

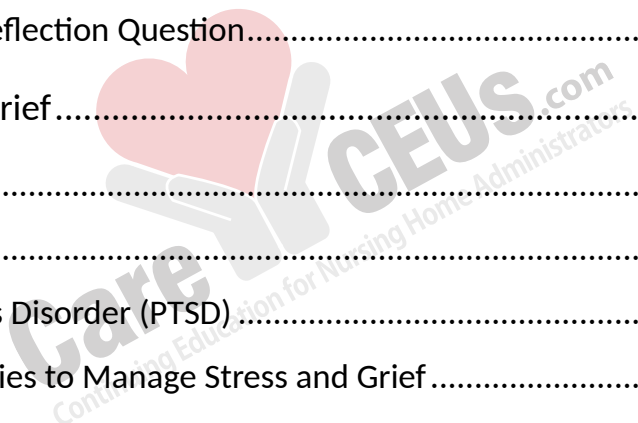


Understanding Hospice



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Introduction

Hospice care is an essential element of health care. Therefore, health care professionals should possess insight into hospice care. This course reviews hospice care, while providing insight into the laws, regulations, and requirements associated with hospice care to build awareness among health care professionals so they can work to optimize patient care.

Section 1: Hospice Care

A 78-year-old male patient is suffering from a terminal illness. After some consideration, a team of health care professionals determine the patient's lifetime prognosis is less than six months. Upon receiving the aforementioned information, the patient's family begins to consider hospice care. Unfortunately, the members of the patient's family are not familiar with hospice care, how to pay for hospice care, and what hospice care includes. Collectively, members of the patient's family begin to ask members of the patient's health care team questions about hospice care.

Much like in the scenario presented above, health care professionals may receive questions about hospice care from patients and members of a patient's family. Additionally, health care professionals may take part in hospice care. Therefore, it is important that health care professionals possess insight into hospice care. This section of the course will review concepts central to hospice care, while providing insight into the type of hospice care provided to patients in need. The information found within this section of the course was derived from materials provided by the National Institute on Aging unless, otherwise, specified (National Institute on Aging, 2021).

What is hospice care?

Hospice care may refer to a comprehensive set of services, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care (Code of Federal Regulations, 2022).

Health care professionals should note the following: hospice care is typically reserved for individuals with an anticipated life expectancy of six months or less and/or those individuals suffering from a serious illness; within the context of hospice care, the term

serious illness may refer to a disease or condition with a high risk of death or one that negatively affects an individual's quality of life or ability to perform daily tasks.

Health care professionals should also note the following: hospice care does not focus on curative therapies or medical intervention designed to prolong life; hospice care may not provide 24/7 bedside care; hospice care does not provide strategies or methods to hasten the death of an individual.

What is hospice?

Hospice may refer to a public agency or private organization or subdivision that is primarily engaged in providing hospice care (Code of Federal Regulations, 2022).

Who is eligible for hospice care?

Individuals with a terminal illness and lifetime prognosis of six months or less are eligible for hospice care.

When do individuals typically enter into hospice care?

Individuals typically enter into hospice care when their life expectancy is six months or less; there is a significant decline in physical and/or cognitive status despite medical treatment; the individual is in the end stage of a serious illness (e.g., cancer, heart disease, dementia, Parkinson's disease, lung disease, chronic kidney disease, and cirrhosis).

Health care professionals should note the following: to qualify for hospice care a hospice physician and an individual's attending physician or specialist must certify that an individual meets specific medical eligibility criteria indicating that an individual's life expectancy is six months or less if the illness or condition runs its typical course.

How should individuals prepare for hospice care?

Individuals can prepare for hospice care in a variety of different ways including preparing advance care planning documents. Specific information regarding advance care planning documents may be found below. The information found below was derived from materials provided by the National Institute on Aging (National Institute on Aging, 2018).

- A living will may refer to a written document that can inform health care professionals how individuals want to be treated if they are dying or permanently unconscious and cannot make their own decisions about emergency treatment.
- A durable power of attorney for health care may refer to a legal document naming a health care proxy; a health care proxy may refer to an individual that can make medical decisions for a patient at times when he or she is unable to do so.
- In addition to a living will and a durable power of attorney for health care, individuals should also consider preparing documents to express their wishes about a single medical issue or health care option, such as: a do not resuscitate (DNR) order; a do not intubate (DNI) order; organ and tissue donation; and brain donation.
- A do not resuscitate (DNR) order may refer to an order that informs health care professionals in a health care facility that an individual does not want them to try to return his or her heart to a normal rhythm if it stops or is beating unsustainably using cardiopulmonary resuscitation (CPR) or other life-support measures (note: if a patient does not have an established DNR order, health care professionals should make every effort to restore patient breathing and the normal rhythm of the heart).
- A do not intubate (DNI) order may refer to an order that informs health care professionals in a health care facility that an individual does not want to be placed on a breathing machine.
- Organ and tissue donation allow organs or body parts from a generally healthy individual who died to be transplanted into individuals who need them; typically, the heart, lungs, pancreas, kidneys, corneas, liver, and skin are donated; there is no age limit for organ and tissue donation; individuals may carry a donation card in their wallet or keep it on their person; some individuals may also include organ donation information in their advance care planning documents.
- Brain donation is different from other organ donation in that the brain is donated to scientific research.

Where can individuals receive hospice care?

Individuals can receive hospice care in a private home, hospital, nursing home, and/or an assisted living facility.

Who provides hospice care?

Typically, an interdisciplinary health care team provides hospice care.

Health care professionals should note that the hospice interdisciplinary health care team may include: a hospice physician (medical director); the patient's personal physician; nurses; hospice aides; social workers; speech therapists; physical therapists; spiritual care providers or other counselors; bereavement professionals.

What is the goal of hospice care?

One of the main goals of hospice care is to provide comfort to help improve the quality of life for patients nearing death.

How does hospice care provide comfort to help improve the quality of life for individuals nearing death?

Hospice care provides comfort to help improve the quality of life for individuals nearing death by managing an individual's physical comfort, mental and emotional needs, practical tasks, and spiritual needs.

How does hospice care typically manage an individual's physical comfort?

Hospice care typically manages an individual's physical comfort by focusing on the following areas of care: pain, skin integrity, dyspnea, digestion, temperature sensitivity, and fatigue. Specific information on the aforementioned areas of care may be found below.

Pain

- Pain may refer to an unpleasant sensory and emotional experience arising from actual or potential tissue damage.

- Acute pain may refer to pain that typically lasts less than three to six months; pain that is directly related to soft tissue damage or other specific injury.
- Chronic pain may refer to pain that lasts more than three to six months.
- The human body's natural healing time is three to six months. Chronic pain lasts beyond the human body's natural, or normal, healing time.
- Chronic pain is typically caused by an injury (e.g., muscle sprain).
- Individuals suffering from chronic pain may experience lower back pain, neck pain, and even headaches.
- Chronic pain can range from mild to severe.
- Pain is often assessed using pain assessment tools, such as a simple numerical pain intensity scale.
- A simple numerical pain intensity scale - within the context of this course, a simple numerical pain intensity scale, when applied to pain assessment, may refer to a numerically based method, which may be used by health care professionals to help patients rate their pain from 0 - 10, with 0 meaning no pain and 10 meaning severe pain or worst possible pain. A simple numerical pain intensity scale may be relatively uncomplicated and/or straightforward - however, it may be the most efficient way for health care professionals to obtain pain-related information from a patient. Health care professionals should note that simple numerical pain intensity scales may be incorporated into other pain assessment guides, scales, and tools.
- Not everyone who is dying experiences pain. Evidence suggests that care should focus on relieving pain without worrying about possible long-term problems of drug dependence or abuse.
- Morphine is often used to manage a hospice patient's pain.
- Morphine is an opioid medication used to treat moderate to severe pain.
- Research suggests that morphine given in clinical settings at the end of life does not hasten death when it is prescribed appropriately.

Skin integrity

- Skin integrity may refer to skin health.
- Impaired skin integrity may refer to a skin diagnosis that can be used to identify relatively unhealthy skin that may show damage, disruption, loss of functionality, and/or may not be intact.
- The risk factors associated with impaired skin integrity include the following: pressure, trauma, moisture, injury involving the skin, immobility, poor nutrition, poor hydration, inadequate hygiene, impaired mental status, and age.
- Health care professionals may adequately identify, evaluate, and assess impaired skin integrity by conducting an adequate patient assessment. An adequate patient assessment, as it relates to the presence of impaired skin integrity, is one that safely and effectively identifies impaired skin integrity, while attempting to determine the potential cause, type, intensity, pain, and related complications associated with impaired skin integrity. Health care professionals should note that impaired skin integrity-related patient assessments may occur at any point in the health care process and may be used to both identify and monitor impaired skin integrity. Health care professionals should also note that an adequate patient assessment regarding impaired skin integrity may include the following elements: etiology determination, nutritional and hydration status determination, mobility determination, impaired tissue integrity/condition, wound characteristics, recognition of high-risk areas, pressure injury evaluation, signs of itching, patient pain and discomfort, patient vital signs, patient management goals, and health care documentation.
- When assessing hospice patients, health care professionals should devote a portion of their attention to impaired skin integrity-related high-risk areas. Such high-risk areas include areas of the skin that cover: the shoulders, elbows, knees, as well as the tailbone and hip bones. Such areas are high risk because they cover bony prominences of the human body, which are especially susceptible to extended pressure and, thus, especially susceptible to impaired skin integrity. Health care professionals should note the following: if a patient is experiencing impaired skin integrity in a high risk area, the area should be monitored and routinely observed; health care professionals should make special efforts to address impaired skin integrity in high-risk areas in a timely manner; a failure to address impaired skin integrity in high-risk areas in a timely manner may result in

extended damage, disruption, and loss of functionality; a failure to address impaired skin integrity in high-risk areas in a timely manner may also result in infections, which often possess the potential for high patient morbidity and mortality rates; patients with decreased mobility may be at a higher risk for impaired skin integrity in high-risk areas. Health care professionals should also note that high-risk areas may be vulnerable to pressure injuries; health care professionals should evaluate the presence of pressure injuries when assessing patients (note: a pressure injury, also referred to as a pressure ulcer or bedsore, may refer to localized damage to the skin and/or underlying soft tissue, usually over a bony prominence).

- Skin moisturizers may be used to address and manage impaired skin integrity. Essentially, skin moisturizers help prevent skin drying and subsequent skin damage. Health care professionals should note that skin moisturizers may be available as an ointment, cream, or lotion.

Dyspnea

- Dyspnea may refer to labored breathing; shortness of breath.
- Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life.
- Some hospice patients may suffer from Cheyne-Stokes breathing. Cheyne-Stokes breathing may refer to an abnormal breathing pattern and/or condition characterized by periods of deep, heavy breaths followed by shallow breathing or a lack of breath.
- Some hospice patients, near death, may suffer from noisy breathing, often referred to as a death rattle.
- Morphine may be administered to hospice patients to ease feelings of shortness of breath.

Digestion

- Hospice patients often suffer from digestion problems, such as nausea, vomiting, constipation, and loss of appetite.
- Medications may be used to manage nausea, vomiting, and/or constipation (e.g., bisacodyl for constipation).

- Loss of appetite is common at the end of life.
- If the hospice patient loses his or her appetite, health care professionals and/or caregivers should try gently offering the patient's favorite foods in small amounts; health care professionals and/or caregivers should serve frequent, smaller meals rather than three larger ones to hospice patients; health care professionals should attempt to help with feeding if the patient wants to eat but is too tired or weak.
- If a hospice patient can still eat or drink, health care professionals should offer small sips of water/liquids, ice chips, or very small amounts of food via spoon; health care professionals should take cues from the patient when to stop.
- If the patient can no longer drink, health care professionals should keep the patient's lips and mouth moist with swabs, a wet washcloth, lip balm, and/or moisturizers.
- Evidence suggests that individuals should not force a dying person to eat; losing one's appetite is a common and normal part of dying; going without food and/or water is generally not painful, and eating and drinking can add to a dying person's discomfort; a lack of eating and drinking can be part of an individual's acceptance that death is near.

Temperature sensitivity

- Often when hospice patients are close to death, their hands, arms, feet, or legs may be cool to the touch; some parts of the body may become darker or blueish.
- Individuals who are dying may not be able to tell health care professionals and/or caregivers that they are too hot or too cold.
- Health care professionals should observe patients for signs of temperature sensitivity (e.g., shivering)

Fatigue

- Fatigue may refer to a condition characterized by tiredness and/or an inability to function due to lack of energy.
- It is common for hospice patients nearing the end of life to feel tired and experience periods of a lack of energy.

- Health care professionals can help manage hospice patient fatigue by recognizing and treating conditions/symptoms that can increase fatigue (e.g., pain, nausea, and constipation).

How does hospice care typically manage a hospice patient's mental and emotional needs?

Hospice care typically manages a hospice patient's mental and emotional needs by focusing on the following areas of care: dementia, cognitive impairment, depression, and anxiety. Specific information on the aforementioned areas of care may be found below.

Dementia

- Some hospice patients may suffer from dementia.
- Dementia may refer to a cluster of symptoms centered around an inability to remember, think clearly, and/or make decisions.
- Dementia is not a normal part of aging.
- Dementia can dramatically impact individuals' ability to function and carry out daily activities; individuals suffering from dementia commonly experience impairments in occupational and social functioning and may present behavioral disturbances.
- Risk factors that may contribute to dementia include the following: age, genetics, poor heart health, and traumatic brain injuries.
- Signs of dementia may include the following: getting lost in a familiar area; forgetting the names of close family and friends; not being able to complete tasks independently.
- Symptoms of dementia may include the following: problems with memory; problems with attention; an inability to communicate effectively; a diminished ability to reason and problem solve; poor judgment.
- Vascular dementia - hospice patients may suffer from vascular dementia. Vascular dementia is a type of dementia that may result from strokes and/or other issues that affect blood flow to the brain; vascular dementia may also result from

diabetes, high blood pressure, and high cholesterol; vascular dementia can result from a blockage of blood vessels in the brain which yields the death of tissue, or infarction, in the affected region; the symptoms of vascular dementia can vary depending on the area and size of the brain impacted; specific symptoms of vascular dementia can include: problems with memory, planning, making decisions, attention, focus, and concentration as well as confusion; vascular dementia progresses in a step-wise fashion - meaning the symptoms of vascular dementia may get worse as an individual experiences strokes, mini-strokes, or other issues that affect blood flow to the brain (i.e., vascular dementia can be progressive in nature) (Centers for Disease Control and Prevention [CDC], 2019).

