Abstract

Peace, comfort, and dignity are the ideal outcomes of both palliative and hospice care, but it is important to recognize that the two types of care are very different. Palliative care focuses on providing patients with serious illness an optimal quality of life, and it seeks to alleviate both the physical pain and the emotional stress caused by the illness. Hospice care, on the other hand, is focused on maximizing quality of life for those who are in the final stages of a serious illness. While all hospice care is palliative in nature, palliative care includes both hospice care and care for those who will recover from a serious illness. An in-depth study is provided for novice and experienced practitioners in the health field of palliative and hospice care.
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Statement of Need
Health professionals providing palliative and hospice care are best supported in everyday practice through evidence-based resources relevant to clinical practice. Palliative and hospice care involve highly specialized training and skills to care for those with serious health conditions or who are dying.

Course Purpose
To provide nursing professionals with knowledge about palliative and hospice care in various settings.
**Learning Objectives**

1. Describe the four types of palliative care.
2. Identify the main roles on the palliative care team.
3. Describe the interaction between members of the palliative care team.
4. Explain how curative treatments are integrated into palliative care.
5. List the primary benefits of palliative care.
6. Identify the goals of hospice care.
7. Describe the caregiver support provided to patients in hospice care.
8. List the most common locations where hospice care takes place.
9. Describe the level of care provided in hospice care.
10. Identify roles on the hospice care team.

**Target Audience**

Advanced Practice Registered Nurses, Registered Nurses, Licensed Practical Nurses, and Associates

**Course Author & Director Disclosures**

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**Acknowledgement of Commercial Support**

There is no commercial support for this course.

**Activity Review Information**

Reviewed by Susan DePasquale, CGRN, MSN, FPMHNP-BC

**Release Date:** 8/5/2015  
**Termination Date:** 8/5/2018

Please take time to complete the self-assessment Knowledge Questions *before* reading the article. Opportunity to complete a self-assessment of knowledge learned will be provided at the end of the course.
1. **Palliative care is distinguishable from hospice care because**
   a. it is designed to manage the patient’s physical symptoms of suffering, but not psychological, spiritual, social, and emotional impacts that a serious illness can have.
   b. it is curative care, whereas hospice care is not.
   c. palliative care, unlike hospice care, is not limited to those with terminal conditions.
   d. it provides holistic care that improves the patient’s sense of well-being.

2. **Dyspnea describes a condition in which a patient suffers**
   a. from a chronic illness that progressively worsens at the end of life.
   b. from breathlessness and difficulty breathing.
   c. an upset feeling in the stomach, the abdomen twisting or churning.
   d. from a lack of appetite and subsequent failure to eat.

3. **True or False: 71 percent of patients in the final days of life suffer from nausea and vomiting.**
   a. True.
   b. False.

4. **When spending time talking to a palliative or hospice patient, a nurse should**
   a. avoid difficult conversations, such as the patient’s failure to respond to treatment.
   b. talk to the patient about his terminal situation if the opportunity arises.
   c. engage in small talk, pretending that the treatment is working.
   d. leave the difficult conversations to other team members, such as the psychologist.
5. **Hospice is designed to manage the patient’s condition**  
   a. while the patient waits for a potential cure or treatment for his condition.  
   b. until he receives a diagnosis from his physician stating that his illness is incurable.  
   c. when the patient has no family members to care for him.  
   d. so that the transition into death is smoother for the patient and his family.

6. **The skilled nursing facility is beneficial in that**  
   a. it may provide holistic care that a stand-alone hospice center cannot.  
   b. it provides the best possible level of quality of life that is appropriate for each patient.  
   c. the patient may reside in a skilled nursing facility for a longer amount of time when compared to a stand-alone hospice center.  
   d. it provides a better level of care for severe illnesses.

7. **Respite is available as a program so that**  
   a. the main caregiver is able to take time away while someone else cares for the hospice patient.  
   b. family members of a high-need patient may have time to rest and recharge.  
   c. a patient in hospice home care may go to an inpatient healthcare facility for a short time.  
   d. All of the above.
8. **When managing pain for the palliative patient, the nurse**
   a. may be asked to administer much larger doses of prescribed drugs than what he or she is used to giving.
   b. should be careful not to administer larger amounts of pain medication for fear of the patient becoming dependent on the drug.
   c. should leave it to the doctor to advocate for higher doses of pain medication if the current dose is not effective enough.
   d. All of the above.

9. **Hospice care is a program designed**
   a. to care for terminally ill patients and their families.
   b. to provide support and warmth from friends and caregivers for the terminally ill patient.
   c. so that the patient may make the most of the life he or she has left.
   d. All of the above.

10. **True or False**: Family members of the hospice patient should not be attended to by the hospice care team and should not receive counseling.
    a. True.
    b. False.
Introduction

Palliative and hospice care are two models of care that have been developed to provide support and comfort for patients struggling with significant medical conditions. Hospice and palliative care seek to provide comfort measures and symptom control for this special patient population. Some patients who receive these services may continue to seek curative measures and may hope for a positive outcome in which they survive their illnesses. Alternatively, there are other patients who have determined that their conditions are terminal and they desire to have comfort measures in place until the end of life.

Both palliative and hospice care are connected in that they utilize many of the same measures and the same team members, but they are two different models of care. Ultimately, though, these two models of care seek to offer services and holistic care that improves the patient’s sense of well-being, and that also serves the family during a very difficult time.

Palliative Care

Palliative care is comfort care. It seeks to help the suffering patient find peace and relief through care measures that focus on illness management and control of symptoms. A patient who develops severe illness and who is suffering from symptoms of the condition can benefit from palliative care. The palliative care system is designed to manage not only the patient’s physical symptoms of suffering, but also to help the patient cope with the psychological, spiritual, social, and emotional impacts of having a serious illness.

Suffering occurs as a form of tolerating a hurtful event, usually with difficulty. Suffering is defined in the Oxford Dictionary of English as “the
state of undergoing pain, distress, or hardship.”

Although many people view suffering to occur as a result of pain, this definition includes the various other forms of strain or difficulty that can go along with pain or that may be present in spite of pain. A patient who needs palliative care may be in pain, but the patient may also struggle emotionally and physically with feelings of distress. The difficulties faced through chronic illness cause hardship that requires strength and endurance that not all people possess. It is therefore essential that palliative care nurses recognize these propensities for suffering and seek to step in to assist patients who are struggling with pain, distress about their situations, and with overcoming the hardships involved.

It is important to remember that each person that receives palliative care has a story: a serious illness that requires comfort measures and pain control. The patient may or may not want to discuss the story in detail and may exhibit a certain amount of denial about the situation, but it remains. The nurse who cares for a patient who needs palliative care services must recognize that each situation is different. Each person has an individual method of coping with suffering and difficult circumstances, and not all patients will respond in the same manner, even if they have similar diagnoses.

Palliative care refers to care given to alleviate symptoms and provide comfort for the patient. It is not curative care, although the patient may seek treatments aimed at curing his condition. A person may receive palliative care and may eventually be cured of his or her condition; palliative care is not limited to those with terminal conditions. Alternatively, patients who receive hospice care may also receive palliative care even though they are not receiving curative treatments for their conditions.
Palliative care may also be utilized to manage symptoms that occur because of some types of treatments. For example, chemotherapy administered for the treatment of cancer has been known to cause negative side effects, including nausea, vomiting, and mouth ulcerations. Palliative care could be administered as a form of managing these negative side effects. The palliative care may help the patient to tolerate more chemotherapy treatments and to undergo treatments for a longer period because the side effects are being managed. In this way, palliative care is not curative but comforting while the patient seeks treatment for his or her condition.

Significant illness, whether it is considered terminal or if it has a potential cure, can be extremely stressful for the patient and the patient’s family. An illness that causes pain significantly limits a patient’s ability to perform self-care and to function within a normal capacity. Other symptoms that may be related to the illness, such as nausea or constipation, can also impact quality of life when the patient spends much of his or her time managing uncomfortable symptoms and possibly seeking treatment for illness.

