize that this is *not* a sign of neurologic dysfunction. Advanced wasting leads to loss of the retro-orbital fat pad, and muscles pull the orbit posteriorly into the orbital socket [19].

The patient's eyelids are not long enough to extend the additional distance backward and fully cover the conjunctiva. As a result, the eyelids no longer appose and some conjunctiva remains exposed even when the patient is sleeping. Explain this to the family and caregivers so they will understand what is happening and not find it distressing. When the conjunctiva is exposed, maintain moisture with the use of ophthalmic lubricants, artificial tears, or physiologic saline (see the subsequent section on oral, nasal, and conjunctival care) [20].

#### *Decreasing fluid intake and dehydration*

Most patients reduce their fluid intake or stop drinking long before they die [21]. This frequently causes distress to family and caregivers because they worry that the patient will become dehydrated and suffer. Clinicians can help families and caregivers understand that this is an expected event and suggest alternate ways for them to give care.

#### *When fluid intake is reduced*

If the patient is still taking some fluid but not eating, salt-containing fluids, such as soups, soda water, sport drinks, and red vegetable juices (eg, tomato juice) can help to rehydrate the patient, maintain electrolyte balance, and minimize the risk of nausea from hyponatremia. Fluids that are effectively “free water” and do not contain sodium bicarbonate are not rehydrating (eg, water, fruit juices, sodas, soft drinks). Fluids that contain caffeine (eg, coffee, tea, and alcohol) are diuretics and worsen dehydration. Discontinue all diuretics and antihypertensives.

As patients develop cachexia and hypoalbuminemia, the oncotic pressure and intravascular volume decrease, and mild peripheral edema is expected. The absence of mild peripheral edema signals severe dehydration. Increased fluid intake increases the risk of peripheral and pulmonary edema. It does not replenish the intravascular volume.

An albumin infusion can restore temporarily intravascular oncotic pressure, produce a transitory diuresis, and reduce edema for a short period (hours to 1 or 2 days); this may allow the patient to participate in a specific activity, such as a family reunion. Routine albumin infusions are not recommended in cachectic patients, however, because the effect is short-lived. The albumin is catabolized within hours as a fuel source for the patient (or a tumor), and it does not reverse the underlying protein deficit. It also is an expensive procedure.

#### *When the patient stops taking fluids*

When a patient stops taking oral fluids, explain to the family that patients with peripheral edema or ascites have excess body water and salt and are not dehydrated. They will not get lightheaded or dizzy if they are not up in bed. Low blood pressure and a weak pulse are part of the dying process, not just an indication of

dehydration, and most experts believe that dehydration in the last hours of life does not cause distress. It may stimulate endorphin release and add to the patient's sense of well-being [22–24].

During the last hours of life, parenteral fluids (delivered intravenously or subcutaneously using hypodermoclysis) may help to prevent or reverse terminal delirium [25]. They may also cause more harm than benefit. Intravenous lines can be cumbersome, difficult to maintain, and increase the risk of local or systemic infections. Movement of the angiocatheter can be painful, particularly when the access site needs to be changed frequently and the patient is cachectic or has no accessible veins. In the presence of hypoalbuminemia, parenteral fluids can lead to fluid overload, peripheral and pulmonary edema, breathlessness, cough, and excessive orotracheobronchial secretions. Parenteral fluids also can prolong the dying process, which may be inconsistent with the patient's goals of care.

#### *Oral, nasal, and conjunctival care*

During the last hours of life, meticulous oral, nasal, and conjunctival hygiene are essential to maintain comfort [26]. To minimize bad odors and tastes and the sense of thirst and reduce the risk of painful cracking and bleeding, moisturize and clean the oral mucosa every 15 to 30 minutes with either a baking soda mouthwash (1 teaspoon salt [5 mL] plus 1 teaspoon baking soda [5 mL] mixed in 1 quart [1 L] tepid water) or an artificial saliva preparation. If oral candidiasis is present and the patient is able to swallow, treat with systemic fluconazole. Otherwise, dab white plaques with topical nystatin. Avoid swabs containing glycerin and lemon as glycerin is desiccating and lemon is irritating, particularly on open sores.