- Dementia may be related to Parkinson's disease. Parkinson's disease may refer to a progressive disorder that affects individuals' movement.
- Dementia may be related to Alzheimer's disease. Alzheimer's disease may refer to an irreversible, progressive brain disorder that slowly destroys individuals' memory, thinking skills, and ability to carry out simple tasks. Health care professionals should note the following: Alzheimer's disease is the most common cause of dementia among older adults; Alzheimer's disease is not a normal part of aging.

Cognitive impairment

- Some hospice patients may suffer from cognitive impairment.
- Cognitive impairment is when an individual has trouble remembering, learning new things, concentrating, focusing, or making decisions that affect everyday life.
- Evidence suggests that cognitive impairment is not caused by any one disease or condition; cognitive impairment is not limited to a specific age group; however, Alzheimer's disease and other dementias in addition to conditions such as stroke, traumatic brain injury, and developmental disabilities, can lead to cognitive impairment.
- The typical signs of cognitive impairment include the following: memory loss; frequently asking the same question or repeating the same story over and over; not recognizing familiar people and places; trouble exercising judgment, such as knowing what to do in an emergency; changes in mood or behavior; vision problems; difficulty planning and carrying out tasks; inability to concentrate and/or focus.

Depression

- Some hospice patients may suffer from depression.
- A depressive disorder may refer to a mood disorder characterized by a persistent depressed mood and/or anhedonia, which ultimately causes significant interference in daily life (note: anhedonia may refer to a loss of interest in previously enjoyable activities).
- One of the most common forms or types of depressive disorders is major depressive disorder.
- Major depressive disorder may refer to a form of depression that occurs most days of the week for a period of two weeks or longer leading to clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- Signs/symptoms of a major depressive disorder may include the following: depressed mood, anhedonia (a loss of interest in previously enjoyable activities), appetite changes, weight changes, sleep difficulties, psychomotor agitation or retardation, fatigue or loss of energy, diminished ability to think or concentrate, feelings of worthlessness or excessive guilt, and suicidality.
- Health care professionals and/or caregivers can help relieve some of a hospice patient's symptoms of depression by the following methods: provide physical contact (e.g., holding the hand of a hospice patient); set a comforting mood (e.g., use soft lighting in the hospice patient's room); frequently talk to the hospice patient; ask the hospice patient questions.

Anxiety

- Some hospice patients may suffer from anxiety.
- An anxiety disorder may refer to a mental health disorder characterized by prolonged periods of persistent, excessive worry about a number of events or activities, which cause clinically significant distress or impairment in social, occupational, or other important areas of functioning (note: in regards to an anxiety disorder, excessive worry may refer to worrying when there is no specific reason/threat present or in a manner that is disproportionate to the actual risk of an event, activity, and/or situation).

- One of the most common forms or types of anxiety disorders is generalized anxiety disorder.
- Generalized anxiety disorder may refer to a mental health disorder characterized by excessive anxiety and worry occurring more days than not for at least six months, about a number of events or activities (such as work or school performance), which is difficult to control and leads to clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- Signs/symptoms of a generalized anxiety disorder may include the following: excessive anxiety, excessive worry, restlessness, persistent feelings of being keyed up or on edge, easily fatigued, difficulty concentrating, mind feeling blank at times (mind going blank), irritability, muscle tension, and sleep difficulties.
- Health care professionals and/or caregivers can help relieve some of the hospice patients' symptoms of depression by the following methods: provide physical contact (e.g., holding the hand of a hospice patient); set a comforting mood (e.g., use soft lighting in the hospice patient's room); frequently talk to the hospice patient; playing relaxing music.
- Health care professionals should note the following: hospice patients suffering from anxiety may be treated with lorazepam; lorazepam is a benzodiazepine.

How does hospice care typically manage a hospice patient's practical tasks?

Hospice care typically manages an individual's practical tasks by focusing on areas of care such as personal hygiene. Specific information regarding personal hygiene may be found below. The information found below was derived from materials provided by the National Institute on Aging (National Institute on Aging, 2017).

- Personal hygiene may refer to a series of practices that sustain the body's cleanliness in order to maintain healthy skin integrity, as well as overall health and well-being.
- Important aspects of adequate personal hygiene include the following: bathing regularly, water use, skin cleansing product use, drying, and mouth care.

- **Bathing regularly** - bathing regularly can help prevent the spread of infections and diseases among patients. It can also have a positive psychological impact on hospice patients. Bathing regularly can help hospice patients: feel better about themselves, feel more relaxed, maintain their dignity, and feel like they have some semblance of control over their remaining days of life.
- **Water use** - the use of water is a fundamental aspect of adequate personal hygiene. Effective water use in personal hygiene occurs when water is used to clean the skin in a manner that does not jeopardize skin integrity and/or lead to or cause further impaired skin integrity (note: over-cleaning the skin may lead to itching, dryness, and compromised skin integrity).
- **Skin cleansing product use** - the use of a skin cleansing product is another fundamental aspect of adequate personal hygiene. The term skin cleansing product may refer to any product designed to clean the human body while removing dirt, bacteria, dead skin cells, and/or other substances from the skin. Health care professionals should consider encouraging hospice patients to use emollient-based soap substitutes and/or bath emollients, when applicable. Emollient-based soap substitutes and bath emollients are, typically, designed to remove dirt, bacteria, dead skin cells, and/or other substances from the skin, while avoiding skin barrier breakdown, dryness, and irritation. Health care professionals should note the following: emollient-based soap substitutes and bath emollients are designed to promote skin integrity; it is important for health care professionals to consider patient preferences when selecting or determining which emollient-based soap substitutes and/or bath emollients may be used within health care facilities.
- **Drying** - drying, as it relates to adequate personal hygiene, may refer to the act of removing moisture and/or water from the body/skin after a personal hygiene routine, including water and a skin cleansing product, is completed (e.g., a traditional bath). The act of drying the body and skin is essential to personal hygiene, skin integrity, and overall health because it can help patients prevent and avoid maceration. Maceration, as it relates to adequate personal hygiene, may refer to skin breakdown resulting from prolonged moisture. Health care professionals should note the following: pat or gently rub the skin when engaging in drying to help prevent related irritation and skin damage; patients should be encouraged to use soft cloths to dry their skin in order to help prevent related irritation and skin damage.

- **Mouth care** - mouth care may refer to the act of maintaining oral hygiene. Aspects of mouth care may include methods to clean teeth and gums. Health care professionals should note the following: patients should be encouraged to brush their teeth twice a day with fluoride toothpaste, when appropriate.

How does hospice care typically manage a hospice patient's spiritual needs?

Hospice care typically manages a hospice patient's spiritual needs by observing and recognizing a patient's spiritual directives. Specific information regarding the potential spiritual needs of a hospice patient may be found below.

- For some hospice patients nearing the end of life, spiritual needs may be as important as physical needs.
- Spiritual needs for hospice patients may include the following: finding meaning in one's life, ending disagreements with others, resolving unsettled issues with friends or family, making peace with life circumstances, and/or experiencing nature.
- Some hospice patients may want to read religious text and/or speak to a religious leader to meet their spiritual needs.
- Hospice patients' family and friends should be encouraged to talk to the patient in order to help meet spiritual needs.
- Hospice patients' family and friends, who cannot be present, should be encouraged to call or message patients to help meet spiritual needs.
- Sharing memories of good times may help patients meet their spiritual needs.
- Health care professionals should note the following: some hospice patients suffering from dementia may experience "moments of clarity" characterized by the ability to communicate with others; individuals should take advantage of "moments of clarity" to communicate and engage with patients to help meet their spiritual needs.

How do hospice patients pay for hospice care?

Hospice patients typically pay for hospice care via Medicare. Specific information regarding hospice care and Medicare may be found below. The information found below was derived from materials provided by the U.S. government (U.S. Centers for Medicare and Medicaid Services, 2022).

- To qualify for hospice care, a hospice doctor and the patient's doctor, when applicable, must certify that the patient is terminally ill, meaning the patient has a life expectancy of six months or less.
- When a patient agrees to hospice care, he or she is agreeing to comfort care (palliative care) instead of care to cure an illness; therefore, patients must sign a statement choosing hospice care instead of other benefits Medicare covers to treat terminal illnesses and related conditions.
- Medicare hospice coverage typically includes the following: all items and services needed for pain relief and symptom management; medical, nursing, and social services; drugs for pain management; durable medical equipment for pain relief and symptom management; aide and homemaker services; other covered services the patient needs to manage pain and other symptoms, as well as spiritual and grief counseling for the patient and the patient's family.
- Depending on the patient's terminal illness and related conditions, the plan of care the hospice team creates can include any or all of the following services: doctors' services; nursing and medical services; durable medical equipment for pain relief and symptom management; medical supplies, like bandages or catheters; drugs for pain management; aide and homemaker services; physical therapy services; occupational therapy services; speech-language pathology services; social services; dietary counseling; spiritual and grief counseling; short-term inpatient care for pain and symptom management (note: the aforementioned type of care must be in a Medicare approved facility, like a hospice facility, hospital, or skilled nursing facility that contracts with the hospice); inpatient respite care; any other services Medicare covers to manage pain and other symptoms related to terminal illnesses and related conditions, as a hospice team recommends.
- Medicare-certified hospice care is usually given in the home or other facility where an individual lives (e.g., a nursing home); original Medicare will still pay for covered benefits for any health problems that are not part of terminal illnesses

and related conditions, but hospice should cover most of the care received by the patient.

- Medicare does not cover any of the following once hospice benefits initiate:
 - Treatment intended to cure a terminal illness and/or related conditions - hospice patients should be encouraged to talk with their doctors if they are thinking about getting treatment to cure an illness; a hospice patient has the right to stop hospice care at any time.
 - Prescription drugs to cure an illness - prescription drugs to cure an illness (rather than for symptom control or pain relief) are not covered by Medicare.
 - Care from any hospice provider that was not initiated/set up by the hospice medical team - hospice patients must get hospice care from the hospice provider they chose; all of the care that a patient receives for a terminal illness must be given by or arranged by the hospice team; a hospice patient cannot receive the same type of hospice care from a different hospice, unless the patient changes his or her hospice provider; however, hospice patients can still see their regular doctor or nurse practitioner if they chose him or her to be the attending medical professional who helps supervise hospice care.
 - Room and board - Medicare does not cover room and board if a patient receives hospice care in his or her home or if the patient lives in a nursing home or a hospice inpatient facility; if the hospice team determines that a patient requires short-term inpatient or respite care services that they arrange, Medicare will cover the patient's stay in the facility; a patient may have a small copayment for a respite stay.
 - Care a patient receives as a hospital outpatient (e.g., an emergency room), care a patient receives as a hospital inpatient, or ambulance transportation - Medicare does not cover care a patient receives as a hospital outpatient (e.g., an emergency room), care a patient receives as a hospital inpatient, or ambulance transportation unless they are either arranged by a patient's hospice team or are unrelated to a terminal illness/condition.

Are there federal regulations that apply to hospice length of stay?

Yes, there are federal regulations that apply to hospice length of stay. Specific information regarding hospice length of stay may be found below.

- Hospice care is given in benefit periods: two 90-day periods followed by an unlimited number of 60-day periods; medical eligibility generally relies on a physician's opinion that the patient's life expectancy is six months or less, the patient nor the physician is penalized if the patient lives longer than six months; the patient can be re-certified for hospice care, provided medically eligibility is validated.
- If a patient's condition stabilizes or improves sufficiently, he or she may no longer meet medical eligibility for hospice services; at that time, the patient is "discharged" from the hospice program and his or her Medicare benefits revert to the coverage before electing hospice care.
- Hospice patients may choose to pursue curative therapies (e.g., enter into a clinical study for a new medication or procedure); in order to do so, patients must withdraw their selection of hospice care, called "revocation."
- Patients who are discharged from hospice care, or who choose to leave hospice care, can re-enroll at any time provided they meet the medical eligibility criteria (e.g., life expectancy is six months or less).

Do hospice patients have specific rights protected by federal law?

Yes, hospice patients have specific rights protected by federal law. Specific hospice patient rights may be found below. The information found below was derived from materials provided by the U.S. government unless, otherwise, specified (Code of Federal Regulations, 2022).

- Hospice patients have the right to be admitted by a hospice organization only if it is assured that all necessary palliative and supportive services will be provided to promote the physical, psychological, social, and spiritual well-being of the dying patient.
- Hospice patients have the right to be notified in writing of their rights and obligations before their hospice care begins; consistent with state laws, the patient's family or guardian may exercise the potential hospice patient's rights when the patient is unable to do so.

- Hospice patients have the right to be notified in writing of the care the hospice organization will provide,
- Hospice patients have the right to be notified in writing of the types of caregivers who will provide care, and the frequency of the services that are proposed.
- Hospice patients have the right to speak with their caregivers.
- Hospice patients have the right to patient autonomy (note: patient autonomy may refer to a patient's right to make decisions regarding his or her own personal health care, without the direct influence of a health care professional).
- Hospice patients have the right to be advised of any change in the care plan before the change is made.
- Hospice patients have the right to participate in the care planning and in planning changes in care, and to be advised that they have the right to do so.
- Hospice patients have the right to refuse services.
- Hospice patients have the right to be advised of the consequences of refusing care.
- Hospice patients have the right to request a change in caregiver without fear of discrimination.
- Hospice patients have the right to not be physically abused (note: physical abuse may refer to the intentional use of physical force against an individual that leads to illness, pain, injury, functional impairment, distress, and/or death).
- Hospice patients have the right to not be verbally/emotionally abused (note: verbal/emotional abuse may refer to verbal and/or nonverbal behaviors that inflict anguish, mental pain, fear, or distress on an individual).
- Hospice patients have the right to not be psychologically abused (note: psychological abuse may refer to a type of coercive or threatening behavior that establishes a power differential between two or more individuals).
- Hospice patients have the right to not be financially exploited/abused (note: financial exploitation/abuse may refer to the illegal, unauthorized, or improper use of an individual's money, benefits, belongings, property, and/or assets).