The emotional impact and stress caused by illness is even more debilitating when the patient struggles with both physical and emotional symptoms. The discomfort of symptoms because of illness, the financial burden of paying for treatments, and the fear of an unknown future are just some of the elements contributing to a patient’s stress. Palliative care seeks to control some of the symptoms of illness, which can relieve some of the stress associated with the condition. For example, a patient suffering from cancer who is experiencing chronic pain may be unable to focus on any other activities and may be feeling significant stress about his or her condition. When the patient receives palliative care and is able to obtain improved pain
control, the patient may feel some stress relief and may be better able to focus on normal tasks and responsibilities.

**Holistic Care For Palliative Patients**

While palliative care is considered a specialized form of medical care provided for comfort and relief, it also consists of various forms of care delivery. Different members of the patient’s care team may participate in various aspects of palliative care for the patient, whether it is physical care, emotional or spiritual support, or help for practical aspects of day-to-day living. Each type of care delivered is designed to provide holistic care for the patient’s unique treatment needs and those of family, as well as improve the patient’s quality of life during this time.

**Physical Care**

Physical care of the palliative patient is one element of providing holistic care. It may be the most recognized form of care delivery, but it certainly is not the only type. Physical care often focuses on the patient’s physical health: the management of illness, control of symptoms, and pain management. It may involve helping the patient to feel better during periods of suffering from side effects of certain kinds of treatments. It could mean providing education and comfort measures when the patient is nauseated or fatigued as a result of treatments, the illness itself, or in response to the situation as a whole.
When faced with a significant illness, the patient may be forced to consider those types of physical losses that occur as a result, whether they are loss of a body part, an inability to continue functioning in a method that is familiar and routine, or even eventual loss of life if the patient has a terminal condition. For example, a patient with breast cancer may receive palliative care to help keep comfortable during a period during the illness when the situation is extremely painful and debilitating. If the patient underwent a radical mastectomy as part of treatment for breast cancer, the physical pain caused by the surgery requires the palliative care nurse to provide comfort measures as well as to address the patient’s level of individual coping due to altered body image that follows such a surgery; the loss of a breast and change in identity the patient may experience as a result of the surgical treatment for breast cancer.

The physical care provided for the patient during palliative care often seeks to control the physical symptoms the patient is experiencing. These physical symptoms may also affect the patient’s emotional or spiritual health. Because of this, when physical symptoms, such as pain, nausea, or anorexia are well managed, the patient may be more likely to cope with having an illness and maintain his or her psychological or emotional health.

**Pain Management**

Pain management is a common element of physical care for the palliative care patient. Pain is a common theme among many kinds of illnesses and part of providing support and easing suffering involves recognizing the impact of pain, and taking steps to control the amount of pain the patient experiences. Pain is not only physically uncomfortable for the patient but it imparts a certain amount of psychological and spiritual distress for the patient as well.
The American Society for Pain Management Nursing has issued a position statement that describes the role of nurses when caring for palliative or hospice care patients, which states that nurses who care for these populations of patients should be competent in providing pain control throughout the continuum of the patient’s life. The statement goes on to say that these nurses have an obligation to assist patients with controlling their pain and other uncomfortable symptoms associated with their conditions by using pain medications at effective doses, and by advocating for these patients when the pain medication is not effective enough to offer relief and comfort.²²

Pain management is essential to improve quality of life for the palliative or hospice care patient. Effective pain management has been shown in some cases to actually extend the length of a patient’s life. Palliative care patients, particularly those who are nearing the end of life, require greater amounts of pain medication when compared to other patients who have pain for different reasons, such as when recovering from surgery. The nurse who provides pain medication to a patient for palliative care may be administering much larger amounts of drugs, a fact that has been proven to be ethically justified.²² A caregiver of a patient who needs pain medications for palliative care should not back away from administering larger amounts of pain medication for fear of the patient developing tolerance for the drug or becoming addicted to the medication.

Patients and their families may also fear pain control measures because of a belief that if the patient requires pain relief then it’s an indication their condition is somehow progressing. Although pain has been shown to be present in a large percentage of patients receiving palliative and hospice care at the end of life, an increase in pain does not necessarily signify a
worsening of the patient’s condition. Additionally, some patients or families may believe that pain is part of the disease process and that it is something to be accepted; they may avoid asking for pain control measures when this belief is in place.

A tenet of palliative care services is that a patient who receives palliative care has a right to treatment and management of his or her pain. The patient should be involved in decision-making regarding of pain control methods, including discussion of pain medications, the potential for adverse side effects, and non-pharmacological interventions. The patient should be part of the interdisciplinary team; if possible, to discuss these interventions and to help the team to best determine what therapies and techniques are working and what should be changed.

Physicians, nurses, and others on the team who provide pain management must stay current with evidence-based practices that have been shown to assist patients in this special population with pain control. Coordination of prescribed medications between the members of the interdisciplinary team is imperative to maintain a schedule of drugs and to avoid overlapping of medications. Because the patient may be receiving much larger amounts of pain medications, it is possible that prescriptions could overlap and the patient could end up receiving either inadequate or too much pain medication. Proper communication between caregivers and providers ensures that the patient’s prescriptions for pain and other symptom management are well controlled.

Pain medication administration for severe pain among palliative care patients differs slightly when compared to treatment of acute pain in the hospital or clinic setting. Although pain medication may be administered through
various methods, including oral, transdermal, or parenteral administration in either setting, pain medicine is typically administered on a schedule around the clock in palliative care, rather than being given on a *prn* (as needed) basis as in the case with acute care. In other words, most palliative care patients benefit from consistent dosing of pain medications given at regularly scheduled times and should not ordinarily have prn orders for pain medication.

Patients who are treated at home should be given orders for pain medication that can be easily administered and managed by the patient or the patient’s family in the home. This typically means the oral route of medication, but other modes of drug administration may also be available.

A patient may experience some episodes of breakthrough pain that may be refractory to the standard treatment developed for the patient. The team should have a plan in place for medications and methods designed to control breakthrough pain as well, which can be debilitating and unbearable for the patient. When breakthrough pain occurs, it is necessary to have rescue or prn medications available for this type of pain control.

Pain control is most often achieved with the administration of opioid analgesics, but the type and amount to give varies between patients. These drugs may be supplemented with non-opioid pain medications, such as acetaminophen or non-steroidal anti-inflammatory drugs, as well as with other adjuvant drugs, including antidepressants, antihistamines, or muscle relaxants, to assist with symptom control.

Because the patient may be receiving frequent doses of opioid medications, there is always the potential for side effects, which the interdisciplinary team
must consider and have a plan in place to manage as well. The most common side effects from opioids include constipation, nausea, urinary retention, pruritus, drowsiness, and confusion. When these side effects occur, the caregiver may need to provide medications to counteract the effects or engage non-pharmacological methods to improve the patient’s comfort.

Just as there are multiple types of pain that the patient may struggle with while enduring an illness that warrants palliative care, there are also multiple methods of pain medication administration and control. Management of the patient’s pain must be considered on a continuous basis by the interdisciplinary team. The team must discuss and confer on a regular and frequent basis to ensure adequate control and relief of side effects or complications of the illness or the drugs used as treatment. Because pain is so prominent in this population of patients, physical care of pain control is one of the most common and frequent types of care given as part of palliative care and symptom control.

**Dyspnea**

Dyspnea describes a condition in which a patient suffers from breathlessness and difficulty breathing. Some have described it as a feeling of suffocating or simply not getting enough oxygen. Dyspnea is a symptom affiliated with some types of chronic disease in which a patient may receive palliative care, such as with chronic obstructive pulmonary disease, heart failure, or cancer. Because the ability to breathe is central to life, a patient may struggle and feel significant distress if he or she has dyspnea, feeling as though fighting for every breath, which seriously hampers the patient’s quality of life.
Dyspnea may also be accompanied by fear and anxiety, particularly if the patient feels unable to breathe in enough air or of suffocation. The nurse’s role in caring for a patient who has dyspnea as a result of a disease process is to not only manage the breathlessness and improve the patient’s gas exchange, but also to support the patient in his or her fears and anxiety related to having breathing problems. Dyspnea is known not only as a physical symptom related to chronic disease, but it also creates a psychological impact on the affected patient in that it can cause anxiety, it can lead to depression, and it impacts the patient’s welfare when the patient feels no longer able to participate in routine activities, attend social gatherings, or maintain relationships because of having breathing difficulties.