Coat the lips and anterior nasal mucosa with a thin layer of petroleum or other nonaqueous jelly every 4 hours to reduce evaporation, drying, and painful cracking. Take care not to occlude the nasal cannulae. Although not flammable, petroleum jelly can soften some plastics if exposure is prolonged. Avoid perfumed lip balms because they can be irritating.

To minimize the risk of painful, dry eyes, particularly when the eyes remain open, moisten the conjunctiva with artificial tears or physiologic saline solution every 15 to 30 minutes (these evaporate quickly) or an ophthalmic lubricating gel every 3 to 4 hours.

#### *Cardiac dysfunction and renal failure*

Cardiac output, intravascular volume, and urinary output normally decrease toward the end of life. As oliguria develops, the remaining urine typically becomes a dark "tea" color. Most dying patients ultimately become anuric, and rehydration with parenteral fluids is unlikely to reverse this circulatory shutdown or renal failure, particularly when the patient is hypoalbuminemic [27].

*Neurologic dysfunction: the two roads to death*

Neurologic changes typically manifest as one of two patterns that have been described as the “two roads to death” (Fig. 2) [28]. Of dying patients, 70% to 90% follow the “usual road” and die quietly, and 10% to 30% follow the “difficult road” and become terminally delirious.

*Usual road*

Patients who follow the usual road to death typically experience increasing drowsiness, decreasing ability to communicate, changes in their perception of pain, respiratory dysfunction, inability to swallow, loss of sphincter control, coma, and finally a quiet death. The eyelash reflex is a useful indicator to estimate the patient’s level of awareness during the dying process. Anesthesiologists use the eyelash reflex to guide the induction of anesthesia. The disappearance of the eyelash reflex suggests a profound level of coma equivalent to full anesthesia and lack of any awareness by the patient.

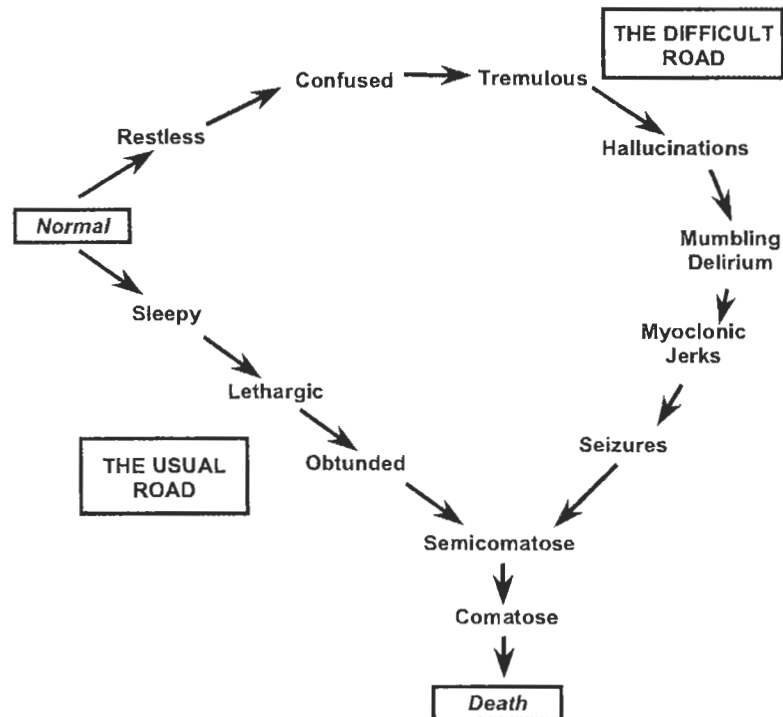


Fig. 2. The two roads to death. (From Freeman FR. Delirium and organic psychosis. In: Organic mental disease. Jamaica [NY]: SP Medical and Scientific Books; 1981. p. 81-94.)

*Pain.* Many people fear that pain increases suddenly during the last hours of life. The experience of pain during the dying process may decrease due to decreasing neurologic activity such as nociception and transmission, decreasing awareness and perception, and buildup of endorphins and other endogenous metabolites that have anesthetic properties (eg, ketones). Although difficult to assess in a semiconscious or obtunded patient, continuous pain may be associated with grimacing and continuous facial tension, particularly across the forehead and between the eyebrows. Physiologic signs, such as transitory tachycardia, also may signal acute changes.