- Hospice patients have the right to be free from restraint or seclusion, of any form, imposed as a means of coercion, discipline, convenience, or retaliation by staff.
- Hospice patients have the right to safe implementation of restraint or seclusion by trained staff.
- Hospice patients have the right to privacy.
- Hospice patients have the right to confidentiality with regard to information about their health, social, and financial circumstances.
- Hospice patients have the right to be informed of the extent to which payment may be expected from Medicare and/or Medicaid.
- Hospice patients have the right to have access to all bills for service the patient received.
- Hospice patients have the right to be informed of the procedure they can follow to lodge complaints with the hospice organization about the care that is provided.
- Hospice patients have the right to know how to file complaints.
- Hospice patients have the right to voice grievances without fear of discrimination.
- Hospice patients have the right to voice grievances without fear of reprisal.
- Hospice patients have the right to be told what to do in the case of an emergency.
- Hospice patients have the right to refuse hospice care and treatment.
- Hospice patients have the right to discontinue hospice care.

Section 1 Summary

Hospice care may refer to a comprehensive set of services, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care (Code of Federal Regulations, 2022). Individuals typically enter into hospice care when their life expectancy is six months or less; there is a significant decline in physical and/or cognitive status despite medical treatment; the individual is in the end stage of a serious illness (e.g., cancer, heart disease, dementia, Parkinson's disease, lung disease, chronic kidney disease, and cirrhosis). Hospice care

provides comfort to help improve the quality of life for individuals nearing death by managing an individual's physical comfort, mental and emotional needs, practical tasks, and spiritual needs. Hospice patients typically pay for hospice care via Medicare. Finally, health care professionals should note that hospice patients have specific rights protected by federal law.

Section 1 Key Concepts

- To qualify for hospice care, a hospice doctor and the patient's doctor, when applicable, must certify that the patient is terminally ill, meaning the patient has a life expectancy of six months or less.
- One of the main goals of hospice care is to provide comfort to help improve the quality of life for patients nearing death.

Section 1 Key Terms

Hospice care - a comprehensive set of services, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care (Code of Federal Regulations, 2022)

Serious illness - a disease or condition with a high risk of death or one that negatively affects an individual's quality of life or ability to perform daily tasks

Hospice - a public agency or private organization or subdivision that is primarily engaged in providing hospice care (Code of Federal Regulations, 2022)

Living will - a written document that can inform health care professionals how individuals want to be treated if they are dying or permanently unconscious and cannot make their own decisions about emergency treatment

Durable power of attorney for health care - a legal document naming a health care proxy

Health care proxy - an individual that can make medical decisions for a patient at times when he or she is unable to do so

Do not resuscitate (DNR) order - an order that informs health care professionals in a health care facility that an individual does not want them to try to return his or her heart

to a normal rhythm if it stops or is beating unsustainably using cardiopulmonary resuscitation (CPR) or other life-support measures

Do not intubate (DNI) order - an order that informs health care professionals in a health care facility that an individual does not want to be placed on a breathing machine

Pain - an unpleasant sensory and emotional experience arising from actual or potential tissue damage

Acute pain - pain that typically lasts less than three to six months; pain that is directly related to soft tissue damage or other specific injury

Chronic pain - pain that lasts more than three to six months

Simple numerical pain intensity scale (within the context of this course) - a numerically based method, which may be used by health care professionals to help patients rate their pain from 0 - 10, with 0 meaning no pain and 10 meaning severe pain or worst possible pain

Morphine - an opioid medication used to treat moderate to severe pain

Skin integrity - skin health

Impaired skin integrity - a skin diagnosis that can be used to identify relatively unhealthy skin that may show damage, disruption, loss of functionality, and/or may not be intact

Pressure injury (also referred to as a pressure ulcer or bedsore) - localized damage to the skin and/or underlying soft tissue, usually over a bony prominence

Dyspnea - labored breathing; shortness of breath

Cheyne-Stokes breathing - an abnormal breathing pattern and/or condition characterized by periods of deep, heavy breaths followed by shallow breathing or a lack of breath

Fatigue - a condition characterized by tiredness and/or an inability to function due to lack of energy

Dementia - a cluster of symptoms centered around an inability to remember, think clearly, and/or make decisions

Vascular dementia - type of dementia that may result from strokes and/or other issues that affect blood flow to the brain

Parkinson's disease - a progressive disorder that affects individuals' movement

Alzheimer's disease - an irreversible, progressive brain disorder that slowly destroys individuals' memory, thinking skills, and ability to carry out simple tasks

Depressive disorder - a mood disorder characterized by a persistent depressed mood and/or anhedonia, which ultimately causes significant interference in daily life

Anhedonia - a loss of interest in previously enjoyable activities

Major depressive disorder - a form of depression that occurs most days of the week for a period of two weeks or longer leading to clinically significant distress or impairment in social, occupational, or other important areas of functioning

Anxiety disorder - a mental health disorder characterized by prolonged periods of persistent, excessive worry about a number of events or activities, which cause clinically significant distress or impairment in social, occupational, or other important areas of functioning

Excessive worry (in regards to an anxiety disorder) - worrying when there is no specific reason/threat present or in a manner that is disproportionate to the actual risk of an event, activity, and/or situation

Generalized anxiety disorder - a mental health disorder characterized by excessive anxiety and worry occurring more days than not for at least six months, about a number of events or activities (such as work or school performance), which is difficult to control and leads to clinically significant distress or impairment in social, occupational, or other important areas of functioning

Personal hygiene - a series of practices that sustain the body's cleanliness in order to maintain healthy skin integrity as well as overall health and well-being

Skin cleansing product - any product designed to clean the human body while removing dirt, bacteria, dead skin cells, and/or other substances from the skin

Drying (as it relates to adequate personal hygiene) - the act of removing moisture and/or water from the body/skin after a personal hygiene routine, including water and a skin cleansing product, is completed

Maceration (as it relates to adequate personal hygiene) - skin breakdown resulting from prolonged moisture

Mouth care - the act of maintaining oral hygiene

Patient autonomy - a patient's right to make decisions regarding his or her own personal health care, without the direct influence of a health care professional

Physical abuse - the intentional use of physical force against an individual that leads to illness, pain, injury, functional impairment, distress, and/or death

Verbal/emotional abuse - verbal and/or nonverbal behaviors that inflict anguish, mental pain, fear, or distress on an individual

Psychological abuse - a type of coercive or threatening behavior that establishes a power differential between two or more individuals

Financial exploitation/abuse - the illegal, unauthorized, or improper use of an individual's money, benefits, belongings, property, and/or assets

Section 1 Personal Reflection Question

How can health care professionals work to provide comfort to help improve the quality of life for patients nearing death?

Section 2: Title 42 Part 418 - Hospice Care

As alluded to in Section 1, there are federal laws and regulations that apply to hospice care. Such laws and regulations can be found in Title 42 Part 418 - Hospice Care. This section of the course will highlight the laws, regulations, and requirements included in Title 42 Part 418 - Hospice Care. The information found within this section of the course was derived from materials provided by the U.S. government unless, otherwise, specified (Code of Federal Regulations, 2022).

- Part 418 indicates that the term attending physician may refer to a doctor of medicine or osteopathy legally authorized to practice medicine and surgery by the state in which he or she performs that function or action; or nurse practitioner who meets training, education, and experience requirements; or physician assistant who meets requirements; and who is identified by the individual, at the time he or she elects to receive hospice care, as having the most significant role in the determination and delivery of the individual's medical care.

- Part 418 indicates that the term physician designee may refer to a doctor of medicine or osteopathy designated by the hospice who assumes the same responsibilities and obligations as the medical director when the medical director is not available.
- Part 418 indicates that the term palliative care may refer to patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering (note: palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice).
- Part 418 indicates that the term representative may refer to an individual who has the authority under State law (whether by statute or pursuant to an appointment by the courts of the State) to authorize or terminate medical care or to elect or revoke the election of hospice care on behalf of a terminally ill patient who is mentally or physically incapacitated (note: this may include a legal guardian).
- Part 418 indicates that the term bereavement counseling may refer to emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment.
- Part 418 indicates that the term comprehensive assessment may refer to a thorough evaluation of the patient's physical, psychosocial, emotional, and spiritual status related to the terminal illness and related conditions (note: a comprehensive assessment includes a thorough evaluation of the caregiver's and family's willingness and capability to care for the patient).
- Part 418 indicates that the term terminally ill means that the individual has a medical prognosis that his or her life expectancy is six months or less if the illness runs its normal course.
- Part 418 indicates that the term restraint may refer to any manual method, physical or mechanical device, material, or equipment that immobilizes or reduces the ability of a patient to move his or her arms, legs, body, or head freely, not including devices, such as orthopedically prescribed devices, surgical dressings or bandages, protective helmets, or other methods that involve the physical holding of a patient for the purpose of conducting routine physical examinations or tests, or to protect the patient from falling out of bed, or to permit the patient to participate in activities without the risk of physical harm

(this does not include a physical escort); or a drug or medication when it is used as a restriction to manage a patient's behavior or restrict a patient's freedom of movement and is not a standard treatment or dosage for the patient's condition.

- Part 418 indicates that the term seclusion may refer to the involuntary confinement of a patient alone in a room or an area from which the patient is physically prevented from leaving.
- In order to be eligible to elect hospice care under Medicare, an individual must be: entitled to Part A of Medicare; and certified as being terminally ill.
- An individual may elect to receive hospice care during one or more of the following election periods: an initial 90-day period; a subsequent 90-day period; or an unlimited number of subsequent 60-day periods.
- The hospice must obtain written certification of terminal illness for each of the periods listed above.
- The hospice must obtain the written certification before it submits a claim for payment.
- If the hospice cannot obtain the written certification within two calendar days, after a period begins, it must obtain an oral certification within two calendar days and the written certification before it submits a claim for payment.
- Certifications may be completed no more than 15 calendar days prior to the effective date of election.
- Recertifications may be completed no more than 15 calendar days prior to the start of the subsequent benefit period.
- A hospice physician or hospice nurse practitioner must have a face-to-face encounter with each hospice patient whose total stay across all hospices is anticipated to reach the 3rd benefit period; the face-to-face encounter must occur prior to, but no more than 30 calendar days prior to, the 3rd benefit period recertification, and every benefit period recertification thereafter, to gather clinical findings to determine continued eligibility for hospice care.
- During a Public Health Emergency, the face-to-face encounter conducted by a hospice physician or hospice nurse practitioner is for the sole purpose of hospice recertification, such encounter may occur via a telecommunications technology

and is considered an administrative expense (note: telecommunications technology may refer to the use of interactive multimedia communications equipment that includes, at a minimum, the use of audio and video equipment permitting two-way, real-time interactive communication between the patient and the distant site health care professionals).

- Certification will be based on the physician's or medical director's clinical judgment regarding the normal course of the individual's illness.
- The certification must specify that the individual's prognosis is for a life expectancy of six months or less if the terminal illness runs its normal course.
- Clinical information and other documentation that support the medical prognosis must accompany the certification and must be filed in the medical record with the written certification; initially, the clinical information may be provided verbally, and must be documented in the medical record and included as part of the hospice's eligibility assessment.
- The physician must include a brief narrative explanation of the clinical findings that supports a life expectancy of six months or less as part of the certification and recertification forms, or as an addendum to the certification and recertification forms.
- If the narrative is part of the certification or recertification form, then the narrative must be located immediately prior to the physician's signature.
- If the narrative exists as an addendum to the certification or recertification form, in addition to the physician's signature on the certification or recertification form, the physician must also sign immediately following the narrative in the addendum.
- The narrative shall include a statement directly above the physician signature attesting that by signing, the physician confirms that he or she composed the narrative based on his or her review of the patient's medical record or, if applicable, his or her examination of the patient.
- The narrative must reflect the patient's individual clinical circumstances and cannot contain check boxes or standard language used for all patients.
- The narrative associated with the 3rd benefit period recertification and every subsequent recertification must include an explanation of why the clinical

findings of the face-to-face encounter support a life expectancy of six months or less.

- The physician or nurse practitioner who performs the face-to-face encounter with the patient must attest in writing that he or she had a face-to-face encounter with the patient, including the date of the visit; the attestation of the nurse practitioner or a non-certifying hospice physician shall state that the clinical findings of the visit were provided to the certifying physician for use in determining continued eligibility for hospice care.
- All certifications and recertifications must be signed and dated by the physician(s), and must include the benefit period dates to which the certification or recertification applies.
- For the initial 90-day period, the hospice must obtain written certification statements (and oral certification statements, when applicable) from the medical director of the hospice or the physician member of the hospice interdisciplinary group; and the individual's attending physician, if the individual has an attending physician.
- Hospice staff must make an appropriate entry in the patient's medical record as soon as they receive an oral certification; and file written certifications in the medical record.
- An individual who meets the eligibility requirement may file an election statement with a particular hospice; if the individual is physically or mentally incapacitated, his or her representative may file the election statement.
- The hospice chosen by the eligible individual (or his or her representative) must file the Notice of Election (NOE) with its Medicare contractor within five calendar days after the effective date of the election statement.
- When a hospice does not file the required Notice of Election for its Medicare patients within five calendar days after the effective date of election, Medicare will not cover and pay for days of hospice care from the effective date of election to the date of filing of the notice of election; these days are a provider liability, and the provider may not bill the beneficiary for them.
- The election statement must include identification of the particular hospice and of the attending physician that will provide care to the individual; the individual

or representative must acknowledge that the identified attending physician was his or her choice.

- The election statement must include the individual's or representative's acknowledgement that he or she has been given a full understanding of the palliative rather than curative nature of hospice care, as it relates to the individual's terminal illness and related conditions.
- The election statement must include acknowledgement that the individual has been provided information on the hospice's coverage responsibility and that certain Medicare services are waived by the election.
- The election statement must include the effective date of the election, which may be the first day of hospice care or a later date, but may be no earlier than the date of the election statement.
- The election statement must include the signature of the individual or representative.
- The hospice must provide notification of the individual's (or representative's) right to receive an election statement addendum if there are conditions, items, services, and drugs the hospice has determined to be unrelated to the individual's terminal illness and related conditions and would not be covered by the hospice.
- The hospice must provide information on the Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO), including the right to immediate advocacy and BFCC-QIO contact information.
- The purpose of the addendum is to notify the individual (or representative), in writing, of those conditions, items, services, and drugs the hospice will not be covering because the hospice has determined they are unrelated to the individual's terminal illness and related conditions.
- The addendum must include language that immediate advocacy is available through the Medicare Beneficiary and Family Centered Care-Quality Improvement Organization (BFCC-QIO) if the individual (or representative) disagrees with the hospice's determination.
- If the addendum is requested within the first five days of a hospice election (that is, in the first five days of the hospice election date), the hospice must provide

specific information, in writing, to the individual (or representative), non-hospice provider, or Medicare contractor within five days from the date of the request.