Dyspnea can interfere with a patient’s ability to perform routine activities or to participate in interests that were once normal activities of daily living. Alternatively, dyspnea can develop quickly and can have a rapid onset, requiring immediate care and treatment to prevent worsening of the patient’s condition. Overall, dyspnea varies in its intensity for a person struggling with chronic illness but tends to progressively worsen over the course of the disease as a patient draws closer to the end of life.21

While working with a patient who suffers from dyspnea, the initial role of the healthcare provider is to determine the extent that the symptom has on the patient’s ability to function. There are several functional scales available that can determine dyspnea severity and that can help the nurse to decide how much the breathing problems are impacting the patient’s level of functioning, as well as how much distress dyspnea is causing the patient. Physical assessment of the patient can also reveal the extent that dyspnea has on the patient’s physical condition; the patient may present with
symptoms that indicate poor gas exchange, such as pale or cyanotic skin tones, clubbing of the nail beds, and anxiety or mental status changes.

If a patient presents with acute dyspnea that was previously nonexistent, diagnostic testing may be warranted to rule out a potential health complication. The patient may have previously suffered from other symptoms associated with his or her illness, even if dyspnea was not one of the symptoms. The acute development of dyspnea that causes breathlessness and rapid change in the patient’s oxygenation warrants an examination and diagnostic testing to rule out physical problems that could have developed because of the patient’s illness or due to another condition or injury, such as a pneumothorax, pneumonia, or myocardial ischemia.

Pharmacological interventions for the management of dyspnea include administration of such drugs as opioids to reduce distress, provide pain relief, and to relieve breathlessness. Oxygen, while frequently administered, has not been proven to provide relief of dyspnea when compared to room air, however, administration of oxygen may help some patients to feel more comfortable.\(^2\) The patient would most likely benefit from a program of pulmonary rehabilitation, which involves exercise, education about breathing issues and practice for improving breathing techniques, and support for patients and their families of whom dyspnea is a common problem.

**Nausea**

Nausea is a very uncomfortable feeling and, unfortunately, it is commonly associated with some illnesses that are considered chronic or terminal. Nausea is an upset feeling in the stomach; a feeling of it being unsettled or of the tissues in the abdomen twisting or churning. It may be accompanied by dizziness or lightheadedness, as well as the feeling of needing to gag or
vomit. Nausea and vomiting can be so intense and common for some people that it prevents normal activity; a patient may fear leaving the house because of the near-constant feeling of nausea and may not feel able to participate in routine activities because of it.

The condition of intractable nausea can also lead to severe complications, including dehydration with repeated vomiting, erosion of the esophageal tissue, and the risk of aspiration. The patient may suffer from malnutrition if unable to keep food down after eating and instead vomits. Additionally, nausea can lead to anorexia in that the patient may lack an appropriate appetite at all.

As death approaches, nausea and vomiting seems to become more common. According to one study noted in the *Annals of Palliative Medicine*, in patients receiving palliative care, thirty-six percent complained of frequent nausea and vomiting when first receiving treatment; and, this number increased to seventy-one percent of patients who were within their final week of life.19 This fact commands control and restraint of this uncomfortable symptom, which becomes even more important when quality of life in the final days and hours is imminent.

Various elements lead to increased nausea and vomiting when associated with disease and while receiving palliative care. Cancer patients who receive chemotherapy frequently complain of nausea as a side effect of treatment. Opioid-induced emesis is another frequently cited cause; a patient who suffers from chronic pain as a result of illness may complain of nausea as a side effect of the drugs taken for pain control. Although the patient may have less pain, opioid-induced emesis causes a secondary state for which patient must then cope. Other examples of known causes of nausea include
side effect of radiation treatment, and nausea caused by such conditions as Meniere’s disease, mesenteric ischemia, constipation, and drug toxicity.

One portion of providing control and relief of nausea during palliative care is to avoid contact with the offending agent or situation. For many, this is not possible, nor is it desirable. A patient with cancer who is seeking curative treatment through chemotherapy often continues this line of treatment despite its nausea-causing side effects. In many cases, patients are willing to continue with a treatment if it causes adverse effects for the hope of managing the disease. Alternatively, there are some situations in which the offending agent could be avoided or the provider could find a substitute that may produce the same benefit, yet without side effects. An example of this would be finding an appropriate method of pain control that still provides pain relief without the side effect of nausea if the current medication the patient is taking is causing too many adverse symptoms. Other items that may need to be avoided include environmental stimuli that can trigger nausea and make the patient feel worse, such as consumption of fatty or greasy foods or exposure to tobacco smoke.

When avoiding a substance that causes nausea is not possible, the next step to improve the patient’s quality of life is to administer medications that have antiemetic properties and that can reduce these difficult symptoms. Antiemetic drugs are targeted toward specific receptors that regulate their actions and reduce nausea symptoms. Some types of drugs used as antiemetics include antihistamines, anticholinergics, phenothiazines, cannabinoids, and sedatives. The type of drug to use depends on the patient’s condition; an oral agent may not be effective if the patient cannot keep food down without vomiting. However, many agents can be effectively
administered via intramuscular injection, intravenously if the patient has an intravenous access, or transdermally as a skin patch.

Some patients may take medications that prevent development of nausea, but these drugs have typically been shown not to be effective once nausea actually develops. Additionally, some drugs that are effective for nausea caused by specific circumstances are not effective in other cases. For example, a drug used for the treatment of motion sickness may not necessarily be as effective when managing nausea related to chemotherapy. Control of nausea and vomiting may develop after a period of trial and error to determine what is most effective, whether it includes administration of medications, avoidance of certain agents or environmental triggers, or implementation of complementary therapies, including relaxation, aromatherapy, or distraction.

**Anorexia and Wasting**

In most cases, anorexia and wasting is not the cause of the patient’s health condition; rather, it develops as a result of symptoms from the disease. Anorexia develops from a lack of appetite and subsequent failure to eat. It can occur from such factors as nausea or electrolyte imbalance and can cause such complications as wasting, malnutrition, poor circulation, and cognitive changes. Often, a patient who receives palliative care develops transient anorexia as a result of his or her condition, but the patient’s family is much more concerned about the lack of eating
than the patient. The family may believe that if the nurse could get the patient to eat, the patient’s condition would actually improve. In reality, the patient may feel better from eating and food intake may avoid wasting disease, but the underlying condition is typically not treated or cured because of food intake.

Anorexia becomes much more common as the patient gets closer to the end of life. In fact, almost every patient cuts back on food intake in the last few weeks or days of life. Before the patient reaches this point, however, the nurse may promote the patient’s food intake by incorporating several measures into patient care. The patient may be more likely to eat if the foods offered are palatable or taste good. The nurse or family may offer the patient his or her favorite foods or those that they know are enjoyed more than others. If chewing or swallowing is a problem, the patient may be able to better tolerate soft foods that naturally have a spongy texture. This is an alternative to offering the patient pureed foods or those whose content has been altered. For example, a patient may normally enjoy roast beef but chewing the meat may become too difficult.

The patient may have a further aversion to the food if a caregiver, in an effort to ease his or her ability to eat, purees the food, such as meat, in a blender and creates a very soft, semi-liquid form of the food. Since food is normally not prepared in this method, the patient may have difficulty eating the food when the consistency has changed, even if the patient had previously enjoyed the food.

Other efforts that may enhance food intake include offering sweets, as sweetened foods are often easier to eat and to tolerate when compared to bland or salty foods. Furthermore, the patient may want to avoid strong-
smelling foods, including those that are very spicy or that contain onions or garlic, as well as greasy, fatty, or fried foods.

If the patient is unable to take in food by mouth and has developed complications of anorexia, such as malnutrition, electrolyte imbalance, or significant weight loss, the patient may benefit from the addition of appetite stimulants or prepared formula products. Appetite stimulants are typically given as medications that work by increasing an individual’s hunger, potentially increasing food consumption. Certain drugs may work better in some situations compared to others and depending on the patient’s diagnosis. For example, megestrol (Megace®) is an appetite stimulant typically given for correction of wasting associated with autoimmune deficiency syndrome (AIDS), while dexamethasone is a steroid that has been shown to improve appetite in patients with cancer. Other examples of appetite stimulant medications include dronabinol (Marinol®) and cyproheptadine (Periactin®).