Clinicians must be careful not to diagnose pain when fleeting forehead tension comes and goes because this might be attributable to movement, passage of gas, mental activity, dreams, or hallucinations. Do not confuse pain with the restlessness, agitation, moaning, or groaning that accompany terminal delirium. If the diagnosis is unclear, a time-limited therapeutic trial of opioids administered on an as-needed basis may help determine whether pain is the source of the observed behaviors.

Knowledge of opioid pharmacology is crucial in pain management during the last hours of life. Codeine is metabolized into morphine. Morphine, oxycodone, and hydromorphone are conjugated into glucuronides by the liver, and 90% to 95% of the metabolites are renally excreted. Some of these metabolites are potent analgesics (eg, morphine 6-glucuronide). Others may cause central nervous system excitation but no analgesia effect (eg, morphine 3-glucuronide). The effects of others (eg, metabolites of hydromorphone and oxycodone) are less certain.

Renal clearance decreases during the dying process, resulting in oliguria and anuria. Discontinue the routine administration of morphine (including continuous infusions) to avoid the accumulation of potentially toxic metabolites, such as morphine 3-glucuronide, and to minimize the risk of terminal delirium. Analgesic relief can be maintained by administering breakthrough doses of morphine to manage expressions suggestive of pain. Alternatively, opioids with inactive metabolites (eg, fentanyl or hydromorphone) can be used.

*Respiratory dysfunction.* Altered breathing patterns may indicate evolving and significant neurologic compromise during the last hours of life [29–31]. As the patient becomes fatigued, breaths may become shallow and frequent with a diminishing tidal volume. Periods of apnea or Cheyne-Stokes pattern respirations frequently develop when the respiratory control center malfunctions. Use of accessory respiratory muscles may become pronounced. A few last reflex breaths may signal death. These “agonal breaths” can persist for minutes to hours, with significant gaps between each breath. They can be agonizing for everyone who watches.

Changes in breathing patterns are often one of the most distressing signs of impending death for families and professional caregivers. Many fear that the comatose patient experiences a sense of suffocation. They frequently find com-

fort in knowing that an unresponsive patient may not be experiencing any sense of breathlessness or suffocation and that oxygen would not be beneficial and might prolong the dying process.

Using standard opioid dosing guidelines, low doses of opioids can be administered to manage any perception of breathlessness without risk of shortening the patient's life. Phenothiazines (eg, chlorpromazine, 10–30 mg orally, per rectum, or subcutaneously) every 1 hour as needed may enhance the effect of opioids. Benzodiazepines (eg, lorazepam, 1–2 mg orally, subcutaneously, intravenously, or per buccal mucosa, elixir or tablet predissolved in 0.5–1 mL water, or injectable) every 1 hour as needed may also help alleviate associated anxiety. The use of these drugs would not shorten the patient's life [32].

*Loss of ability to swallow.* In the last hours of life, weakness and decreased neurologic function frequently impair the patient's ability to swallow, the reflexive clearing of the aerodigestive tract, and the gag reflex. As saliva and other secretions accumulate in the oropharynx and tracheobronchial tree, each breath may result in gurgling, crackling, or rattling sounds that leave unprepared family members and caregivers with the impression that the patient is choking [33]. Some have called these sounds the *death rattle*, but the use of this term is discouraged because families and caregivers frequently find it disconcerting.

If the patient is unable to swallow, stop *all* oral intake. Warn families and caregivers of the risk of aspiration and asphyxiation. Start an anticholinergic early to minimize the accumulation of secretions, particularly in an unconscious patient [34]. Scopolamine can be given, 0.2 to 0.4 mg subcutaneously every 4 hours, 1 to 3 transdermal patches every 72 hours, or 0.1 to 1 mg every 1 hour by continuous intravenous or subcutaneous infusion. Glycopyrrolate can be given, 0.2 mg subcutaneously every 4 to 6 hours or 0.4 to 1.2 mg every 24 hours by continuous intravenous or subcutaneous infusion [35,36]. Although atropine may be equally effective in similar doses, it has an increased risk of producing undesired cardiac or central nervous system excitation [37].