- If the addendum is requested during the course of hospice care (that is, after the first five days of the hospice election date), the hospice must provide this information, in writing, within three days of the request to the requesting individual (or representative), non-hospice provider, or Medicare contractor.
- If there are any changes to the plan of care during the course of hospice care, the hospice must update the addendum and provide these updates, in writing, to the individual (or representative) in order to communicate the changes to the individual (or representative).
- If the individual dies, revokes, or is discharged within the required timeframe for furnishing the addendum, and before the hospice has furnished the addendum, the addendum would not be required to be furnished to the individual (or representative); the hospice must note the reason the addendum was not furnished to the patient and the addendum would become part of the patient's medical record if the hospice has completed it at the time of discharge, revocation, or death.
- To change the designated attending physician, the individual (or representative) must file a signed statement with the hospice that states that he or she is changing his or her attending physician.
- The statement must identify the new attending physician, and include the date the change is to be effective and the date signed by the individual (or representative).
- The individual (or representative) must acknowledge that the change in the attending physician is due to his or her choice.
- The effective date of the change in attending physician cannot be before the date the statement is signed.
- The hospice admits a patient only on the recommendation of the medical director in consultation with, or with input from, the patient's attending physician (if any).
- In reaching a decision to certify that the patient is terminally ill, the hospice medical director must consider at least the following information: diagnosis of the

terminal condition of the patient; other health conditions, whether related or unrelated to the terminal condition; current clinically relevant information supporting all diagnoses.

- A hospice may discharge a patient if: the patient moves out of the hospice's service area or transfers to another hospice; the hospice determines that the patient is no longer terminally ill; or the hospice determines that the patient's (or other persons in the patient's home) behavior is disruptive, abusive, or uncooperative to the extent that delivery of care to the patient or the ability of the hospice to operate effectively is seriously impaired.
- The hospice must do the following before it seeks to discharge a patient for cause: advise the patient that a discharge for cause is being considered; make a serious effort to resolve the problem(s) presented by the patient's behavior or situation; ascertain that the patient's proposed discharge is not due to the patient's use of necessary hospice services; and document the problem(s) and efforts made to resolve the problem(s) and enter this documentation into its medical records.
- The hospice must have in place a discharge planning process that takes into account the prospect that a patient's condition might stabilize or otherwise change such that the patient cannot continue to be certified as terminally ill.
- The discharge planning process must include planning for any necessary family counseling, patient education, or other services before the patient is discharged because he or she is no longer terminally ill.
- An individual or representative may revoke the individual's election of hospice care at any time during an election period.
- During the initial assessment visit in advance of furnishing care the hospice must provide the patient or representative with verbal (meaning spoken) and written notice of the patient's rights and responsibilities in a language and manner that the patient understands.
- The hospice must obtain the patient's or representative's signature confirming that he or she has received a copy of the notice of rights and responsibilities.
- The patient has the right: to exercise his or her rights as a patient of the hospice; to have his or her property and person treated with respect; to voice grievances regarding treatment or care that is (or fails to be) furnished and the lack of

respect for property by anyone who is furnishing services on behalf of the hospice; and to not be subjected to discrimination or reprisal for exercising his or her rights.

- If a patient has been adjudged incompetent under state law by a court of proper jurisdiction, the rights of the patient are exercised by the person appointed pursuant to state law to act on the patient's behalf.
- The hospice must: ensure that all alleged violations involving mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, and misappropriation of patient property by anyone furnishing services on behalf of the hospice, are reported immediately by hospice employees and contracted staff to the hospice administrator; immediately investigate all alleged violations involving anyone furnishing services on behalf of the hospice and immediately take action to prevent further potential violations while the alleged violation is being verified; investigations and/or documentation of all alleged violations must be conducted in accordance with established procedures; take appropriate corrective action in accordance with state law if the alleged violation is verified by the hospice administration or an outside body having jurisdiction, such as the State survey agency or local law enforcement agency; and ensure that verified violations are reported to State and local bodies having jurisdiction (including to the State survey and certification agency) within five working days of becoming aware of the violation.
- The hospice must conduct and document in writing a patient-specific comprehensive assessment that identifies the patient's need for hospice care and services, and the patient's need for physical, psychosocial, emotional, and spiritual care (note: the assessment should include all areas of hospice care related to the palliation and management of the terminal illness and related conditions).
- The hospice registered nurse must complete an initial assessment within 48 hours after the election of hospice care (unless the physician, patient, or representative requests that the initial assessment be completed in less than 48 hours.)
- The hospice interdisciplinary group, in consultation with the individual's attending physician (if any), must complete the comprehensive assessment no later than five calendar days after the election of hospice care.

- The comprehensive assessment must identify the physical, psychosocial, emotional, and spiritual needs related to the terminal illness that must be addressed in order to promote the hospice patient's well-being, comfort, and dignity throughout the dying process.
- The comprehensive assessment must take into consideration the following factors: the nature and condition causing admission (including the presence or lack of objective data and subjective complaints); complications and risk factors that affect care planning; functional status, including the patient's ability to understand and participate in his or her own care; imminence of death; severity of symptoms; a review of all of the patient's prescription and over-the-counter drugs, herbal remedies, and other alternative treatments that could affect drug therapy; an initial bereavement assessment of the needs of the patient's family and other individuals focusing on the social, spiritual, and cultural factors that may impact their ability to cope with the patient's death (note: information gathered from the initial bereavement assessment must be incorporated into the plan of care and considered in the bereavement plan of care); the need for referrals and further evaluation by appropriate health professionals.
- The hospice must designate an interdisciplinary group or groups in consultation with the patient's attending physician; the hospice must prepare a written plan of care for each patient; the plan of care must specify the hospice care and services necessary to meet the patient and family-specific needs identified in the comprehensive assessment as such needs relate to the terminal illness and related conditions.
- The hospice must designate an interdisciplinary group or groups composed of individuals who work together to meet the physical, medical, psychosocial, emotional, and spiritual needs of the hospice patients and families facing terminal illness and bereavement; interdisciplinary group members must provide the care and services offered by the hospice, and the group, in its entirety, must supervise the care and services.
- The hospice must designate a registered nurse that is a member of the interdisciplinary group to provide coordination of care and to ensure continuous assessment of each patient's and family's needs and implementation of the interdisciplinary plan of care.

- The interdisciplinary group must include, but is not limited to, individuals who are qualified and competent to practice in the following professional roles: a doctor of medicine or osteopathy (who is an employee or under contract with the hospice); a registered nurse; a social worker; a pastoral or other counselor.
- If the hospice has more than one interdisciplinary group, it must identify a specifically designated interdisciplinary group to establish policies governing the day-to-day provision of hospice care and services.
- All hospice care and services provided to patients and their families must follow an individualized written plan of care established by the hospice interdisciplinary group in collaboration with the attending physician (if any), the patient or representative, and the primary caregiver in accordance with the patient's needs if any of them so desire; the hospice must ensure that each patient and the primary care giver(s) receive education and training provided by the hospice as appropriate to their responsibilities for the care and services identified in the plan of care.
- The hospice must develop an individualized written plan of care for each patient; the plan of care must reflect patient and family goals and interventions based on the problems identified in the initial, comprehensive, and updated comprehensive assessments.
- A patient's plan of care must include all services necessary for the palliation and management of the terminal illness and related conditions, including the following: interventions to manage pain and symptoms; a detailed statement of the scope and frequency of services necessary to meet the specific patient and family needs; measurable outcomes anticipated from implementing and coordinating the plan of care; drugs and treatment necessary to meet the needs of the patient; medical supplies and appliances necessary to meet the needs of the patient; the interdisciplinary group's documentation of the patient's or representative's level of understanding, involvement, and agreement with the plan of care, in accordance with the hospice's own policies, in the clinical record.
- The hospice interdisciplinary group (in collaboration with the individual's attending physician, if any) must review, revise and document the individualized plan as frequently as the patient's condition requires, but no less frequently than every 15 calendar days; a revised plan of care must include information from the

patient's updated comprehensive assessment and must note the patient's progress toward outcomes and goals specified in the plan of care.

- The hospice must develop and maintain a system of communication and integration, in accordance with the hospice's own policies and procedures, to: ensure that the interdisciplinary group maintains responsibility for directing, coordinating, and supervising the care and services provided; ensure that the care and services are provided in accordance with the plan of care; ensure that the care and services provided are based on all assessments of the patient and family needs; provide for and ensure the ongoing sharing of information between all disciplines providing care and services in all settings, whether the care and services are provided directly or under arrangement; provide for an ongoing sharing of information with other non-hospice health care providers furnishing services unrelated to the terminal illness and related conditions.
- The hospice must develop, implement, and maintain an effective, ongoing, hospice-wide data-driven quality assessment and performance improvement program.
- The hospice's governing body must ensure that the quality assessment and performance improvement program: reflects the complexity of its organization and services; involves all hospice services (including those services furnished under contract or arrangement); focuses on indicators related to improved palliative outcomes; and takes actions to demonstrate improvement in hospice performance; the hospice must maintain documentary evidence of its quality assessment and performance improvement program and be able to demonstrate its operation.
- The program must use quality indicator data, including patient care, and other relevant data, in the design of its program.
- The hospice must use the data collected to do the following: monitor the effectiveness and safety of services and quality of care; identify opportunities and priorities for improvement.
- The frequency and detail of the data collection must be approved by the hospice's governing body.
- The hospice's performance improvement activities must: focus on high risk, high volume, or problem-prone areas; consider incidence, prevalence, and severity of

problems in those areas; affect palliative outcomes, patient safety, and quality of care.

- Performance improvement activities must track adverse patient events, analyze their causes, and implement preventive actions and mechanisms that include feedback and learning throughout the hospice.
- The hospice must take actions aimed at performance improvement and, after implementing those actions, the hospice must measure its success and track performance to ensure that improvements are sustained.
- The hospice must maintain and document an effective infection control program that protects patients, families, visitors, and hospice personnel by preventing and controlling infections and communicable diseases.
- A hospice must develop, implement, and evaluate performance improvement projects.
- The number and scope of distinct performance improvement projects conducted annually, based on the needs of the hospice's population and internal organizational needs, must reflect the scope, complexity, and past performance of the hospice's services and operations.
- The hospice must document what performance improvement projects are being conducted, the reasons for conducting these projects, and the measurable progress achieved on these projects.
- The hospice's governing body is responsible for ensuring the following: an ongoing program for quality improvement and patient safety is defined, implemented, and maintained, and is evaluated annually; the hospice-wide quality assessment and performance improvement efforts address priorities for improved quality of care and patient safety, and that all improvement actions are evaluated for effectiveness; one or more individual(s) who are responsible for operating the quality assessment and performance improvement program are designated.
- The hospice must follow accepted standards of practice to prevent the transmission of infections and communicable diseases, including the use of standard precautions (note: standard precautions may refer to infection control practices that may be used to prevent the transmission of diseases; the minimum infection prevention practices that apply to all patient care).

- The hospice must maintain a coordinated agency-wide program for the surveillance, identification, prevention, control, and investigation of infectious and communicable diseases.
- The hospice must provide infection control education to employees, contracted providers, patients, and family members and other caregivers.
- The hospice must develop and implement policies and procedures to ensure that all staff are fully vaccinated for coronavirus disease 2019 (COVID-19); staff are considered fully vaccinated if it has been two weeks or more since they completed a primary vaccination series for COVID-19 (note: coronavirus disease 2019 [COVID-19] may refer to a respiratory illness that can spread from person to person, which is caused by a virus known as the severe acute respiratory syndrome coronavirus 2 [SARS-CoV-2]).
- Regardless of clinical responsibility or patient contact, COVID-19-related policies and procedures must apply to the following hospice staff, who provide any care, treatment, or other services for the hospice and/or its patients: hospice employees; licensed practitioners; students, trainees, and volunteers; and individuals who provide care, treatment, or other services for the hospice and/or its patients, under contract or by other arrangement.
- COVID-19-related policies and procedures must include, at a minimum, the following components: a process for ensuring all staff (except for those staff who have pending requests for, or who have been granted, exemptions to the vaccination requirements, or those staff for whom COVID-19 vaccination must be temporarily delayed, as recommended by the CDC, due to clinical precautions and considerations) have received, at a minimum, a single-dose COVID-19 vaccine, or the first dose of the primary vaccination series for a multi-dose COVID-19 vaccine prior to staff providing any care, treatment, or other services for the hospice and/or its patients; a process for ensuring that all staff are fully vaccinated, except for those staff who have been granted exemptions to the vaccination requirements, or those staff for whom COVID-19 vaccination must be temporarily delayed, as recommended by the CDC, due to clinical precautions and considerations; a process for ensuring the implementation of additional precautions, intended to mitigate the transmission and spread of COVID-19, for all staff who are not fully vaccinated for COVID-19; a process for tracking and securely documenting the COVID-19 vaccination status of all staff; a process for tracking and securely documenting the COVID-19 vaccination status of any staff who have obtained any

booster doses as recommended by the CDC; a process by which staff may request an exemption from the staff COVID-19 vaccination requirements based on an applicable federal law; a process for tracking and securely documenting information provided by those staff who have requested, and for whom the hospice has granted, an exemption from the staff COVID-19 vaccination requirements; a process for ensuring that all documentation, which confirms recognized clinical contraindications to COVID-19 vaccines and which supports staff requests for medical exemptions from vaccination, has been signed and dated by a licensed practitioner, who is not the individual requesting the exemption, and who is acting within their respective scope of practice as defined by, and in accordance with, all applicable State and local laws, and for further ensuring that such documentation contains: all information specifying which of the authorized COVID-19 vaccines are clinically contraindicated for the staff member to receive and the recognized clinical reasons for the contraindications; and a statement by the authenticating practitioner recommending that the staff member be exempted from the hospice's COVID-19 vaccination requirements for staff based on the recognized clinical contraindications; a process for ensuring the tracking and secure documentation of the vaccination status of staff for whom COVID-19 vaccination must be temporarily delayed, as recommended by the CDC, due to clinical precautions and considerations, including, but not limited to, individuals with acute illness secondary to COVID-19, and individuals who received monoclonal antibodies or convalescent plasma for COVID-19 treatment; and contingency plans for staff who are not fully vaccinated for COVID-19.