Liquid supplements may also be used when a patient is suffering from malnutrition and cannot take in enough calories and nutrients. Liquid supplements can be administered orally and purchased over the counter or with a medical provider’s prescription. These types of preparations, sometimes referred to as shakes or supplements provide extra calories, vitamins, and nutrients that could be beneficial for some patients. The downside of their use is that they can be expensive and many patients find
the taste to be boring after a while, which further increases the risk that they will discontinue use prematurely.

A formula preparation may also be administered through a feeding tube if the patient is unable to eat or if he or she needs more calorie support than can be obtained through food alone. Administration of this type of preparation requires a feeding tube to be placed, which could be a nasogastric or orogastric tube, or a gastrostomy tube. Obviously, verification of tube placement is required prior to formula administration and having a feeding tube in place can be uncomfortable for some people. The decision about what type of feeding tube to use is based on the patient’s condition and the length of time that feedings will be necessary. Furthermore, a patient may struggle with having a feeding tube in place, which defeats the purpose of promoting quality of life through palliative care.

If a patient is uncomfortable and unhappy with a nasogastric tube secured to his or her face, the patient may have a harder time accepting nutrition in this manner. Another option involves placement of a gastrostomy tube that requires a surgical procedure, which is initially painful. Deciding on the best type of feeding tube to use will require frank discussion between the interdisciplinary team and the patient and his or her family about what is best.

When formula feedings are not tolerated and there are no other options for introducing calories and nutrients for the patient, parenteral nutrition may be considered. This option typically requires placement of a central venous catheter for fluid administration; but once in place, the patient could receive parenteral nutrition for a long time.
Total parenteral nutrition (TPN) typically contains a certain amount of calories from dextrose, as well as protein, vitamins, electrolytes, and trace minerals. Extra fat could also be added through lipid emulsion, if needed. The downside of using TPN is that the dextrose content places the patient at risk of hyperglycemia. Additionally, the patient may have problems with electrolyte imbalances even when trying to correct levels through TPN administration. The presence of a central line also places the patient at greater risk of infection when the line is used for TPN administration. As with other methods of preventing malnutrition and weight loss in the palliative care patient, TPN has benefits and disadvantages. The ultimate goal of increasing nutrient intake for the patient can be met with a thorough understanding of the possibilities for care and the considerations of the best possible options for the patient’s comfort.

**Dehydration**

Patients who suffer from severe illness that may or may not be intractable to treatments often develop dehydration, particularly toward the end of life. Dehydration may develop due to a number of physical symptoms associated with a patient’s illness, including nausea and vomiting, chronic diarrhea and malabsorption of fluids, poor oral intake of fluids, gastrointestinal obstructions, infection, and some types of medications, such as diuretics.  

The nurse’s role in managing dehydration and preventing its complications involves supporting the patient’s intake of fluids. Encouraging oral intake first, if possible, and then moving to intravenous fluid administration is done if required and prescribed by the medical provider. Some patients have difficulty with oral intake of fluids due to swallowing problems, mouth sores, or cognitive changes. The nurse can enhance oral fluid intake by providing good oral care to maintain integrity of the mucous membranes in the mouth.
and by helping the patient to drink fluids, if possible, or consume ice chips or foods that contain liquid, such as some types of fruits.

In some cases, despite attempts to increase oral intake, parenteral fluids are necessary to prevent severe hypovolemia and to maintain patient comfort. Severe dehydration can cause cognitive changes in the patient and administration of parenteral fluids may help to relieve some cognitive changes and may keep the patient more involved in his or her care by improving communication. Correction of dehydration can also improve patient comfort by ensuring the mouth and mucous membranes are not overly dry or cracking, improved circulation, which supports organ and tissue perfusion, facilitation of productive coughing, and promotion of bowel function.

Intravenous administration of fluids is done by prescription after considering the most appropriate route of correcting dehydration for the patient. In some cases, a patient who develops dehydration as a result of a disease process may not be treated with intravenous fluids. Donnelly, author of *Dehydration in the Dying Patient* (2005), contends that there is a difference between a patient who is dying because of dehydration and a patient who is dying and who has developed dehydration.18

In a case when a patient is terminally ill and is dying, providing fluid rehydration is not always part of palliative care and could cause complications, such as urinary incontinence, tissue maceration, and potential fluid overload. These complications obviously go against the goals of palliative care.
As a result, the decision of whether to correct dehydration depends on the patient’s state and the decision is made after thorough discussion with the patient and the patient’s family as to the best course of care. Management of dehydration through intravenous fluids can sometimes present an ethical dilemma that healthcare staff must recognize and manage. Ultimately, when providing palliative care, the use of intravenous fluids is done to promote comfort and to relieve symptoms for the patient; the type of fluids, the rate of delivery, and the use of other intravenous medications are considered on a case-by-case basis.

**Surgery**

A surgical procedure may be part of the care plan for a palliative patient. Because the goal of palliative care is to improve a patient’s quality of life and to relieve suffering, these outcomes may be accomplished by surgery to provide pain control, extend the patient’s life by removing tumors or other tissue that is contributing to the illness, or make the patient more comfortable in the long run. Whether or not the surgical procedure is designed to be curative, surgery as part of palliative care remains a valid form of treatment and promotes patient quality of life. Surgery is not just relegated to early stages of disease, but can also take place during even late stages of illness and can still promote quality of care for the affected patient.¹⁴

An article by Krouse (2009) entitled *Future Directions in Palliative Surgery* stated that palliative surgery can be best considered when it is divided into two categories, listed as:¹⁵
1. Procedures performed near the end of the patient’s life that are designed to improve patient function and that could lengthen the survival time.

2. Procedures performed for patients who do not have a terminal prognosis that are done to relieve suffering of problems acquired as a result of the patient’s condition.

The types of surgical procedures that fall into these categories can vary widely based on the exact nature of the surgery. The categories may overlap slightly when considering what kind of surgery the patient is undergoing; for instance, a patient who has a terminal prognosis and who undergoes a lung tumor resection because of a lung cancer diagnosis may still have improved breathing capabilities during the time left to live. Other examples of palliative surgical options for patient symptom control include a bowel drainage of fluid from the abdomen or lung fields that develops and causes dyspnea or pain, gastrostomy tube placement to facilitate easier feeding methods, surgical repair of fracture that has occurred as a result of the disease process, tumor removal to rid the body of a source of cancer, or amputation of a diseased and non-functional painful extremity. The surgeon may also perform some types of procedures that are meant to support treatment processes provided during palliative care, such as a cut-down for placement of a central venous catheter or biopsy to identify malignant tissue.

Palliative surgery may or may not focus on extending the patient’s life; it is instead intended to improve the patient’s quality of life, regardless of how much time the patient has to live. While surgery may cause some pain or
disability for a limited time, the goal of surgery is to perform an act that ultimately decreases the amount of suffering the patient experiences.

As with any type of surgical procedure, there are potential issues that can risk the health of the patient, such as with administration of anesthesia for the surgery. With a palliative care patient, however, there may be further ethical issues that are not always well understood prior to the start of the procedure. For example, a patient may be having surgery as part of palliative care but is not a hospice patient. However, during the surgery, if the patient’s heart stops and the patient goes into cardiac arrest, the surgeon and healthcare providers on the case have a duty to resuscitate the patient unless the patient has an advance directive saying otherwise. Without an advance directive that specifies the patient’s wishes regarding lifesaving measures, the caregivers face something of an ethical dilemma, particularly if the palliative surgery is being performed at a late stage of the patient’s illness.

Another element to consider related to palliative care surgery is the effect of the surgery on the patient’s quality of life during the time that the patient has left to live. A patient who undergoes a very painful surgical procedure in order to extend life by a couple of months may end up spending their last months in pain while recovering from surgery. This certainly is not the case in most surgical procedures, but it must be considered as a potential dilemma. It is this situation that brings back to mind the fact that palliative surgery is for improving quality of life and potentially reducing symptoms, not necessarily prolonging life. If a procedure prolongs a patient’s life for a time but also causes more suffering due to undergoing the procedure, the patient and the surgeon will need to discuss the ramifications of the procedure to determine if it is the best option.
Some patients may have other health problems that limit their capabilities to undergo surgical procedures. These problems all must be considered and carefully thought out before going ahead with a surgical procedure. Some other factors to consider include the patient’s mental status before surgery, including a change in cognitive status that has developed as a result of the illness and that can affect the patient’s decision-making capacity; the wishes of family members and their level of involvement in the patient’s care, and whether the patient would otherwise benefit from a different procedure that would have similar results as surgery but that would not require the same commitment as undergoing the surgical procedure. These and other issues may surface when considering palliative surgery. They all must be considered and thought through carefully before going forward with surgical decisions.