If gurgling sounds persist, the patient can be moved onto his or her side or placed in a semiprone position to try to drain the secretions. Secretions also can be cleared by postural drainage using the Trendelenburg position: The patient is placed in a semiprone position with the head turned to the side, the head of bed is lowered, and the bottom is raised. Gravity may draw fluids into the oropharynx, where they can be removed with a sponge, gauze on a stick, or oropharyngeal suction. Do not maintain the Trendelenburg position for more than a few minutes at a time because stomach contents also may be expelled unexpectedly. To avoid personal injury, never pass your fingers beyond the patient's teeth.

If movement and postural drainage are ineffective, bedside oropharyngeal suction is likely to be ineffective as well. It is not recommended because the secretions cause gurgling and frequently accumulate in the hypopharynx and lower airways, where the suction catheter cannot reach. Deep suctioning may be highly stimulating and painful to an otherwise peaceful patient and may cause distress to family members who are watching.

*Loss of sphincter control.* Fatigue and loss of sphincter control may lead to bladder and bowel incontinence in the last hours of life. This incontinence can be distressing to patients, family members, and caregivers, especially if they are not warned in advance that this may happen. If incontinence occurs, clean the patient promptly and provide appropriate skin care. If urine flow is minimal, manage recurrent incontinence by placing absorbent pads under the patient. Persistent urinary incontinence may require the use of a condom or indwelling urinary catheter to reduce the need for frequent changing and cleaning and to prevent skin breakdown. Although convenient for caregivers, an indwelling urinary catheter may be uncomfortable for the patient, particularly men. Always instill lidocaine 2% gel into the urethra 10 to 15 minutes before catheterizing men. A rectal tube may be helpful if diarrhea is considerable and persistent.

#### *Difficult road*

*Terminal delirium.* Terminal delirium that is associated with other signs of the dying process (see Box 1) may be the first change to herald the difficult road to death and can be distressing to family members and caregivers who do not understand it. It can present as day-night reversal, confusion, agitation, or restlessness [38]. Slowly, or abruptly, it frequently evolves into a highly agitated state associated with repetitious and purposeless movement, unintelligible vocalization, and moaning and groaning. It also may be accompanied by myoclonic jerks and focal or grand mal seizures, particularly when cerebral metastases are present.

Terminal delirium may be the result of any of the standard causes of delirium listed in the *Diagnostic and Statistical Manual of Mental Disorders* [39] that are part of the dying process, including hypoxia, metabolic disturbances such as acidosis, infections, toxin accumulation due to liver and renal failure, adverse effects of medications, disease-related factors, reduced cerebral perfusion, or altered electrical conduction. It is often difficult, if not impossible, to differentiate terminal delirium from a psychological or spiritual crisis at the end of life, although the latter two typically do not occur in a patient who was previously calm and prepared for the end of life.

To differentiate the moaning and groaning of terminal delirium from pain, it is helpful to look for tension across the forehead, frowning of the eyebrows, or facial grimacing. If these signs are absent, the vocalization is more likely to be related to delirium than pain [40]. A time-limited trial of opioids also may be diagnostic, but if renal clearance is compromised, the extra doses might lead to opioid metabolite accumulation and add to the delirium [41,42].

Focus on relaxing muscles (particularly the muscles that close the vocal cord and cause moaning and groaning), minimizing the patient's awareness of the experience, preventing seizures, and settling the patient and everyone who is watching [43]. Benzodiazepines (eg, lorazepam, 1–2 mg, elixir or tablet predissolved in 0.5–1 mL of water) placed against the buccal mucosa every 1 hour as needed and titrated to effect are ideal for managing terminal delirium because they are anxiolytics, amnestics, skeletal muscle relaxants, and anti-



epileptics [44]. When the patient is settled, administer the medication in divided doses, every 4 hours to maintain sedation. Doses of 2 to 10 mg of lorazepam settle most patients, although a few extremely agitated patients may require 20 to 50 mg or more in a 24-hour period. Midazolam is a fast-acting alternative. Start with 0.5 to 2 mg intravenously every 15 minutes and titrated to effect. When the patient is settled, adjust the dose to 1 to 5 mg subcutaneously or intravenously every 1 hour to maintain sedation.