- The hospice must develop and implement a process for tracking and securely documenting the COVID-19 vaccination status of all required staff.
- The hospice medical director, physician employees, and contracted physician(s) of the hospice, in conjunction with the patient's attending physician, are responsible for the palliation and management of the terminal illness and conditions related to the terminal illness.
- All physician employees and those under contract, must function under the supervision of the hospice medical director.
- All physician employees and those under contract shall meet requirements by either providing the services directly or through coordinating patient care with the attending physician.

- If the attending physician is unavailable, the medical director, contracted physician, and/or hospice physician employee is responsible for meeting the medical needs of the patient.
- The hospice must provide nursing care and services by or under the supervision of a registered nurse.
- Nursing services must ensure that the nursing needs of the patient are met as identified in the patient's initial assessment, comprehensive assessment, and updated assessments.
- If State law permits registered nurses to see, treat, and write orders for patients, then registered nurses may provide services to beneficiaries receiving hospice care.
- Highly specialized nursing services that are provided so infrequently that the provision of such services by direct hospice employees would be impracticable and prohibitively expensive, may be provided under contract.
- Medical social services must be provided by a qualified social worker, under the direction of a physician; social work services must be based on the patient's psychosocial assessment and the patient's and family's needs and acceptance of these services.
- Counseling services must be available to the patient and family to assist the patient and family in minimizing the stress and problems that arise from the terminal illness, related conditions, and the dying process.
- The hospice must: have an organized program for the provision of bereavement services furnished under the supervision of a qualified professional with experience or education in grief or loss counseling; make bereavement services available to the family and other individuals in the bereavement plan of care up to one year following the death of the patient; ensure that bereavement services reflect the needs of the bereaved; develop a bereavement plan of care that notes the kind of bereavement services to be offered and the frequency of service delivery.
- Dietary counseling, when identified in the plan of care, must be performed by a qualified individual, which include dietitians as well as nurses and other individuals who are able to address and assure that the dietary needs of the patient are met.

- The hospice must provide an assessment of the patient's and family's spiritual needs.
- The hospice must provide spiritual counseling to meet these needs in accordance with the patient's and family's acceptance of this service, and in a manner consistent with patient and family beliefs and desires.
- Physical therapy services, occupational therapy services, and speech-language pathology services must be available, and when provided, offered in a manner consistent with accepted standards of practice.
- A hospice located in a non-urbanized area may submit a written request for a waiver of the requirement for providing physical therapy, occupational therapy, speech-language pathology, and dietary counseling services; the hospice may seek a waiver of the requirement that it make physical therapy, occupational therapy, speech-language pathology, and dietary counseling services (as needed) available on a 24-hour basis; the hospice may also seek a waiver of the requirement that it provide dietary counseling directly; the hospice must provide evidence that it has made a good faith effort to meet the requirements for these services before it seeks a waiver.
- A qualified hospice aide is a person who has successfully completed one of the following: a training program and competency evaluation.
- Hospice aide training must include classroom and supervised practical training in a practicum laboratory or other setting in which the trainee demonstrates knowledge while performing tasks on an individual under the direct supervision of a registered nurse, or a licensed practical nurse, who is under the supervision of a registered nurse; classroom and supervised practical training combined must total at least 75 hours; a minimum of 16 hours of classroom training must precede a minimum of 16 hours of supervised practical training as part of the 75 hours.
- A hospice aide training program must address each of the following subject areas: communication skills, including the ability to read, write, and verbally report clinical information to patients, care givers, and other hospice staff; observation, reporting, and documentation of patient status and the care or service furnished; reading and recording temperature, pulse, and respiration; basic infection control procedures; basic elements of body functioning and changes in body function that must be reported to an aide's supervisor; maintenance of a clean, safe, and

healthy environment; recognizing emergencies and the knowledge of emergency procedures and their application; the physical, emotional, and developmental needs of and ways to work with the populations served by the hospice, including the need for respect for the patient, his or her privacy, and his or her property; appropriate and safe techniques in performing personal hygiene and grooming tasks, including items on the following basic checklist: bed bath, sponge, tub, and shower bath, hair shampoo (sink, tub, and bed), nail and skin care, oral hygiene, toileting and elimination; safe transfer techniques and ambulation; normal range of motion and positioning; adequate nutrition and fluid intake; any other task that the hospice may choose to have an aide perform.

- The hospice is responsible for training hospice aides, as needed.
- The hospice must maintain documentation that demonstrates that the aforementioned requirements are met.
- An individual may furnish hospice aide services on behalf of a hospice only after that individual has successfully completed a competency evaluation program.
- The competency evaluation must address specified subjects; subject areas must be evaluated by observing an aide's performance of the task with a patient or pseudo-patient; the remaining subject areas may be evaluated through written examination, oral examination, or after observation of a hospice aide with a patient or a pseudo-patient during a simulation.
- A hospice aide competency evaluation program may be offered by any organization.
- The competency evaluation must be performed by a registered nurse in consultation with other skilled professionals, as appropriate.
- A hospice aide is not considered competent in any task for which he or she is evaluated as unsatisfactory. An aide must not perform that task without direct supervision by a registered nurse until after he or she has received training in the task for which he or she was evaluated as "unsatisfactory," and successfully completes a subsequent evaluation. A hospice aide is not considered to have successfully completed a competency evaluation if the aide has an "unsatisfactory" rating in more than one of the required areas.

- A hospice aide must receive at least 12 hours of in-service training during each 12-month period; in-service training may occur while an aide is furnishing care to a patient.
- In-service training may be offered by any organization, and must be supervised by a registered nurse.
- The hospice must maintain documentation that demonstrates the in-service training requirements are met.
- Classroom and supervised practical training must be performed by a registered nurse who possesses a minimum of two years nursing experience, at least one year of which must be in home care, or by other individuals under the general supervision of a registered nurse.
- A hospice aide competency evaluation program may be offered by any organization except by a home health agency that, within the previous two years: had been out of compliance; permitted an individual that does not meet the definition of a “qualified home health aide” to provide home health aide services (with the exception of licensed health professionals and volunteers); was subjected to an extended (or partial extended) survey as a result of having been found to have furnished substandard care; was assessed a civil monetary penalty of \$5,000 or more as an intermediate sanction; was found to have compliance deficiencies that endangered the health and safety of the home health agency's patients and had temporary management appointed to oversee the management of the home health agency; had all or part of its Medicare payments suspended; had its participation in the Medicare program terminated; was assessed a penalty of \$5,000 or more for deficiencies in Federal or State standards for home health agencies; was subjected to a suspension of Medicare payments to which it otherwise would have been entitled; operated under temporary management that was appointed by a governmental authority to oversee the operation of the home health agency and to ensure the health and safety of the home health agency's patients; was closed by the State, or had its patients transferred by the State.
- Hospice aides are assigned to a specific patient by a registered nurse that is a member of the interdisciplinary group.
- Written patient care instructions for a hospice aide must be prepared by a registered nurse who is responsible for the supervision of a hospice aide.

- Hospice aides must report changes in a patient's medical, nursing, rehabilitative, and social needs to a registered nurse, as the changes relate to the plan of care and quality assessment and improvement activities; hospice aides must also complete appropriate records in compliance with the hospice's policies and procedures.
- A registered nurse must make an on-site visit to a patient's home no less frequently than every 14 days to assess the quality of care and services provided by the hospice aide and to ensure that services ordered by the hospice interdisciplinary group meet the patient's needs (note: the hospice aide does not have to be present during this visit).
- If an area of concern is noted by the supervising nurse, then the hospice must make an on-site visit to the location where the patient is receiving care in order to observe and assess the aide while he or she is performing care.
- If an area of concern is verified by the hospice during the on-site visit, then the hospice must conduct, and the hospice aide must complete, a competency evaluation of the deficient skill and all related skill(s).
- A registered nurse must make an annual on-site visit to the location where a patient is receiving care in order to observe and assess each aide while he or she is performing care.
- The supervising nurse must assess an aide's ability to demonstrate initial and continued satisfactory performance in meeting outcome criteria that include, but is not limited to - following the patient's plan of care for completion of tasks assigned to the hospice aide by the registered nurse; creating successful interpersonal relationships with the patient and family; demonstrating competency with assigned tasks; complying with infection control policies and procedures; reporting changes in the patient's condition
- Homemaker services must be coordinated and supervised by a member of the interdisciplinary group.
- Instructions for homemaker duties must be prepared by a member of the interdisciplinary group.
- Homemakers must report all concerns about the patient or family to the member of the interdisciplinary group who is coordinating homemaker services.

- The hospice must maintain, document, and provide volunteer orientation and training that is consistent with hospice industry standards.
- Volunteers must be used in day-to-day administrative and/or direct patient care roles.
- The hospice must document and demonstrate viable and ongoing efforts to recruit and retain volunteers.
- The hospice must document the cost savings achieved through the use of volunteers.
- The hospice must organize, manage, and administer its resources to provide the hospice care and services to patients, caregivers and families necessary for the palliation and management of the terminal illness and related conditions.
- The hospice must provide hospice care that optimizes comfort and dignity; and is consistent with patient and family needs and goals, with patient needs and goals as priority.
- A hospice may not discontinue or reduce care provided to a Medicare or Medicaid beneficiary because of the beneficiary's inability to pay for that care.
- The hospice must designate a physician to serve as medical director; the medical director must be a doctor of medicine or osteopathy who is an employee, or is under contract with the hospice; when the medical director is not available, a physician designated by the hospice assumes the same responsibilities and obligations as the medical director.
- The medical director or physician designee reviews the clinical information for each hospice patient and provides written certification that it is anticipated that the patient's life expectancy is six months or less if the illness runs its normal course.
- The physician must consider the following when making the aforementioned determination: the primary terminal condition; related diagnosis(es), if any; current subjective and objective medical findings; current medication and treatment orders; and information about the medical management of any of the patient's conditions unrelated to the terminal illness.

- Before the recertification period for each patient the medical director or physician designee must review the patient's clinical information.
- The medical director or physician designee has responsibility for the medical component of the hospice's patient care program.
- A clinical record containing past and current findings is maintained for each hospice patient. The clinical record must contain correct clinical information that is available to the patient's attending physician and hospice staff. The clinical record may be maintained electronically.
- The clinical record, its contents and the information contained therein must be safeguarded against loss or unauthorized use; the hospice must be in compliance with the Department's rules regarding personal health information.
- Patient clinical records must be retained for six years after the death or discharge of the patient, unless State law stipulates a longer period of time; if the hospice discontinues operation, hospice policies must provide for retention and storage of clinical records; the hospice must inform its State agency where such clinical records will be stored and how they may be accessed.
- The clinical record, whether hard copy or in electronic form, must be made readily available on request by an appropriate authority.
- Medical supplies and appliances; durable medical equipment; and drugs and biologicals related to the palliation and management of the terminal illness and related conditions, as identified in the hospice plan of care, must be provided by the hospice while the patient is under hospice care.
- Drugs may be ordered by any of the following practitioners: a physician; a nurse practitioner in accordance with state scope of practice requirements; a physician assistant in accordance with state scope of practice requirements and hospice policy who is: the patient's attending physician; and not an employee of or under arrangement with the hospice.
- If the drug order is verbal or given by or through electronic transmission - it must be given only to a licensed nurse, nurse practitioner (where appropriate), pharmacist, or physician; and the individual receiving the order must record and sign it immediately and have the prescribing person sign it in accordance with State and Federal regulations.

- The hospice must obtain drugs and biologicals from community or institutional pharmacists or stock drugs and biologicals itself.
- The hospice that provides inpatient care directly in its own facility must: have a written policy in place that promotes dispensing accuracy; and maintain current and accurate records of the receipt and disposition of all controlled drugs.
- The interdisciplinary group, as part of the review of the plan of care, must determine the ability of the patient and/or family to safely self-administer drugs and biologicals to the patient in his or her home.
- Patients receiving care in a hospice that provides inpatient care directly in its own facility may only be administered medications by the following individuals: a licensed nurse, physician, or other health care professional in accordance with their scope of practice and State law; an employee who has completed a State-approved training program in medication administration; and the patient, upon approval by the interdisciplinary group.
- Patient drugs and biologicals must be labeled in accordance with currently accepted professional practice and must include appropriate usage and cautionary instructions, as well as an expiration date (if applicable).
- The hospice must have written policies and procedures for the management and disposal of controlled drugs in the patient's home.
- At the time when controlled drugs are first ordered the hospice must: provide a copy of the hospice written policies and procedures on the management and disposal of controlled drugs to the patient or patient representative and family; discuss the hospice policies and procedures for managing the safe use and disposal of controlled drugs with the patient or representative and the family in a language and manner that they understand to ensure that these parties are educated regarding the safe use and disposal of controlled drugs; and document in the patient's clinical record that the written policies and procedures for managing controlled drugs was provided and discussed.
- The hospice that provides inpatient care directly in its own facility must dispose of controlled drugs in compliance with the hospice policy and in accordance with State and Federal requirements. The hospice must maintain current and accurate records of the receipt and disposition of all controlled drugs.

- The hospice that provides inpatient care directly in its own facility must comply with the following additional requirements - all drugs and biologicals must be stored in secure areas; all controlled drugs listed in Schedules II, III, IV, and V of the Comprehensive Drug Abuse Prevention and Control Act of 1976 must be stored in locked compartments within such secure storage areas; only personnel authorized to administer controlled drugs may have access to the locked compartments; and discrepancies in the acquisition, storage, dispensing, administration, disposal, or return of controlled drugs must be investigated immediately by the pharmacist and hospice administrator and where required reported to the appropriate State authority; a written account of the investigation must be made available to State and Federal officials if required by law or regulation.
- The hospice must ensure that manufacturer recommendations for performing routine and preventive maintenance on durable medical equipment are followed; the equipment must be safe and work as intended for use in the patient's environment; where a manufacturer recommendation for a piece of equipment does not exist, the hospice must ensure that repair and routine maintenance policies are developed; the hospice may use persons under contract to ensure the maintenance and repair of durable medical equipment.
- The hospice must ensure that the patient, where appropriate, as well as the family and/or other caregiver(s), receive instruction in the safe use of durable medical equipment and supplies.
- Inpatient care must be available for pain control, symptom management, and respite purposes, and must be provided in a participating Medicare or Medicaid facility.
- Inpatient care for pain control and symptom management must be provided in one of the following: a Medicare-certified hospice that meets the conditions of participation for providing inpatient care; a Medicare-certified hospital or a skilled nursing facility.
- Inpatient care for respite purposes must be provided by one of the following: a specified provider; a Medicare or Medicaid-certified nursing facility that also meets the standards.
- The facility providing respite care must provide 24-hour nursing services that meet the nursing needs of all patients and are furnished in accordance with each

patient's plan of care; each patient must receive all nursing services as prescribed and must be kept comfortable, clean, well-groomed, and protected from accident, injury, and infection.