Despite these issues, palliative surgery remains a valid option for many patients as part of pain and symptom control. Because the goal of palliative care is to improve the patient’s quality of life and because surgery has been developed as a specialty that is a suitable treatment option, palliation and surgery can go together as options for patient treatment. The patient who considers palliative surgery, as part of his or her care, has many factors to consider but could ultimately benefit from a surgical procedure and could have enhanced quality of life while battling the illness.

Beyond the most prominent illness symptoms of pain, nausea, gastrointestinal issues, and complications that require surgical intervention, there are a multitude of other physical symptoms the patient may experience during the course of palliative care. With each situation, the nurse or caregiver providing physical care must recognize what constitutes a problem and what requires further intervention. Other symptoms that may
need to be managed include sleep problems and insomnia, pruritus, constipation, chronic hiccups, and mental status changes. Management of these and other symptoms that occur is all part of the comprehensive physical care that is required and that must be carefully considered when addressing the physical needs of palliative care patients.

**Emotional And Spiritual Care**

Palliative care is more than providing physical care of a patient’s symptoms. The effects of illness can cause emotional distress for the patient and the patient’s family members, and a significant part of palliative care is providing support and emotional encouragement during this stressful time. In order to best promote quality of life for the patient, the caregiver focuses on enhancing the patient’s well being and helps the family to remain optimistic and positive in the face of illness. When the patient’s emotional health has been strengthened, he or she is more likely to face eventual physical symptoms with courage, regardless of the end result of the illness.

The nurse who provides care for the palliative patient often develops a relationship with family members in the course of providing holistic care. While being aware of and supportive of most aspects of the patient’s life, the nurse attends to the patient’s medical condition, feelings and emotions about the patient’s illness and symptoms, and whether the condition is causing psychological problems. Talking about emotions and feelings can lead to a sense of vulnerability for some individuals, and the patient may or may not feel comfortable sharing deep feelings associated with being ill, often exacerbated by feelings of weakness because of the condition itself. The nurse who provides care in this situation should maintain an open and accepting position and be someone the patient can trust with some of the difficult feelings and emotions.
Part of palliative care treatment is discussing those aspects of the patient’s illness that are causing emotional suffering and that are difficult for the patient to accept and as part of their life. The emotional toll of suffering can impact a patient’s ability to accept and cope with the treatments required for the patient’s condition, ability to relate to others, and personal acceptance of the situation and how it impacts the patient’s own self-perception. This part of treatment may involve spending time with the patient to listen, and to have ongoing conversations and discussions about not only the patient’s illness and condition, but also about other things in life that are important to the patient, such as family, friends, home, or job.

It may help to talk with the patient about how illness or the experience of being ill is affecting the patient’s feelings about his or her life and relationships with others. The nurse could ask the patient if a change has been noticed in the patient’s emotions or an overall difference in his or her emotional state, such as an increased propensity toward anger and outbursts, periods of breaking down into tears and crying, or lack of emotional response about the situation at all.

For many people who use palliative care, emotional suffering develops because of a response to the actual loss or even the perceived threat of a loss. The idea of loss associated with significant illness is very real, whether or not the patient has a terminal condition. The threat of loss causes the patient to think about consequences of the condition and its effects on the patient and those important to the patient. This can take a toll on one’s emotional health.

When a patient undergoes procedures and treatments in addition to palliative care, he or she may struggle with body image disturbance or self-
acceptance of the patient’s situation because of the effects of the treatments. A patient who has hair loss because of cancer treatments may have a difficult time accepting the new look but may also struggle with feelings of shame, embarrassment, and self-doubt because of the condition itself. These and other feelings must be discovered and managed through therapeutic intervention designed to handle the patient’s emotional health during palliative care treatments.

Sometimes, there is nothing more important to a patient than to feel as if someone is listening. This means taking the time out from a busy schedule and stopping to sit with a patient if he or she needs to talk about how having an illness affects the patient, and resulting feelings of being in that situation. Patients often feel as if their healthcare providers or nurses do not spend enough time listening to them, often because they are too busy or preoccupied to spend adequate time helping others to meet the emotional needs of the patient.

Unfortunately, many hospitalized patients, whether they are receiving palliative care or not, do not receive enough one-to-one care in which the nurse or other caregivers are able to spend adequate time with them. Often an individualized approach to care that offers time to sit with the patient and talk about the patient’s feelings and attitude is replaced by nursing interventions for physical ailments and the focus on technology and medical equipment used for patient care. The approach to holistic care has started to change the idea of the nurse practicing physical care at the bedside and is starting to evolve into an approach that considers all of the needs of the patient. Through this care approach, the patient who needs more emotional support than physical during a particular visit may spend time with the caregiver concentrating on the patient’s emotional health. This greater focus
on the emotional status of the patient takes into account the person as an individual with multiple needs, rather than someone who needs healthcare services to manage a physical illness.

The illness or injury that requires palliative care and the recovery process for the patient often instills a variety of emotional responses, many of which can be debilitating and troubling. The emotional elements of palliative care require attention to these feelings and how psychological responses can impact the patient’s healing or participation in palliative care. Some types of emotional responses the nurse may note in the palliative care patient may include fear, anger, grief, anxiety, or guilt, however, each case is different and there may be many others.

Nurses are in a key position to help patients overcome affective disorders and emotional issues that develop as a result of severe illness. A meta analysis in the *Journal of Advanced Nursing* describes studies of communication between nurses and palliative care patients as falling into one of two categories:24

1. The effects of the structure and process of how nurses interact with patients.

2. How nursing interactions with patients can affect change.

When spending time talking to patients about their emotional health, nurses should not avoid the difficult parts of conversation that may include sharing uncomfortable topics, such as the patient’s failure to respond to a certain type of treatment. For example, a patient who is seeking curative treatment for lung cancer who does not respond to the latest round of radiation
therapy may feel discouraged and hopeless about his or her condition. Although it may be difficult, the nurse must communicate with the patient about how he or she feels about the situation, rather than attempting small talk or pretending that the problem doesn’t exist.

At times nurses feel uncomfortable talking about subjects to which they cannot change, or do not know what to say. The nurse in this situation may feel ill at ease because the nurse has no control over the patient’s outcome and feels upset that the patient is not getting better. Instead, a focus on the importance of the nurse’s caring presence, of simply being with and listening to the patient, is what best supports the patient during the patient’s course of care and treatment outcomes. This is the basis of emotional support and this process of listening and being present can positively affect the emotional needs of the patient, even though the nurse has no control over whether or not the treatment is successful.

When the nurse approaches a patient’s situation hoping to affect change through interactions with the patient, there may be more success with providing the patient with the emotional support needed. There are many ways to provide caring interventions that support the patient’s emotions and feelings. The nurse may use touch, which is a powerful human interaction, to convey a sense of caring and understanding, even if the nurse cannot change the patient’s condition. Being respectful of the patient and his or her choices about care delivery is another method of being supportive, even when the patient’s choices have caused frustration or negative emotional outcomes. The patient is often learning how to handle the illness and is making decisions based on what he or she understands and what has been explained. The patient may not always be able to make the best choices, but
the caregiver in this situation must continue to be supportive, even when disagreeing with some of the patient’s preferences.

If the patient is struggling with severe psychological distress as a result of being ill, such as with a diagnosis of depression or anxiety, further measures are often warranted, including referral to a psychologist or counselor and possibly administration of mood-stabilizing medications. A counselor is trained to provide education and emotional support to the patient so that he or she will be better able to cope with a medical and co-occurring mental health diagnosis.

When a patient is having difficulty coping with a diagnosis or a change in health status, a counselor may also teach the patient about helpful strategies that would further support the patient’s emotional state and promote emotional stability. This may mean such interventions as teaching the patient relaxation exercises, journaling about feelings, practicing mindfulness or meditating, and focusing anger and hurt feelings on more useful activities. Patients can learn to draw on support and resources that they have or to develop new ideas for support so that they do not feel alone during this fearful time.