Benzodiazepines may have a paradoxical effect and cause excitation in some patients [45], and these patients require neuroleptic medications to settle their symptoms. Chlorpromazine, 10 to 25 mg or more orally, per rectum, or intravenously, every 6 hours is preferred because it is more sedating [46]. Haloperidol, 0.5 to 2 mg every 4 to 6 hours intravenously, subcutaneously, or per rectum, may be titrated to effect, but it is frequently not as sedating [47]. Caution is advised when using neuroleptics because they can lower the seizure threshold and increase the risk of seizures. If benzodiazepines and neuroleptics are ineffective, barbiturates and propofol have been suggested as alternatives [48,49].

*Seizures.* Manage seizures that occur during the dying process with high doses of benzodiazepines (eg, lorazepam or midazolam subcutaneously or intravenously). If the seizures are resistant, other antiepileptics may be needed to establish control (eg, phenytoin per rectum, to load 900 mg every 2 hours for 3 doses, then 300 mg every 8 hours to maintain, or intravenously, to load 15–20 mg/kg (elderly low end, obese high end) diluted to 5 mg/mL or less in saline and infuse no faster than 50 mg/min (25 mg/min in elderly or those with a history of CAD), then 100 mg every 6–8 hours; or phenobarbital, 60–120 mg per rectum, intravenously, or intramuscularly every 10–20 minutes as needed).

### **When death occurs**

When the expected death occurs (see Box 1), the focus of care shifts from the patient to the family and caregivers (see Box 2). Everyone has a different experience and a personal sense of loss. Even though the death had been anticipated for some time, no one knows what the loss feels like until it actually occurs. To help them address their acute grief, encourage family members and caregivers to spend as much time as they need with the body. It may take hours, days, weeks, or even months for each person to realize the full impact of the changes [50–52].

It is rarely obligatory for physicians or health care professionals to rush to the bedside to witness what has happened, unless the patient has requested organ donation or made an anatomic gift to a medical school. The presence of a professional may be helpful to family members, however, who are distressed, have questions, and need immediate support with acute grief reactions [53,54].

Members of the health care team who have not been present for the death can assess how family members are handling their loss by listening to a recounting of events leading up to the death and what occurred afterward. Look for signs of acute grief reaction that are beyond cultural norms because this could suggest a significant risk of complicated grief reaction. Be aware of individuals who show little or no emotional reactions to the death or individuals who may be catatonic. These individuals need significant acute support and interventions for them to realize and accept what has just happened. These individuals are almost certainly at high risk of complicated grief reactions. Spiritual advisors or other interdisciplinary team members may be instrumental in orchestrating events to facilitate the transition that the individuals present are experiencing.

#### *Pronouncing and certifying death*

Medical students and residents usually are called to “pronounce” death in teaching hospitals. In nonteaching settings, the responsibility may fall on the attending physician or nursing staff. When a patient dies at home with hospice care, a nurse usually confirms the absence of vital signs. Although local regulations differ, if an expected death occurs at home without hospice care and the patient’s physician is willing to sign a death certificate, the body does not need to be transported to a hospital for confirmation of death.

The patient’s identity must first be verified; this can be accomplished by asking the persons present for the patient’s full name and verifying the information by comparing it with the hospital ID tag if one is available. Observe the patient for several minutes. Note the general appearance of the body particularly the color, the presence of mottling (livedo reticularis) or venous pooling along dependent skin surfaces. Examine the patient for the absence of spontaneous respirations, heart sounds, and carotid pulse. Note the size of the pupils. Test for the absence of pupillary light reflex and the response to verbal or tactile stimuli. Overtly painful stimuli, such as nipple or testicle twisting or deep nailbed or sternal pressure, are neither appropriate nor necessary.

If the team member pronouncing the death knew the patient, the team member should stop and spend a few moments taking in what has happened. This may be the only personal opportunity to realize what has happened and say goodbye. When the pronouncement is complete, document all activities in the medical record.

All funeral directors require a completed death certificate to proceed with body preparation and registration of the death. Some funeral directors insist on having the death certificate before they pick up the body. Ensure that the physician who will complete the death certificate knows when it must be ready.