- If the hospice has an arrangement with a facility to provide for short-term inpatient care, the arrangement is described in a written agreement, coordinated by the hospice, and at a minimum specifies - that the hospice supplies the inpatient provider a copy of the patient's plan of care and specifies the inpatient services to be furnished; that the inpatient provider has established patient care policies consistent with those of the hospice and agrees to abide by the palliative care protocols and plan of care established by the hospice for its patients; that the hospice patient's inpatient clinical record includes a record of all inpatient services furnished and events regarding care that occurred at the facility; that a copy of the discharge summary be provided to the hospice at the time of discharge; and that a copy of the inpatient clinical record is available to the hospice at the time of discharge; that the inpatient facility has identified an individual within the facility who is responsible for the implementation of the provisions of the agreement; that the hospice retains responsibility for ensuring that the training of personnel who will be providing the patient's care in the inpatient facility has been provided and that a description of the training and the names of those giving the training are documented; and a method for verifying that the requirements.
- The hospice is responsible for ensuring that staffing for all services reflects its volume of patients, their acuity, and the level of intensity of services needed to ensure that plan of care outcomes are achieved and negative outcomes are avoided.
- The hospice facility must provide 24-hour nursing services that meet the nursing needs of all patients and are furnished in accordance with each patient's plan of care; each patient must receive all nursing services as prescribed and must be kept comfortable, clean, well-groomed, and protected from accident, injury, and infection.
- If at least one patient in the hospice facility is receiving general inpatient care, then each shift must include a registered nurse who provides direct patient care.
- The hospice must address real or potential threats to the health and safety of the patients, others, and property.

- The hospice must develop procedures for controlling the reliability and quality of: the routine storage and prompt disposal of trash and medical waste; light, temperature, and ventilation/air exchanges throughout the hospice; emergency gas and water supply; and the scheduled and emergency maintenance and repair of all equipment.
- The hospice must meet applicable provisions and must proceed in accordance with the Life Safety Code.
- Corridor doors and doors to rooms containing flammable or combustible materials must be provided with positive latching hardware; roller latches are prohibited on such doors.
- In consideration of a recommendation by the State survey agency or Accrediting Organization or at the discretion of the Secretary, may waive, for periods deemed appropriate, specific provisions of the Life Safety Code, which would result in unreasonable hardship upon a hospice facility, but only if the waiver will not adversely affect the health and safety of the patients.
- A hospice may place alcohol-based hand rub dispensers in its facility if the dispensers are installed in a manner that adequately protects against access by vulnerable populations.
- When a sprinkler system is shut down for more than 10 hours, the hospice must: evacuate the building or portion of the building affected by the system outage until the system is back in service, or establish a fire watch until the system is back in service.
- Buildings must have an outside window or outside door in every sleeping room; windows in atrium walls are considered outside windows for the purposes of this requirement.
- The hospice must provide a home-like atmosphere and ensure that patient areas are designed to preserve the dignity, comfort, and privacy of patients.
- The hospice must provide: physical space for private patient and family visiting; accommodations for family members to remain with the patient throughout the night; and physical space for family privacy after a patient's death.
- The hospice must provide the opportunity for patients to receive visitors at any hour, including infants and small children.

- The hospice must ensure that patient rooms are designed and equipped for nursing care, as well as the dignity, comfort, and privacy of patients.
- The hospice must accommodate a patient and family request for a single room whenever possible.
- Each patient's room must: be at or above grade level; contain a suitable bed and other appropriate furniture for each patient; have closet space that provides security and privacy for clothing and personal belongings; accommodate no more than two patients and their family members; provide at least 80 square feet for each residing patient in a double room and at least 100 square feet for each patient residing in a single room; and be equipped with an easily-activated, functioning device accessible to the patient, that is used for calling for assistance.
- Each patient room must be equipped with, or conveniently located near, toilet and bathing facilities.
- The hospice must provide a sanitary environment by following current standards of practice, including nationally recognized infection control precautions, and avoid sources and transmission of infections and communicable diseases.
- The hospice must have available at all times a quantity of clean linen in sufficient amounts for all patient uses; linens must be handled, stored, processed, and transported in such a manner as to prevent the spread of contaminants.
- The hospice must furnish meals to each patient that are: consistent with the patient's plan of care, nutritional needs, and therapeutic diet; palatable, attractive, and served at the proper temperature; and obtained, stored, prepared, distributed, and served under sanitary conditions.
- All patients have the right to be free from physical or mental abuse, and corporal punishment. All patients have the right to be free from restraint or seclusion, of any form, imposed as a means of coercion, discipline, convenience, or retaliation by staff.
- Restraint or seclusion may only be imposed to ensure the immediate physical safety of the patient, a staff member, or others and must be discontinued at the earliest possible time.

- Restraint or seclusion may only be used when less restrictive interventions have been determined to be ineffective to protect the patient, a staff member, or others from harm.
- The type or technique of restraint or seclusion used must be the least restrictive intervention that will be effective to protect the patient, a staff member, or others from harm.
- The use of restraint or seclusion must be: in accordance with a written modification to the patient's plan of care; and implemented in accordance with safe and appropriate restraint and seclusion techniques as determined by hospice policy in accordance with State law.
- Orders for the use of restraint or seclusion must never be written as a standing order or on an as needed basis (PRN).
- The medical director or physician designee must be consulted as soon as possible if the attending physician did not order the restraint or seclusion.
- Unless superseded by State law that is more restrictive, each order for restraint or seclusion used for the management of violent or self-destructive behavior that jeopardizes the immediate physical safety of the patient, a staff member, or others may only be renewed in accordance with the following limits for up to a total of 24 hours: four hours for adults 18 years of age or older; two hours for children and adolescents nine to 17 years of age; or one hour for children under nine years of age; and after 24 hours, before writing a new order for the use of restraint or seclusion for the management of violent or self-destructive behavior, a physician authorized to order restraint or seclusion by hospice policy in accordance with State law must see and assess the patient.
- Each order for restraint used to ensure the physical safety of the non-violent or non-self-destructive patient may be renewed as authorized by hospice policy.
- Restraint or seclusion must be discontinued at the earliest possible time, regardless of the length of time identified in the order.
- The condition of the patient who is restrained or secluded must be monitored by a physician or trained staff that completed the related training.
- Physician, including attending physician, training requirements must be specified in hospice policy. At a minimum, physicians and attending physicians authorized

to order restraint or seclusion by hospice policy in accordance with State law must have a working knowledge of hospice policy regarding the use of restraint or seclusion.

- When restraint or seclusion is used for the management of violent or self-destructive behavior that jeopardizes the immediate physical safety of the patient, a staff member, or others, the patient must be seen face-to-face within one hour after the initiation of the intervention by a physician or registered nurse who has been trained.
- The physician or registered nurse should evaluate the patient's immediate situation; the patient's reaction to the intervention; the patient's medical and behavioral condition; and the need to continue or terminate the restraint or seclusion.
- States are free to have requirements by statute or regulation that are more restrictive.
- If the face-to-face evaluation is conducted by a trained registered nurse, the trained registered nurse must consult the medical director or physician designee as soon as possible after the completion of the one-hour face-to-face evaluation.
- Simultaneous restraint and seclusion use is only permitted if the patient is continually monitored face-to-face by an assigned, trained staff member; or by trained staff using both video and audio equipment. This monitoring must be in close proximity to the patient.
- When restraint or seclusion is used, there must be documentation in the patient's clinical record of the following: the one-hour face-to-face medical and behavioral evaluation if restraint or seclusion is used to manage violent or self-destructive behavior; a description of the patient's behavior and the intervention used; alternatives or other less restrictive interventions attempted (as applicable); the patient's condition or symptom(s) that warranted the use of the restraint or seclusion; and the patient's response to the intervention(s) used, including the rationale for continued use of the intervention.
- The medical director or physician designee must be consulted as soon as possible if the attending physician did not order the restraint or seclusion.
- The patient has the right to safe implementation of restraint or seclusion by trained staff.

- All patient care staff working in the hospice inpatient facility must be trained and able to demonstrate competency in the application of restraints, implementation of seclusion, monitoring, assessment, and providing care for a patient in restraint or seclusion.
- Individuals providing staff training must be qualified as evidenced by education, training, and experience in techniques used to address patients' behaviors.
- The hospice must document in the staff personnel records that the training and demonstration of competency were successfully completed.
- Hospices must report deaths associated with the use of seclusion or restraint.
- The hospice must comply with all applicable Federal, State, and local emergency preparedness requirements.
- The hospice must develop and maintain an emergency preparedness communication plan that complies with Federal, State, and local laws and must be reviewed and updated at least every two years.
- All services must be performed by appropriately qualified personnel, but it is the nature of the service, rather than the qualification of the person who provides it, that determines the coverage category of the service.
- Nursing care may be covered on a continuous basis for as much as 24 hours a day during periods of crisis as necessary to maintain an individual at home; either homemaker or home health aide (also known as hospice aide) services or both may be covered on a 24-hour continuous basis during periods of crisis but care during these periods must be predominantly nursing care; a period of crisis is a period in which the individual requires continuous care to achieve palliation and management of acute medical symptoms.
- Respite care is short-term inpatient care provided to the individual only when necessary to relieve the family members or other persons caring for the individual.
- Respite care may be provided only on an occasional basis and may not be reimbursed for more than five consecutive days at a time.
- Medicare payment to the hospice discharges an individual's liability for payment for all services, other than the hospice coinsurance amounts that are considered

covered hospice care; the individual is liable for the Medicare deductibles and coinsurance payments and for the difference between the reasonable and actual charge on unassigned claims on other covered services that are not considered hospice care; examples of services not considered hospice care include: services furnished before or after a hospice election period; services of the individual's attending physician, if the attending physician is not an employee of or working under an arrangement with the hospice; or Medicare services received for the treatment of an illness or injury not related to the individual's terminal condition.

Section 2 Summary

Federal laws and regulations that apply to hospice care can be found in Title 42 Part 418 - Hospice Care. Such laws and regulations protect hospice patients' rights, as well as establish standards of care. Additionally, the laws and regulations included in Title 42 Part 418 - Hospice Care indicate methods for hospice care payment, and requirements for hospice facilities and health care professionals administering care to hospice patients. Health care professionals should be familiar with the laws, regulations, and requirements included in Title 42 Part 418 - Hospice Care.

Section 2 Key Concepts

- Federal laws and regulations that apply to hospice care can be found in Title 42 Part 418 - Hospice Care.

Section 2 Key Terms

Attending physician - a doctor of medicine or osteopathy legally authorized to practice medicine and surgery by the State in which he or she performs that function or action; or nurse practitioner who meets training, education, and experience requirements; or physician assistant who meets requirements; and who is identified by the individual, at the time he or she elects to receive hospice care, as having the most significant role in the determination and delivery of the individual's medical care

Physician designee - a doctor of medicine or osteopathy designated by the hospice who assumes the same responsibilities and obligations as the medical director when the medical director is not available

Palliative care - patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering

Representative - an individual who has the authority under State law (whether by statute or pursuant to an appointment by the courts of the State) to authorize or terminate medical care or to elect or revoke the election of hospice care on behalf of a terminally ill patient who is mentally or physically incapacitated

Bereavement counseling - emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment

Comprehensive assessment - a thorough evaluation of the patient's physical, psychosocial, emotional and spiritual status related to the terminal illness and related conditions

Terminally ill - the individual has a medical prognosis that his or her life expectancy is six months or less if the illness runs its normal course

Restraint - any manual method, physical or mechanical device, material, or equipment that immobilizes or reduces the ability of a patient to move his or her arms, legs, body, or head freely, not including devices, such as orthopedically prescribed devices, surgical dressings or bandages, protective helmets, or other methods that involve the physical holding of a patient for the purpose of conducting routine physical examinations or tests, or to protect the patient from falling out of bed, or to permit the patient to participate in activities without the risk of physical harm (this does not include a physical escort); or a drug or medication when it is used as a restriction to manage a patient's behavior or restrict a patient's freedom of movement and is not a standard treatment or dosage for the patient's condition

Seclusion - the involuntary confinement of a patient alone in a room or an area from which the patient is physically prevented from leaving

Telecommunications technology - the use of interactive multimedia communications equipment that includes, at a minimum, the use of audio and video equipment permitting two-way, real-time interactive communication between the patient and the distant site health care professionals

Standard precautions - infection control practices that may be used to prevent the transmission of diseases; the minimum infection prevention practices that apply to all patient care

Coronavirus disease 2019 (COVID-19) - a respiratory illness that can spread from person to person, which is caused by a virus known as the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)

Period of crisis - a period in which the individual requires continuous care to achieve palliation and management of acute medical symptoms

Respite care - short-term inpatient care provided to the individual only when necessary to relieve the family members or other persons caring for the individual

Section 2 Personal Reflection Question

How can health care professionals ensure the laws, regulations, and requirements included in Title 42 Part 418 - Hospice Care are met and followed within an applicable health care facility?

Section 3: Stress and Grief

Unfortunately, hospice care can lead to stress and grief for hospice care patients, their family and friends, and the health care professionals who care for hospice care patients. Therefore, health care professionals should possess insight into stress and grief, as well as methods and strategies to manage stress and grief. This section of the course will review concepts related to stress and grief, as well as methods and strategies to manage stress and grief. The information found within this section of the course was derived from materials provided by the CDC unless, otherwise, specified (CDC, 2021).

Stress

- Stress may refer to a factor that causes emotional, physical, or psychological tension.
- Stress can be related to a "negative" event such as an accident, as well as a "positive" event such as a job promotion.
- Stress may also arise from a significant life event, such as the death of a loved one (note: a significant life event may refer to any major shift in an individual's life).
- Signs/symptoms of stress include the following: disbelief and shock; tension and irritability; fear and anxiety about the future; difficulty making decisions; feeling

numb; sadness and other symptoms of depression; loss of interest in normal activities; loss of appetite; nightmares and recurring thoughts about an event; anger; increased use of alcohol and drugs; feeling powerless; crying; sleep problems; headaches; back pains; stomach problems; trouble concentrating.