Because of the complex dynamics associated with palliative care, the emotional support through counseling, discussion, and education is vital to promote patient health. Emotional support reduces patient loneliness and feelings of isolation, and improves the patient’s ability to cope with a difficult situation and to experience feeling cared for and loved. When a patient is facing health difficulties that require palliative care, emotional support may better protect his or her health and help to promote improved coping strategies.
Practical Interventions During Palliative Care

Practical interventions describe those actions that are useful for the patient and that actually involve doing something, rather than thinking about it. Practical palliative care involves teaching the patient ways to be involved in one’s own care and to maintain optimal function. The caregiver of the palliative care patient may help to optimize his or her level of functioning in order to help the patient remain productive and feel purposeful during the course of illness. Being able to continue to function and perform routine tasks not only helps the patient to achieve these activities but it improves quality of life and supports the patient to feel useful.

Patient disability can develop as a result of numerous factors associated with the disease process during the palliative care period. The patient may spend more time immobile while receiving treatments and may lose muscle mass, leading to weakness and fatigue, develop malnutrition or electrolyte imbalance, causing physical or cognitive changes that affect ability to perform activities of daily living, or suffer health complications as the result of disease progression, which limits the patient’s ability to function at previous levels. Disability can also take many forms, including an inability to perform activities of daily living, difficulties with transfers, self-care deficit, and problems with ambulation.

Disability can lead to depression and feelings of despair among affected persons. When a palliative care patient requires more help to perform routine tasks, it increases caregiver burden and can place strain on the patient-caregiver relationship. Furthermore, increased disability in the palliative care patient may lead to greater resource utilization and an increased need for institutionalization, when the patient could otherwise manage his or her health from home.\(^{25}\)
While it may seem that rehabilitation is a meaningless exercise among patients who receive palliative care, the opposite has, in fact, been shown to be true. Most patients who are ill and who receive palliative care services want to remain independent as long as possible, throughout the course of their illnesses.

Many patients struggle with the idea of dependence on others for their most basic care and may feel as though they are a burden. Rehabilitation offers assistance with patients achieving some of their functional goals and promoting their independence in practical activities of daily living so that they are more self-sufficient and are not as reliant on others for their basic care.

**Rehabilitation**

According to the *Journal of Palliative Medicine*, rehabilitation is:

“"The process of helping a person to reach the fullest physical, psychological, social, vocational, and educational potential consistent with his or her physiological or anatomical impairment, environmental limitations, desires, and life plans."”

Rehabilitation can take many forms, and may have various goals outlined for the patient. *Preventive* rehabilitation seeks to keep the patient at his or her current level of function, and prevent disability or impairment and loss of function. *Restorative* rehabilitation is designed to bring the patient back to a previous level of function. *Supportive* rehabilitation works with the patient at a current level of functioning and helps the patient to cope despite impairment that has developed as a result of the patient’s condition.
Supportive care does not try to increase functioning or push the patient to achieve more than he or she can do. Rather, the provider offering supportive care meets the patient where he or she is at in terms of functional abilities, helping the patient to accomplish all that is possible and according to the patient’s ability.

Rehabilitation is not just limited to physical functioning, although this is one of the main components of the focus of care. In addition to physical therapy, other areas of rehabilitation that may be needed for some palliative care patients include occupational therapy, speech therapy, and respiratory therapy. The program should be developed for the patient utilizing all members of the interdisciplinary team to organize activities into the most productive method available for the patient, and including those areas of deficits that the patient needs the most assistance. As an example, a patient who has suffered a stroke and who is receiving palliative rehabilitation may need assistance with physical therapy and with speech therapy as he or she undergoes recovery.

**Physical Therapy**

Physical therapy has a place as part of palliative care. Physical therapy is mainly designed to promote patient movement, improve flexibility, and control pain among affected patients, so it makes sense that it should be included as part of palliative care. A physical therapist may see a palliative care patient in a variety of settings, including in the hospital, as part of outpatient care at the physical therapy facility, at a rehabilitation center, within a skilled nursing facility, or in the patient’s home.

The physical therapist is capable of examining the patient to best determine care needs, whether it is for symptom control, such as with pain or dyspnea,
or whether the patient would also benefit from improved functioning, enhanced flexibility, or improved strength. The physical therapist uses equipment that can help the patient to achieve these goals and may implement weights, treadmills, or other exercise equipment. The therapist also has other methods of reaching goals of physical therapy, including application of heat or cold, use of trans-electrical nerve stimulation (TENS), massage, or water therapy, such as through a whirlpool bath.

A patient who suffers from a chronic and/or progressive illness may develop a number of symptoms that can be well managed with physical therapy. Physical therapists work with patients in two dimensions: the physical dimension and the functional dimension. The work involved that addresses the patient’s physical dimension often targets symptoms of illness that are causing the patient discomfort, such as chronic pain, dyspnea, weakness, or deformity.

The physical therapist addresses the physical dimension by working with the patient to help control these symptoms through therapy, including increasing the patient’s stamina, applying heat or cold packs to certain areas that are causing pain, improving exercise tolerance, or assisting a patient with ambulation who has developed gait disturbances. As an example, a patient who suffers from pain, muscle weakness, and dyspnea from a progressive neurological condition may work with a physical therapist to control these symptoms by addressing the physical dimension. The therapist may apply a TENS unit to help with pain control or to assist the patient with walking and ambulation by utilizing assistive gait devices.

The functional dimension of physical therapy addresses the patient’s abilities to function in daily life and to perform activities of daily living. Addressing
this dimension is also beneficial and an appropriate part of palliative care because it helps to improve the patient’s quality of life. Because of chronic illness, a patient may suffer a decline in an ability to carry out the normally routine activities of daily living. Even getting out of bed, moving across the room, or bending over to pick up an item can become difficult tasks for certain patients. The physical therapist can work with a patient to help improve functional status, such as by helping the patient gain muscle strength to pick up or move objects, assist with finding easier methods of transferring from the bed to the chair, or utilizing assistive devices to get dressed in the morning.

Because physical inactivity contributes to early death, even among those who do not suffer from chronic or extensive illness, physical therapy is beneficial in improving patient strength and stamina and increasing exercise and movement. The role of the physical therapist in palliative care continues to expand, and this specialty contributes guidance and expertise to the interdisciplinary team about physical patient care and rehabilitation. Patients who utilize physical therapy as part of palliative care can maintain their strength or even regain some strength that was once lost. This improvement in function and movement is part of the core of palliative care, in that physical therapy recognizes the importance of movement and strength on the patient’s quality of life and seeks to improve these areas in order to best promote the patient’s well being.

**Speech Therapy**

The speech therapist who works with palliative care patients may play several roles, including helping some patients reach better levels of communication, and assisting patients who have difficulties with swallowing. Impaired communication because of an inability to speak clearly and
effectively can lead affected patients to feel frustrated and helpless. When a patient has a speech deficit because of illness, the speech-language pathologist can help the patient to better communicate by making sounds that others can understand, improving articulation abilities so that speech is correct and clear, helping to coordinate breathing and speaking, or coming up with alternative methods of communication, such as with augmentative devices designed for those with speech impairments.

If a patient develops dysphagia and has difficulty swallowing, he or she may be at risk of malnutrition and dehydration if an inability exists to take in enough food or fluids by mouth. The speech-language pathologist may work with a palliative care patient in the rehabilitation setting to evaluate the patient’s swallowing abilities and to recommend certain tests that will discern the patient’s swallowing abilities. These tests can determine if there is a physiological reason, such as an obstruction, that may prevent the patient from swallowing normally. Alternatively, the testing may also highlight other elements that contribute to dysphagia, such as a change in the patient’s cognitive status, pain that has developed with swallowing, aspiration and regurgitation of food and fluids, or neurological degeneration that blocks the brain’s messages to the body that stimulate swallowing.