#### *Notifying the coroner*

The medical coroner is responsible for reviewing cases in which the circumstances surrounding a death are unknown, or there is suspicion of malice. In most jurisdictions, regulations also exist that trigger mandatory scrutiny of

deaths that occur under specific circumstances, such as deaths that occur in acute care facilities within 48 to 72 hours of transfer from a long-term care facility. Because regulations vary, health care professionals must know the local regulations. If there are any doubts about the circumstances surrounding a death, call the coroner's office and review the case. If it is necessary to call the coroner's office, do not touch or move anything in the room, including the patient, until the coroner has reviewed and released the case. The coroner usually completes the death certificate before closing the case.

#### *Notifying family*

When the patient has been pronounced dead, the family should be informed, even if the coroner has not completed the investigation. Communicate unexpected news in person rather than by telephone. Face-to-face contact offers a much greater opportunity for assessment and support. Follow the six-step guideline for communicating bad news such as this [55].

#### *Preparing the body for viewing*

When the pronouncement is complete (and the coroner, if called, has released the body), create a visually peaceful and accessible environment to make viewing of the body easier. Position the body in such a way that it looks comfortable. Disconnect lines and machinery, remove catheters, clean up any trash or mess [56,57]. If the patient's eyes remain open, hold the eyelids closed for a few minutes (they will usually remain closed when they dry). If they remain open, a small amount of surgical tape or a short adhesive surgical strip will hold them closed without pulling out eyelashes when the tape is removed. If the jaw falls open as muscles relax, place a rolled-up towel under the chin and elevate the head. This usually holds the jaw closed until muscles stiffen as rigor mortis sets in 4 to 6 hours after the death. To make transfers and funeral arrangements easier, place the patient's body in a straight, flat position with the arms placed across the chest before rigor mortis occurs.

#### *Inviting others to bedside*

When the body is ready for viewing, invite the family to the bedside first, then anyone who has been close to the patient, including friends, caregivers, and health care professionals. Before taking visitors into the room, spend a few minutes to inform them of the changes that have taken place in body color and temperature and prepare them for the scene they will see. This preparation can reduce the surprise and make the transition easier for everyone. Tell everyone that there is no need to rush; that each person can take the time necessary to witness what has happened and say goodbye.

### *Moving the body*

When family members and caregivers have had the time they need to witness what has happened, deal with their acute grief reactions, and observe their customs and traditions, preparations can begin for a funeral or memorial service. Families who have not discussed funeral arrangements in advance may have many questions about embalming, burial, cremation, and different types of services. If the funeral director is not available, spend a little time answering questions; this eases the anxiety about what happens next.

Invite family members and caregivers to help prepare the body for transfer to the funeral home or the hospital morgue. Some people find the touching, bathing, and preparation to be therapeutic, and it helps them realize that the patient has died. For many individuals, such rituals are the final act of direct caring. Occasionally a family wants to keep the body at home or in the patient's room at the acute or long-term care facility until the funeral service, burial, or cremation. This is possible in most jurisdictions. Some additional preparation of the body and good ventilation are essential. The staff at the funeral home can be asked to help prepare the body before rigor mortis sets in.

When the family is ready for the body to be moved, call the funeral service provider and arrange for removal of the body. Most funeral services have transfer staff available 24 hours a day, 7 days a week, and can pick up the body soon after notification. Tell the family when the body is to be removed by the funeral home. If the patient is in a health care institution, the transfer service deals directly with the institution.

For many people, the arrival of the funeral directors and the removal the body is the next major confrontation with reality, particularly when the death occurred at home. Some family members want to witness the removal, but others find it difficult and may want to be in another room while professional caregivers handle the transfer. The thought of a person's body enclosed in a body bag is intolerable to some people. Health care professionals and funeral directors need to be sensitive to this issue and negotiate a suitable alternative, perhaps not closing the bag until it has been removed from the vicinity of the home. Institutional staff will need to be aware of similar reactions by family members when they prepare the body for transfer to the morgue.

### *After the body has been moved*

When the body has been removed and family members are settled, offer assistance with some of the immediate next steps, such as notifying attending and consulting physicians, caregivers, and other health care service agencies that the patient has died. Explain local regulations governing waste disposal and ownership of medications after a death. Help family members dispose of medications, particularly opioids, in the toilet. Document the type and quantity of medications disposed of. Have a witness cosign the medical record. Biologic wastes can be disposed of by double bagging and placing in a trash container.