- Stress can play a role in the development of the following: headaches, high blood pressure, heart disease, diabetes, skin conditions, asthma, arthritis, depression, anxiety, and substance abuse.
- Stress is associated with burn-out.
- Burn-out may refer to a syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed (World Health Organization [WHO], 2019).
- Burn-out is characterized by the following three dimensions: feelings of energy depletion or exhaustion; increased mental distance from one's job, or feelings of negativism or cynicism related to one's job; and reduced professional efficacy (WHO, 2019).
- Burn-out can lead to both physical and behavioral signs/symptoms.
- The physical signs/symptoms of burn-out may include the following: fatigue; muscle stiffness; back pain; frequent headaches; gastrointestinal dysfunction; shortness of breath.
- The behavioral signs/symptoms of burn-out may include the following: irritability; ill-tempered behavior; emotional exhaustion; heightened emotional responses (e.g., quick to anger); distressed; suspicious and paranoid.
- Stress is often associated with personal complications. Specific information regarding the personal complications associated with stress may be found below.
 - Pain - pain in the lower back and from headaches is often associated with chronic stress and related burn-out.
 - Muscle stiffness - muscle stiffness may result from chronic stress and related burn-out. Muscle stiffness may refer to a state of muscle tightness and contraction that may affect movement. Health care professionals should note that muscle stiffness may be accompanied by pain, cramping, and discomfort.

- Digestive issues - chronic stress and related burn-out may lead to digestive issues. The digestive issues associated with chronic stress and related burn-out may lead to diarrhea, constipation, bloating, and stomach discomfort. Health care professionals should note that severe stress may lead to vomiting.
- Low self-esteem - individuals suffering from chronic stress and related burn-out may struggle with low self-esteem. Self-esteem may refer to an individual's subjective evaluation of his or her own value or worth. Health care professionals should note the following signs of low self-esteem: poor confidence; self-doubt; negative view of oneself; talking about oneself in a negative manner; negative outlook towards life; an inability to accept acknowledgement or positive feedback; outward feelings of shame; anxious mood; and depressed mood.
- Relationship problems - chronic stress, related burn-out, and resulting low self-esteem may lead to relationship problems (e.g., problems maintaining relationships with other individuals; individuals cannot sustain long-term romantic or platonic relationships with other individuals). Health care professionals should note that chronic stress, related burn-out, and resulting low self-esteem may impact both personal and professional relationships.
- Social isolation - chronic stress, related burn-out, resulting low self-esteem, and relationship problems may lead to social isolation (note: the term social isolation may refer to a lack of social connections that may impact an individual's health and quality of life). Health care professionals should note the following signs of social isolation: consistently avoiding social situations, consistently canceling plans with others, and feeling distressed when isolated.
- Depression - chronic stress and related burn-out, as well as associated complications may lead to a depressive disorder. Health care professionals should note that the traumatic and/or prolonged death of a loved one can contribute to depression.
- Anxiety - chronic stress and related burn-out, as well as associated complications may lead to an anxiety disorder. Health care professionals

should note that the traumatic and/or prolonged death of a loved one can contribute to anxiety.

- Sleep disorders - chronic stress and related burn-out, as well as associated complications may lead to a sleep disorder. The term sleep disorders may refer to a group of disorders that affect the way individuals sleep. One of the most common sleep disorders is insomnia. Insomnia may refer to a sleep disorder characterized by an inability to fall asleep and/or stay asleep. Insomnia may also be characterized by early morning awakening (i.e., an individual awakens early in the morning or several hours early and is unable to resume sleeping). Health care professionals should note the following signs/symptoms of insomnia: daytime fatigue, low energy, difficulty concentrating, mood disturbances, and decreased performance at work or at school.
- Substance abuse - chronic stress and related burn-out, as well as associated complications may lead to substance abuse. Health care professionals should note that substance abuse may refer to the harmful or hazardous use of a psychoactive substance such as alcohol or illicit drugs. Health care professionals should also note the following signs of alcohol and/or illicit drug use: slurred speech, an active tremor, shakiness, poor coordination, sweating, nausea, vomiting, aggression, agitation, compulsive behavior, craving, red eyes, dry mouth, drowsiness, involuntary eye movements, dilated pupils, nasal congestion, mouth sores, reduced consciousness, lack of pain sensation, intolerance to loud noise, dizziness, confusion, lack of awareness to surroundings, and needle marks.
- Suicidal ideation - finally, chronic stress, burn-out, and related complications may, collectively or independently, lead to suicidal ideation. Suicidal ideation may refer to thoughts of suicide and/or thoughts of planning suicide. Suicidal ideation may lead to a suicide attempt and/or suicide. A suicide attempt may refer to a non-fatal self-directed and potentially injurious behavior with any intent to die as a result of the behavior (note: a suicide attempt may or may not result in injury). Suicide may refer to a death caused by injuring oneself with the intent to die. Health care professionals should work to prevent suicide, when applicable.

Grief

- Grief may refer to deep sorrow and/or distress that is caused by a traumatic event (e.g., the death of a loved one).
- Grief is the normal response of sorrow, heartache, and confusion that comes from losing someone or something important.
- Grief is a normal response to loss during or after a disaster or other traumatic event.
- Grief can happen in response to loss of life, as well as to drastic changes to daily routines and ways of life that usually bring comfort and stability.
- Typical grief reactions include: shock, disbelief, or denial; anxiety; distress; anger; periods of depression; loss of sleep; loss of appetite.
- Grief may lead to physical reactions such as: trembling or shakiness; muscle weakness; nausea and trouble eating; trouble sleeping; difficulty breathing; dry mouth.
- Grief is different for every individual and every loss; the manner of a death or loss and related personal circumstances can affect how long an individual experiences grief.
- Grief can help an individual make progress toward getting back to typical activities and/or a typical routine; grief can help an individual get back to his or her "normal life" or "normal way of life."
- Complicated or traumatic grief may refer to grief that does not end and does not help an individual make progress toward getting back to typical activities and/or a typical routine.
- Symptoms of complicated or traumatic grief may include: feeling deeply angry about the death or loss; being unable to think about anything except for a loved one; being unable to concentrate or focus; not wanting any reminders of a loved one at all; having nightmares or intrusive thoughts; feeling deep loneliness and longing for the dead loved one; feeling distrustful of others; feeling unable to maintain regular activities or fulfill responsibilities; feeling bitterness about life and envying others not affected by grief; being unable to enjoy life or remember happy times with a loved one.

- For most people, intense feelings of grief will lessen gradually over time, beginning to ease within six months of the loss; however, individuals experiencing complicated or traumatic grief may not feel any reduction of grief over many months or even years; feelings of sadness, anger, and loneliness may even become more intense over time.
- Individuals suffering from complicated or traumatic grief may require additional assistance to help cope with grief.
- Going through the grieving process and healing from loss does not mean forgetting about loved ones who died; individuals may still feel deeply connected to an individual who died, but will also be able to imagine a life without him or her; individuals will start to be reengaged in daily life and reconnected to others; when moving out of or away from grief, individuals may start to experience the following: feeling the pain of loss without resisting or avoiding it; adjusting to a new reality in which a loved one is no longer present; engaging in and forming new relationships with others.
- Children may display grief differently when compared to adults.
- Some children may have a particularly hard time understanding and coping with the loss of a loved one.
- Sometimes children may appear depressed and talk about missing a dead loved one or act out; other times, they may play, interact with friends, and engage in their usual activities.
- Common reactions to grief for children three to six years old may include the following: preschool and kindergarten children may return to behaviors that they outgrew (e.g., toileting accidents, bed-wetting, or being frightened about being separated from their parents/caregivers); they may experience frequent tantrums; they may experience a hard time sleeping.
- Common reactions to grief for children seven to 10 years old may include the following: older children may feel sad, mad, or afraid that the event will happen again; they may focus on details of the event and want to talk about it all the time or not want to talk about it at all; they may experience trouble concentrating.
- Common reactions to grief for preteens and teenagers may include the following: some preteens and teenagers may respond to trauma by acting out (e.g., reckless driving, and alcohol or drug use); they may become afraid to leave the home;

they may reduce how much time they spend with their friends; they may experience feelings of being overwhelmed by their intense emotions; they may experience increased arguing and even fighting with siblings, parents/caregivers, and/or other adults.

- Common reactions to grief for special needs children may include the following: they might have more intense distress, worry, or anger than children without special needs because they often have less control over their day-to-day well-being than other people; children with special needs may need extra words of reassurance, more explanations about the event, and more comfort and other positive physical contact, such as hugs from loved ones.
- Signs that children may need assistance dealing with grief include: changes in their behavior; acting out; not interested in daily activities; changes in eating and sleeping habits; persistent anxiety; sadness or depression.
- To support a child who may be experiencing grief: ask questions to determine the child's emotional state and better understand their perceptions of the event; give children permission to grieve by allowing time for children to talk or to express thoughts or feelings in creative ways; provide age and developmentally appropriate answers; maintain routines as much as possible; spend time with the child, reading, coloring, or doing other activities the child may enjoy.

Post-Traumatic Stress Disorder (PTSD)

Stress and grief, as well as a traumatic event, such as the death of a loved one, can contribute to post-traumatic stress disorder (PTSD). Therefore, health care professionals should be aware of PTSD when considering stress, grief, and hospice care. Specific information regarding PTSD may be found below. The information found below was derived from materials provided by the National Institute of Mental Health (National Institute of Mental Health, 2019).

- PTSD may refer to a psychiatric disorder characterized by intense physical and emotional responses to thoughts and reminders of a traumatic event(s) (e.g., the death of a loved one) (note: the term traumatic event may refer to an event, or series of events, that cause a moderate to severe stress reaction).
- The risk factors associated with PTSD include the following: experienced a traumatic event; witnessed a traumatic event; a close family member or friend

experiences a traumatic event; social isolation after a traumatic event; the sudden, unexpected death of a loved one; history of mental illness; history of substance abuse; stress; prolonged periods of unrelenting stress; consistent feelings of horror or extreme fear; consistent feelings of helplessness.

- PTSD may lead to re-experiencing symptoms, avoidance symptoms, arousal and reactivity symptoms, and cognition and mood symptoms.
- Re-experiencing symptoms - re-experiencing symptoms may refer to symptoms that force or trigger a person to re-experience a traumatic event. Re-experiencing symptoms include the following: nightmares; fearful thoughts; guilty thoughts; flashbacks (note: the term flashback may refer to the re-emergence of memories associated with a traumatic event that manifest a collection of overwhelming sensations, such as emotionally disturbing images and sounds).
- Avoidance symptoms - avoidance symptoms may refer to symptoms that force an individual to alter his or her daily routines. Avoidance symptoms include the following: avoids thoughts related to a traumatic event; avoids feelings related to a traumatic event; avoids individuals related to a traumatic event; avoids places, events, or objects related to a traumatic event.
- Arousal and reactivity symptoms - arousal and reactivity symptoms may refer to symptoms that cause long-term feelings of rage, anger, and stress. Arousal and reactivity symptoms include the following: rage; anger; anger outbursts; feeling stressed; feeling tense; feeling on edge; easily startled; problems sleeping.
- Cognition and mood symptoms - cognition and mood symptoms may refer to symptoms that impact an individual's ability to think, reason, apply logic, and perceive reality that are not related to injury or substance use. Cognition and mood symptoms include the following: forgetfulness; inability to remember important aspects of a traumatic event; negative and distorted thoughts about oneself and others; negative and distorted thoughts about feelings and emotions; negative and distorted thoughts about reality; anhedonia.
- PTSD is typically diagnosed by a health care professional using criteria outlined in the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth edition (DSM-5).

Methods and Strategies to Manage Stress and Grief

- **Acknowledge stress and grief** - often the first step in managing and/or relieving stress and grief is to acknowledge the presence of stress and grief. Individuals should be encouraged to acknowledge the presence of stress and grief, when appropriate. Health care professionals should note that some individuals may choose to acknowledge stress and grief through art, writing, talking to friends or family, cooking, music, and/or other creative practices.
- **Psychotherapy** - psychotherapy, also known as talk therapy, may refer to the use of psychological techniques and/or psychotherapeutic approaches to help individuals overcome specific problems and develop healthier, positive approaches to life. Health care professionals should note that many different forms of psychotherapy may be used to manage stress and grief.
- **Bereavement counseling** - as previously mentioned, bereavement counseling may refer to emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment (Code of Federal Regulations, 2022). Health care professionals should note that bereavement counseling may be provided by a hospice.
- **Support groups** - support groups may be used as an option for those suffering from stress and grief. Support groups can help individuals suffering from stress and/or grief avoid social isolation and other associated complications. Health care professionals should note the following: various types of support groups exist; an individual may participate in one or more support groups at a time.
- **Avoid substance abuse** - individuals should avoid abusing substances, such as alcohol and illicit drugs, when attempting to manage stress and grief. Health care professionals should note the following: substance abuse may be associated with addiction; addiction may refer to the compulsive or uncontrolled use of one or more substances (e.g., alcohol; illicit drugs); substance abuse may be associated with binge drinking; binge drinking may refer to a pattern of drinking that brings an individual's blood alcohol concentration (BAC) to 0.08 g/dl or above; the act of consuming four or more alcoholic beverages per occasion for women or five or more alcoholic beverages per occasion for men; substance abuse may be associated with heavy drinking; heavy drinking is defined as eight or more drinks a week for women; 15 or more drinks a week for men. Health care professionals should also note the following: some individuals suffering from substance abuse

may abuse opioids, such as: prescription opioids, pharmaceutical Fentanyl, or illegal opioids such as heroin; prescription opioids may refer to opioids prescribed by a health care professional to treat pain; anyone who takes prescription opioids can become addicted to them; pharmaceutical Fentanyl may refer to a synthetic opioid, approved for treating severe pain; Fentanyl is 50 to 100 times more potent than morphine; heroin may refer to an illegal, highly addictive opioid drug processed from morphine and extracted from certain poppy plants; an individual suffering from substance abuse involving opioids may be at risk for an opioid overdose, and related death; signs of an opioid overdose may include the following: constricted pupils, loss of consciousness, slow/shallow breathing, choking sounds, limp body, and pale, blue cold skin; the medication naloxone, an opioid antagonist, may be used for the emergency treatment of a known or suspected opioid overdose; naloxone may be used to reverse the life-threatening respiratory depression associated with an opioid overdose; health care professionals may be required or called upon to administer naloxone to patients and/or other individuals suffering from a potential opioid overdose.