The role of the speech-language pathologist in helping a patient with swallowing further involves assistance with finding food and fluids that the patient is able to swallow, providing thickening agents that will facilitate easier swallowing of liquids, positioning the patient’s head and neck to aid in swallowing, and maximizing what the patient may be able to swallow.²⁶

Ultimately, the speech-language pathologist works with the patient and the patient’s family to improve quality of life through speech rehabilitation when
it is needed. This practical aspect of providing care improves the patient’s ability to function and helps the patient to feel more capable to perform activities and able to communicate with others. When illness symptoms affect a person’s ability to talk or eat, the interdisciplinary team can discuss the situation with the speech therapist and come up with a plan to support these essential areas of palliative care.

**Occupational Therapy**

The occupational therapist plays an important role in rehabilitation through palliative care by determining what activities are meaningful to the patient and helping the patient to continue to participate in these activities. For instance, a patient may be able to get up and dressed each morning, and continue to participate in activities of daily living without requiring outside help. The patient’s ability to function in this manner may help him or her continue to feel productive and useful, enhancing quality of life and helping the patient to feel less of a burden on others. When the patient is not able to achieve these tasks without help, he or she may feel distress, ashamed, or depressed about the existing situation. The occupational therapist can help the patient with regaining or maintaining many of these skills and continuing to function at the highest level possible.

Depending on the patient’s level of functioning, an occupational therapist may work with a palliative care patient for weeks, months, or even years. The occupational therapist works as part of the interdisciplinary team to call attention to those areas in the patient’s life that need skill development and where the patient could benefit from occupational therapy. The therapist makes recommendations for functional testing for the patient to determine the patient’s level of skills and brings this information back to the team. The therapist also keeps the team apprised of what techniques and exercises the
patient is using through occupational therapy, and how much progress the patient is making. Additionally, the occupational therapist may also need to coordinate services between other members of the interdisciplinary team who are focused on the patient’s rehabilitation, such as the physical or speech therapists.

The tasks that the occupational therapist works on with the patient brings meaning to the patient’s life in terms of being more functional and having more freedom by being able to independently pursue these activities. Some of the activities that the occupational therapist may incorporate involve practice by the affected patient to perform routine basic skills, such as dressing, brushing or combing the hair, brushing the teeth, bathing or showering, preparing meals; or performing light tasks around the house, such as organizing paperwork or dusting furniture.27

The occupational therapist may be involved in a number of other areas in the patient’s life that promote function and independence. The therapist may assess the patient’s sleep habits and help the patient to develop a sleep schedule to increase times of rest and quality sleep; and, may also instruct the patient about areas around the home that could be hazardous for the patient or those areas where additional support may be necessary. For instance, an occupational therapist may assess a patient’s home and find that several throw rugs placed in a high-traffic area could increase the patient’s risk of falling; alternatively, the patient could also benefit from adding a non-slip mat to the shower floor to prevent falling while taking a shower.

Other areas where an occupational therapist provides helpful service include teaching the patient about relaxation and control of anxiety, and helping the
patient to engage in meaningful pursuits, such as with hobbies or leisure activities, and increasing the patient’s confidence in performing activities of daily living. Not all patients require occupational therapy, and the amount of functioning and participating in activities of daily living will vary between palliative care patients. However, for those who do utilize occupational therapy, they often find that the therapist is there to help them to maximize their abilities and to improve functional status, which ultimately improves their wellbeing and sense of self.

**Spiritual Care**

Spiritual beliefs often give meaning or purpose to life. A portion of the palliative care process involves focusing on how the situation has affected the patient’s spirituality, which is an integral part of providing comprehensive and holistic patient care. The caregiver may need to determine the patient’s sources of spiritual beliefs, which may or may not include participation in religious practices.

The palliative care patient may be suffering from spiritual distress to the point that it impacts the patient’s emotions, relationships with others, and physical healing. Spiritual distress can occur when the patient’s beliefs are in conflict with what is happening. For instance, a patient may wonder why the illness developed in the first place or why it is not responding to treatment. The patient’s situation may conflict with having spiritual beliefs that normally support the idea of healing and wholeness. The patient may wonder if he or she has done something wrong that caused the condition, or lack of healing. For example, a patient who believes that healing can occur through prayer may worry that he or she is not praying enough or is not doing enough to get prayers answered when recovery from illness is not happening. Spiritual
distress develops when these worries and fears continue and the patient is unable to find answers that align with the patient’s spiritual beliefs.

Some patients who have terminal illnesses may begin to search for spiritual meaning when previously there was none. As a person nears the end of his or her life, there may be a propensity to wonder about the meaning of life, how the person had impacted others and will be remembered, and if the person made a difference in life. There may be curiosity about what happens after death and if the state of a person’s life will make a difference after the person has died. The patient may have questions or may be seeking answers that the nurse may not be able to answer. In order to support the patient’s spiritual health during palliative care, the patient may need to meet with a spiritual advisor for support and to discuss those ideas that are associated with having a spiritual belief.

The spiritual advisor may be a minister or priest, a member of a faith community, or even a lay person who has experience with a particular set of spiritual beliefs who can meet with the patient to discuss these matters and answer questions. The nurse may also be a source of spiritual support if the patient is comfortable discussing spiritual beliefs. It should be noted that the nurse is not necessarily the first option in this role and it is often preferable to have another member of the interdisciplinary team provide spiritual support. However, there are times when the nurse, who is the primary caregiver, develops a bond with the patient to the point that they find they share similar spiritual ideas or that they practice the same religion. If both the patient and the nurse are in agreement, discussions of a spiritual nature may be comforting to the patient and beneficial in supporting the patient’s spiritual health.
Providing spiritual care is foundational to promoting quality of life for the patient. *The Indian Journal of Palliative Care* explains that even if a palliative care patient’s pain and physical discomfort is well controlled and the patient is not suffering from physical symptoms associated with an illness, the patient may still be suffering terribly because of spiritual distress and during a search for life’s meaning. Part of supporting the patient’s spirituality while providing palliative care is to recognize the impact that a person’s spiritual beliefs have on his or her life and help the person to draw comfort from one’s own beliefs.

A spiritual advisor may meet with the patient and with family members to discuss spiritual matters that are affecting the patient. This may involve discussion of beliefs, questions that the patient has about faith or beliefs, and assessment of where the patient seeks to find strength and support. The spiritual advisor is empathic to the patient’s situation and strives to help the patient feel that he or she is being heard, and that the patient’s concerns are valid.

Providing spiritual care may involve setting goals, measuring outcomes, and identifying what the patient wants to achieve through the relationship with the spiritual advisor. For example, a patient may want to talk with a mentor who shares the same faith background may decide that he or she wants to spend time discussing some of the tenets of their mutual faith, rather than trying to find a way to fix the situation or solve all of the patient’s problems.

In order to be empathic to the patient’s situation and to really listen to the spiritual concerns expressed, the spiritual advisor often must spend more time actively listening to the patient rather than doing all of the talking. The advisor acknowledges that the patient may be suffering or may have
questions that will remain unanswered. Together, the advisor and the patient work through these thoughts and questions to help the patient to find peace.

It may be that the patient does not find answers to his or her questions. The patient may talk and discuss the situation with another, and may have a lot of support, and yet still struggle with asking “why?” Sometimes, the important thing to remember when providing spiritual support is that the person will not always have the answers, and that answers may never come. Spirituality involves believing in something that is beyond the realm of everyday living. As a result, a person cannot always achieve answers to questions about those things affected by what cannot always be seen or heard. When providing spiritual support, the advisor may sometimes need to tell the patient that he or she does not have an answer to the patient’s question, but that the advisor and other members of the patient’s care team will still be there and to support the patient during a difficult time.

The nurse should remember that spirituality as part of palliative care may involve some ethical choices and that people who ascribe to some spiritual beliefs may make healthcare choices based on these beliefs. The nurse may not agree with the spiritual beliefs of the patient or of the choices made based on these beliefs, but it is the nurse’s professional role as a caregiver to uphold care of the patient, to recognize that the patient has spiritual beliefs that may affect care, and to continue to provide care as the patient needs.

The nurse can help to support the patient’s spirituality by asking the patient about who he or she has for spiritual support, or finding out where the patient finds strength. In addition to a spiritual advisor, it may be helpful for
the patient to have friends or associates who ascribe to the same spiritual beliefs visit and spend time with the patient. The nurse may also ask the patient what he or she does to uphold spiritual beliefs that make the patient feel better, such as praying, crying, reading, or spending time alone, and then helping the patient to practice these activities. Even if team members caring for the patient do not share the same spiritual beliefs as the patient and the patient’s family, it is important to continue to provide support, be present when needed, remain empathic and avoid being judgmental, encourage, and to help the patient know that others are listening and that the patient’s beliefs matter.