Sharps containers usually are removed by health care professionals for proper disposal. Secure any valuables left by the patient with specific family members.

The patient's family members and friends may want to have some private time together. Before leaving, ensure the family knows whom to call if they have questions or need help or support. Establish the time for the first follow-up call from the team.

### Bereavement

Immediately after a death, bereaved individuals need time to recover from the acute stress and fatigue and to restore their environments to a more normal state. As they begin to realize the significance of the loss and its impact on their lives, they are likely to experience an intense grief reaction with multiple cognitive, emotional, and physical responses (Table 3), and they may require considerable ongoing support to help them deal with all the changes [58–62]. Some individuals make a conscious effort to deal with the loss, emotions, and changes that follow the death of a loved one by seeking ongoing assistance from their physicians to help address their emotions and the feelings of loss. Others deny what is happening and avoid dealing with any of these issues. These individuals are at high risk for a prolonged, complicated grieving process.

### Follow-up

Most families expect the physician and other health care professionals who knew the patient to provide initial follow-up support. An initial phone call, followed by a sympathy card, may be an appropriate way to provide initial follow-up, whether or not one attends the funeral or memorial service. A phone call to offer condolences to key family members can be made 2 to 5 days after the

Table 3  
Cognitive, emotional, and physical responses to loss and grief

Cognitive	Emotional	Physical
Confusion	Abandonment	Appetite change
Disbelief	Ambivalence	Fatigue
Distrust	Anger	Gastrointestinal disturbances,
Dreams/nightmares of the deceased	Despair	eg. diarrhea, heartburn,
Lack of concentration	Fear	nausea/vomiting
Preoccupation with the deceased	Guilt	Heart palpitations
	Loneliness	Hiccups
	Numbness	Hollowness in the stomach
	Relief	Insomnia
	Sadness	Skin reactions
		Tightness in the chest
		Weakness
		Weight gain or loss

death occurred. This call gives the team member the opportunity to find out how everyone is doing and to plan further follow-up. A condolence note sent by the physician within 2 weeks of the death is an opportunity to offer tribute to the deceased as someone who was important. Hand-write the note on standard stationery. Grieving family members appreciate that the physician took the time to compose and send a personal message about their loved one.

#### *Attendance at funerals and memorial services*

Members of the health care team may want to attend some funeral or memorial services [63]. Many find that, in addition to supporting the family, it helps them personally to close long-standing relationships they have had with the patient and the family. It is best to ask the family's permission in advance because they may have planned for only a small, intimate family gathering. Although most families do not expect health care providers to attend services, they are touched by and grateful for the thoughtfulness.

#### *Tasks of the grieving*

After a major loss, there typically are four tasks the bereaved must complete before they can deal effectively with their loss [64]. These tasks apply to the many losses that precede a death and to the loss due to death itself. Although the tasks are interdependent, they need not be completed in sequence. All of these tasks may seem relatively straightforward to the inexperienced onlooker. For the person who is emotionally distraught and now feels lonely and abandoned, however, each task may seem insurmountable and may take months or years to resolve.

Support from family members and caregivers may be intense for the first few days or weeks after the death; the degree of support inevitably diminishes as others who were less affected get on with their lives. Some family members may become impatient if the person who has suffered the greatest loss is unable to move on or continually dwells on the loss, and a rift develops that increases tensions further between the bereaved and other members of the family, who become stressed when they do not know what to do.

#### *Task 1: realize the loss*

For many individuals, the realization and acceptance that the loss has occurred can be a major hurdle. If the bereaved person spent little or no time at the bedside after the death observing the change that had taken place, he or she may continue to deny for months that anything has happened, and that denial can be unwavering. Some bereaved may continue to look for the deceased person, expecting him or her to return home or call on the phone. Until the bereaved person realizes that his or her loved one has died, he or she cannot begin to resolve what has happened and move on.