- **Take a "time-out," when appropriate** - taking time-outs can help individuals slow down their thoughts, and provide individuals with an opportunity to "recharge their batteries" (note: within the context of this course, the term time-out may refer to a short pause in daily activities, which allows individuals an opportunity to compose themselves and gather their thoughts). Time-outs can be taken throughout the day and may be advantageous to individuals when they feel overwhelmed, overworked, and/or unhappy. Health care professionals should note that time-outs may allow individuals an opportunity to improve upon their state of mind in order to, ultimately, relieve/prevent stress and grief.
- **Engage in journaling** - journaling may refer to the act of keeping a journal or writing in a journal/diary. Journaling can provide individuals with an opportunity to engage in introspective reflection and introspective self-evaluation. Health care professionals should note that journaling can be an opportunity and means for individuals to take a time-out. Health care professionals should also note that journaling can help individuals relieve/prevent stress and grief.
- **Engage in breathing exercises** - breathing exercises can help individuals calm their minds and relieve stress. Therefore, individuals should consider engaging in breathing exercises when working to relieve/prevent stress and grief. Specific information and recommendations regarding breathing exercises may be found

below. The information found below was derived from materials provided by the National Center for Complementary and Integrative Health (National Center for Complementary and Integrative Health [NCCIH], 2021).

- A breathing exercise may refer to the practice of clearing the mind, relaxing, and breath focus.
- Research suggests that breathing exercises may reduce stress, improve mood, and potentially help to improve many health problems and promote healthy behaviors.
- Breathing exercises are generally considered to be safe for healthy individuals.
- The three essential elements of breathing exercises include the following: a quiet location with as few distractions as possible; a comfortable posture or position (e.g., sitting down; lying down; standing); and a focus of attention on the sensations of breath.
- **Engage in physical activity** - physical activity can help individuals remain active, which in turn can help individuals relieve/prevent stress and grief. Therefore, individuals should consider engaging in physical activity to help relieve/prevent stress and grief. Specific recommendations regarding physical activity may be found below. The information found below was derived from materials provided by the U.S. Department of Health and Human Services (U.S. Department of Health and Human Services, 2018).
 - Physical activity may refer to bodily movement produced by the contraction of skeletal muscle that increases energy expenditure above a basal level.

Physical Activity Recommendations for Preschool-Aged Children

- Preschool-aged children (ages 3 through 5 years) should be physically active throughout the day to enhance growth and development.
- Adult caregivers of preschool-aged children should encourage active play that includes a variety of activity types.

Physical Activity Recommendations for Children and Adolescents

- It is important to provide young people opportunities and encouragement to participate in physical activities that are appropriate for their age, that are enjoyable, and that offer variety.
- Children and adolescents ages 6 through 17 years should do 60 minutes (1 hour) or more of moderate-to-vigorous physical activity daily.
- Most of the 60 minutes or more per day should be either moderate- or vigorous-intensity aerobic physical activity and should include vigorous-intensity physical activity at least 3 days a week.
- As part of their 60 minutes or more of daily physical activity, children and adolescents should include muscle-strengthening physical activity at least 3 days a week.
- As part of their 60 minutes or more of daily physical activity, children and adolescents should include bone-strengthening physical activity at least 3 days a week.

Physical Activity Recommendations for Adults

- Adults should move more and sit less throughout the day. Some physical activity is better than none. Adults who sit less and do any amount of moderate-to-vigorous physical activity gain some health benefits.
- For substantial health benefits, adults should do at least 150 minutes (2 hours and 30 minutes) to 300 minutes (5 hours) a week of moderate-intensity, or 75 minutes (1 hour and 15 minutes) to 150 minutes (2 hours and 30 minutes) a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity aerobic activity. Preferably, aerobic activity should be spread throughout the week.
- Additional health benefits are gained by engaging in physical activity beyond the equivalent of 300 minutes (5 hours) of moderate-intensity physical activity a week.
- Adults should also do muscle-strengthening activities of moderate or greater intensity and that involve all major muscle groups on two or

more days a week, as these activities provide additional health benefits.

Physical Activity Recommendations for Older Adults

- As part of their weekly physical activity, older adults (note: the term older adult may refer to an individual 65 years or older) should do multicomponent physical activity that includes balance training, as well as aerobic and muscle-strengthening activities.
- Older adults should determine their level of effort for physical activity relative to their level of fitness.
- Older adults with chronic conditions should understand whether and how their conditions affect their ability to do regular physical activity safely.
- When older adults cannot do 150 minutes of moderate-intensity aerobic activity a week because of chronic conditions, they should be as physically active as their abilities and conditions allow.

Physical Activity Recommendations for Safe Physical Activity

- Individuals should understand the risks, yet be confident that physical activity can be safe for almost everyone.
- Individuals should choose types of physical activity that are appropriate for their current fitness level and health goals, because some activities are safer than others.
- Individuals should increase physical activity gradually over time to meet key guidelines or health goals. Inactive people should “start low and go slow” by starting with lower intensity activities and gradually increasing how often and how long activities are done.
- Individuals should protect themselves by using appropriate gear and sports equipment, choosing safe environments, following rules and policies, and making sensible choices about when, where, and how to be active.
- Individuals should be under the care of a health care professional if they have chronic conditions or symptoms. Individuals with chronic

conditions and symptoms can consult a health care professional or physical activity specialist about the types and amounts of activity appropriate for them.

- **Engage in yoga and/or tai chi** - to build on the previous recommendation, individuals should consider engaging in yoga and/or tai chi to help relieve/prevent stress and grief. Health care professionals should note the following: yoga may refer to a practice that promotes physical and mental well-being through asanas, breathing techniques, and meditation; the term asanas may refer to the physical postures of yoga; tai chi may refer to the practice that involves postures and gentle movements with mental focus, breathing, and relaxation.
- **Adequate nutrition** - evidence presented by the CDC suggests that individuals suffering from stress/grief may benefit from adequate nutrition. Therefore, individuals should be encouraged to take in adequate nutrition when experiencing stress and/or grief. Specific information and recommendations regarding adequate nutrition may be found below. The information found below was derived from materials provided by the U.S. Department of Health and Human Services (U.S. Department of Health and Human Services, 2020).
 - Individuals should follow a healthy dietary pattern at every life stage.
 - From 12 months through older adulthood, individuals should follow a healthy dietary pattern across their lifespan to meet nutrient needs, help achieve a healthy body weight, and reduce the risk of chronic disease (note: the term healthy dietary pattern may refer to the combination of foods and beverages that constitutes an individual's complete dietary intake over time; a description of a customary way of eating or a description of a combination of foods recommended for consumption).
 - Individuals should focus on meeting food group needs with nutrient-dense foods and beverages, and stay within calorie limits - nutrient-dense foods provide vitamins, minerals, and other health-promoting components and have no or little added sugars, saturated fat, and sodium. A healthy dietary pattern consists of nutrient-dense forms of foods and beverages across all food groups, in recommended amounts, and within calorie limits (note: the term nutrient-dense foods may refer to the foods and beverages that provide vitamins, minerals, and other health-promoting components and have little added sugars, saturated fat, and sodium).

- Individuals should note that the core elements that make up a healthy dietary pattern include the following: vegetables of all types; fruits, especially whole fruit; grains, at least half of which are whole grain; dairy, including fat-free or low-fat milk, yogurt, and cheese, and/or lactose-free versions and fortified soy beverages and yogurt as alternatives; protein foods, including lean meats, poultry, and eggs; oils, including vegetable oils and oils in food, such as seafood and nuts.
- Alcoholic beverages - adults of legal drinking age can choose not to drink, or to drink in moderation by limiting intake to two drinks or less in a day for men and one drink or less in a day for women, when alcohol is consumed. Drinking less is better for health than drinking more. There are some adults who should not drink alcohol, such as women who are pregnant.
- Individuals ages two through eight years should take in approximately 1,000 to 2,000 calories per day, depending on activity level.
- Individuals ages nine through 17 years should take in approximately 1,400 to 3,200 calories per day, depending on activity level.
- Male adults and male older adults should take in approximately 2,000 to 3,000 calories per day, depending on activity level.
- Female adults and female older adults should take in approximately 1,600 to 2,400 calories per day, depending on activity level.
- **Connect with other individuals** - finally, and perhaps most importantly, individuals should be encouraged to connect with other individuals to help relieve/prevent stress and grief. Specific recommendations on how to connect with other individuals during times of stress and grief may be found below.
 - Make an effort to talk to others.
 - Invite individuals to call or host conference calls with family members and friends to stay connected.
 - Ask family and friends to share stories and pictures via mailed letters, email, phone, or video chat, or via apps or social media that allow groups to share with each other (e.g., group chat).

- Coordinate a date and time for family and friends to honor a loved one by reciting a selected poem, spiritual reading, or prayer within their own households.
- Develop a virtual memory book, blog, or webpage to remember a loved one, and ask family and friends to contribute their memories and stories.
- Take part in an activity, such as planting a tree or preparing a favorite meal, that has significance to the loved one who died.
- Seek out grief counseling or mental health services, support groups, or hotlines, especially those that can be offered over the phone or online.
- Seek spiritual support from faith-based organizations, including religious leaders and congregations, if applicable.
- Seek support from other trusted community leaders and friends.

Section 3 Summary

Unfortunately, hospice care can lead to stress and grief for hospice care patients, their family and friends, and the health care professionals who care for hospice care patients. Health care professionals should work to manage stress and grief. Methods and strategies that may be used to manage stress and grief include the following: acknowledge stress and grief; psychotherapy; bereavement counseling; support groups; avoid substance abuse; take a "time-out," when appropriate; engage in journaling; engage in breathing exercises; engage in physical activity; engage in yoga and/or tai chi; adequate nutrition; connect with other individuals.

Section 3 Key Concepts

- Hospice care can lead to stress and grief.
- Stress and grief, as well as a traumatic event, such as the death of a loved one, can contribute to PTSD.
- Health care professionals should provide counseling on, as well as utilize, specific methods and strategies to manage stress and grief.

Section 3 Key Terms

Stress - a factor that causes emotional, physical, or psychological tension

Significant life event - any major shift in an individual's life

Burn-out - a syndrome conceptualized as resulting from chronic workplace stress that has not been successfully managed (WHO, 2019)

Muscle stiffness - a state of muscle tightness and contraction that may affect movement

Self-esteem - an individual's subjective evaluation of his or her own value or worth

Social isolation - a lack of social connections that may impact an individual's health and quality of life

Sleep disorders - a group of disorders that affect the way individuals sleep

Insomnia - a sleep disorder characterized by an inability to fall asleep and/or stay asleep

Substance abuse - the harmful or hazardous use of a psychoactive substance, such as alcohol or illicit drugs

Suicidal ideation - thoughts of suicide and/or thoughts of planning suicide

Suicide attempt - a non-fatal, self-directed, and potentially injurious behavior with any intent to die as a result of the behavior

Suicide - a death caused by injuring oneself with the intent to die

Grief - deep sorrow and/or distress that is caused by a traumatic event

Complicated or traumatic grief - grief that does not end and does not help an individual make progress toward getting back to typical activities and/or a typical routine

Post-traumatic stress disorder (PTSD) - a psychiatric disorder characterized by intense physical and emotional responses to thoughts and reminders of a traumatic event(s)

Traumatic event - an event, or series of events, that causes a moderate to severe stress reaction

Re-experiencing symptoms - symptoms that force or trigger a person to re-experience a traumatic event

Flashback - the re-emergence of memories associated with a traumatic event that manifest a collection of overwhelming sensations, such as emotionally disturbing images and sounds

Avoidance symptoms - symptoms that force an individual to alter his or her daily routines

Arousal and reactivity symptoms - symptoms that cause long-term feelings of rage, anger, and stress

Cognition and mood symptoms - symptoms that impact an individual's ability to think, reason, apply logic, and perceive reality that are not related to injury or substance use

Psychotherapy (also known as talk therapy) - the use of psychological techniques and/or psychotherapeutic approaches to help individuals overcome specific problems and develop healthier, positive approaches to life

Addiction - the compulsive or uncontrolled use of one or more substances

Binge drinking - a pattern of drinking that brings an individual's blood alcohol concentration (BAC) to 0.08 g/dl or above; the act of consuming four or more alcoholic beverages per occasion for women or five or more alcoholic beverages per occasion for men

Heavy drinking - the act of consuming eight or more alcoholic beverages per week for women or 15 or more alcoholic beverages per week for men

Prescription opioids - opioids prescribed by a health care professional to treat pain

Pharmaceutical Fentanyl - a synthetic opioid, approved for treating severe pain

Heroin - an illegal, highly addictive opioid drug processed from morphine and extracted from certain poppy plants

Time-out (within the context of this course) - a short pause in daily activities, which allows individuals an opportunity to compose themselves and gather their thoughts

Journaling - the act of keeping a journal or writing in a journal/diary

Breathing exercise - the practice of clearing the mind, relaxing, and breath focus

Physical activity - bodily movement produced by the contraction of skeletal muscle that increases energy expenditure above a basal level (U.S. Department of Health and Human Services, 2018)

Older adult - an individual 65 years or older

Yoga - a practice that promotes physical and mental well-being through asanas, breathing techniques, and meditation

Asanas - the physical postures of yoga

Tai chi - the practice that involves postures and gentle movements with mental focus, breathing, and relaxation

Healthy dietary pattern - the combination of foods and beverages that constitutes an individual's complete dietary intake over time; a description of a customary way of eating or a description of a combination of foods recommended for consumption (U.S. Department of Health and Human Services, 2020)

Nutrient-dense foods - foods and beverages that provide vitamins, minerals, and other health-promoting components and have little added sugars, saturated fat, and sodium (U.S. Department of Health and Human Services, 2020)

Section 3 Personal Reflection Question

How can health care professionals utilize the methods and strategies presented above to help individuals manage stress and grief?

Conclusion

Hospice care is an essential element of health care. Laws, regulations, and requirements that apply to hospice care may be found in Title 42 Part 418 - Hospice Care. Finally, to optimize hospice care, health care professionals should utilize methods and strategies to manage stress and grief.

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