*Task 2: realize the pain*

Knowing that the death has occurred is not enough. To be able to move on, a bereaved person needs to experience the pain caused by the loss. This pain can be distressing, and many bereaved try to avoid it, and physicians frequently try to blunt it with medication. Although medication may be necessary for temporary management of severe depression or destructive reactions, it can prolong the grief reaction and the pain associated with the loss if it is overused.

*Task 3: recognize the significance*

When a bereaved person has realized what has happened and the pain that the loss has caused, he or she needs to recognize the significance of the losses and their impact on his or her life. These ramifications can be numerous and profound.

*Task 4: rebuild*

Finally, as the grieving process evolves, a bereaved person needs to reinvest his or her energy in new activities and relationships.

*Ongoing assessment*

Cognitive, emotional, and physical reactions to grief and the need for bereavement support can last for months. Physicians and health care workers will need to be skilled at assessing grief reactions and providing basic supportive care. They also must understand the importance of quickly referring individuals to bereavement experts when grief reactions become complicated. To anticipate and reduce the intensity of grief reactions effectively, frequently assess each patient's anticipated and actual losses, emotional responses, and coping strategies during the first months after a death. Gentle inquiry can help the physician provide support and understand how the survivor is coping. Individuals who are at particular risk should be identified early. Other health care professionals can facilitate greatly the assessment and monitoring of grief. When religion is an important component of coping, engage a chaplain or pastoral care professional to help determine and understand the family's religious background.

*Management**Uncomplicated grief*

After the loss, if grief reactions and coping strategies seem to be appropriate and effective, the situation can be monitored and supportive counseling provided. When survivors feel they are "going crazy" or "losing their mind," encourage them to discuss their feelings. It may help to explain that grief is painful and prolonged but normal and that the length of time needed for the grief process varies with each person and situation; that there is no "right" way to grieve; and that each person has his or her own way. Encourage the survivor to talk about

what it is like to live without the deceased and participate in rituals such as attending the funeral or memorial services.

Most bereaved people are able to reenter the world after 1 to 3 weeks, although their active grieving can go on for 1 year or more. The sadness can continue for a much longer period but usually does not intrude on or prevent moving on with life. Hospice and palliative care programs typically provide a wide range of bereavement services, including individual, general, and specialty group counseling; support newsletters; memorial celebrations; and specific strategies to help cope with holidays and particular types of loss. If the patient was enrolled in hospice care, the family members might be eligible for bereavement support services without charge through the hospice. Other bereaved individuals may be able to access the services for a fee.

#### *Complicated grief*

Some bereaved people continue to experience intense cognitive, emotional, and physical grief reactions over long periods that interfere with their physical or emotional well-being. When this occurs, the person may be experiencing complicated grieving that needs more attention [65,66].

There are four categories of complicated grief reactions: (1) *Chronic grief* is characterized by normal grief reactions that do not subside and continue over extended periods. (2) *Delayed grief* is characterized by normal grief reactions that are suppressed or postponed; the person consciously or unconsciously avoids the pain of the loss. (3) In *exaggerated grief*, some coping strategies may accelerate and even become destructive (eg, increased smoking, alcohol, or medication intake; overworking; even suicidal ideation) in the face of seemingly insurmountable loss. (4) In *masked grief*, the person is not aware that the behaviors that are interfering with normal functioning are a result of the loss.

Physicians and other health care professionals will want to be attuned to behaviors that might indicate complicated grief, especially if the signs continue beyond 6 to 12 months [51]. The survivor may not be able to speak of the deceased without experiencing intense sadness, and themes of loss may continue to occur in every topic during a clinical interview. Minor events may trigger unexpectedly intense grief and sadness. The survivor may be unwilling to move possessions that belonged to the deceased. The survivor may develop symptoms similar to the symptoms of the deceased.

Inappropriate, ineffective, or prolonged grief reactions and coping strategies have the potential to cause harm (eg, destructive behaviors or suicide) and must be assessed and managed quickly and aggressively. Some people need ongoing support, psychotherapy, or medication to manage the depression and reduce the intensity and protracted course of their suffering as they struggle to adapt to the profound changes in their lives. A psychiatrist, psychologist, or other specialist skilled in complicated loss, grief, and bereavement should be consulted so that therapy can be instigated rapidly to reduce the risk of harmful or destructive activities.



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