The Palliative Care Team

Because there are so many specialties working to provide different types of palliative care to patients, this type of care would not be well coordinated without a combined effort from team members who meet together to discuss the patient’s condition, progress and setbacks, and any other issues that have developed throughout the process. The team is a group of professionals who are focused on providing patient care within each of their own specialties, and by communicating with each other to make sure that the patient receives holistic care that does not overlap in any areas. The team members and the professions they represent vary between teams.

Most palliative care teams have at least a medical provider, nurse, and social worker. There may be a variety of other team members who play important roles in providing palliative care as well. Pastoral care providers, respiratory therapists, speech pathologists, physical or occupational therapists, dietitians, clinical nurse specialists, and psychologists are just some of the professions represented within this interdisciplinary team. Regardless of who is called to meet with the group and to be a part of the team, all participants
have the same goal in mind, which is to provide care for the patient and the patient’s family that will improve quality of life, enhance feelings of comfort, and be supportive throughout the patient’s illness, no matter what the outcome.

**Medical Providers**

A palliative care medical provider is an important part of the interdisciplinary team. Because the provider is responsible for prescribing medications and treatments for the patient, he or she may be one of the coordinating members of the team. While a primary care provider or specialist who knows and has worked with a patient before may serve on a palliative care team, it is desirable that a provider who has experience with palliative care be a member of the patient’s care team. A palliative care provider is familiar with the challenges associated with certain types of symptom control and is aware of common needs of palliative patients.

The role of the palliative care provider is to promote the patient’s quality of life whether the patient has reached the end of life or whether the patient needs help with achieving comfort and symptom control. Palliative care, as with other specialties, such as orthopedics or emergency medicine, is a specialization all its own. The palliative care provider gets to know the patient and his or her unique care needs and is focused on a holistic approach to care, rather than concentrating on one area of the patient’s life or one body system.

A palliative care provider may perform a variety of duties as an interdisciplinary team member. The provider may meet with the patient and talk about how the patient is feeling, if any new symptoms have developed, or if there are any setbacks in health being experienced. The provider may
also meet with the patient’s family to determine if they have needs that could be met through the services of the team. The focus of a general practitioner or specialist is on treatment of the patient’s condition, while a palliative care provider focuses on relieving the patient’s suffering and managing the patient’s symptoms.

The palliative care provider may work with other providers who are also managing the patient’s case to provide care for relief of suffering. For example, a patient with cancer who receives palliative care services may have an oncologist who manages cancer, but the palliative care provider may work with the oncologist to coordinate the patient’s care. The oncologist may order treatments such as radiation and chemotherapy, and may coordinate with the palliative care provider to prescribe other helpful measures for the patient, such as medication for cancer pain or medicine to control nausea that occurs as a side effect of chemotherapy.

The palliative care provider may also prescribe some treatments, such as radiation treatment or may recommend surgery and coordinate care with the surgeon if the treatment will facilitate symptom control and greater comfort for the patient. Furthermore, the palliative care provider, after coordinating with the interdisciplinary team, will also prescribe certain therapeutic treatments for the patient, such as by recommending physical therapy, suggesting psychotherapy and counseling, or advising a consult with a dietitian.

The medical provider is attentive to the patient’s physical and psychological conditions and prescribes therapeutic regimens in response. He or she may follow the patient’s lab results and know if the patient has developed an electrolyte imbalance; by receiving reports from other members of the team,
the provider may learn of complications in the patient’s condition, such as urinary retention, and can order medication or treatments to manage these adverse effects. The provider is conscious of the patient’s overall condition, including if the patient develops problems such as tumor growth or a decline in physical functioning and can prescribe treatments or therapy in response.

The palliative care provider typically works within all areas where palliative care is provided. He or she meets with the interdisciplinary team and is often the team leader. Hospice and palliative care medicine is a specialty within the United States and much of the palliative care provided to patients is covered under Medicare. A physician who specializes in palliative care medicine must have gone through college and medical school and must have completed a residency with a specialization in a particular area. Some examples of residency areas include oncology, surgery, emergency medicine, internal medicine, pediatrics, obstetrics, or psychiatry.

To become board certified as a palliative care provider, the physician must then complete a fellowship after residency; the fellowship is usually at least one year long and focuses almost exclusively on palliative and/or hospice care. More and more physicians are moving into palliative care, changing their outlook from one of fixing or curing a patient’s condition to focusing on the patient’s overall wellbeing, even if the patient does not survive the illness in the end.

**Nurses**

Nurses are the mainstay of palliative care. They are most likely the caregivers that will provide bedside care, spend time with the patient and the patient’s family, talk to or counsel the patient and the family about the patient’s condition and outlook, provide specialty care services for different
treatments, such as wound care or pain control, and advocate for the patient and the family about the specific needs related to the patient’s health. The nurse serves as an integral part of the interdisciplinary team. Often, the nurse is the person who spends the most time with the patient and can report back to the team about the patient’s progress or setbacks. The nurse communicates with other members of the team to provide accurate information and to campaign on behalf of the patient to ensure that the patient gets the help that is needed.

Quality of life throughout the lifespan is the core of nursing care; nurses serve to improve patient quality of life through their work whether it is provided in the acute care setting with the patient-nurse relationship only lasting a few minutes or hours, or whether the nurse is engaged in a long-term care relationship with the patient whom she sees and cares for regularly. A nurse acts as a stable presence in the face of serious illness that requires palliative care. It is this presence that allows the nurse to be constant and available to patients who may feel fear, anger, frustration, guilt, sadness, or any other number of emotions related to the disease process.

The nurse is a source of education to the patient and the patient’s family, teaching them about relevant aspects of the disease process, as well as what to expect as far as symptom management is concerned. When a physician or another provider gives new orders for a therapeutic intervention for the patient, the nurse may explain the situation to the patient and the family so that they can be aware of what to expect and understands why the item has been ordered. Nurses use their knowledge of complex procedures and of the disease process to educate and guide patients throughout the palliative care process.
The nurse who works in palliative care must be well educated regarding the effects of illness on various body systems, as well as how the palliative care process can affect the patient’s emotional or spiritual health. This is part of providing holistic care, which is established within the field of nursing. The nurse is aware not only of how the disease process affects the patient’s body, mind, and spirit, but also seeks to support ethical principles of promoting the patient’s well-being through patient autonomy, beneficence, and justice while providing this essential care. For instance, a nurse who is working with a patient with multiple sclerosis may be aware of the physical symptoms that are occurring and may seek to provide comfort to the patient both for physical symptoms and by helping calm the patient’s fears. As part of providing this care, the nurse supports the patient’s autonomy by helping the patient to make as many decisions as possible, and by respecting the patient’s choices, even if the nurse does not agree with them.

A nurse also provides direct patient care in some situations; and, the amount of physical care provided by the nurse may also depend on the patient’s situation. For example, a nurse who cares for a palliative care patient in the hospital may provide more direct care when compared to one who meets with a palliative care patient in the patient’s home and with family present to provide some of the caregiving measures. The type and amount of direct care interventions will vary between patients and may include such measures as administration of medications to help with pain or other side effects, assisting a patient with performing activities of daily living, and assisting with procedures performed by the physician or nurse practitioner, such as helping with placement of a central line. Additionally, helping the patient perform range of motion exercises, performing minor care procedures such as dressing changes, or implementing a skin care
regimen to prevent complications is part of the nursing role in palliative care.

The Hospice and Palliative Nurses Association (HPNA) has issued a position statement regarding the role of the professional nurse in palliative care, which states:

“Competent, professional nursing is critical to achieving healthcare goals of patients and their families to the end of life; the increased demand for nurses within a complex healthcare system requires nurses who possess leadership skills to be able to meet the demands of expanding roles, and that support for palliative and hospice-care research is necessary to provide evidence-based care.”

The HPNA further goes on to say that palliative care nurses should serve as leaders in local, regional, and national activist roles to promote the profession and that palliative care nurses serve as a model for addressing the needs of the chronically ill. The value of nurses within palliative care cannot be underestimated. It is a role that distinctly defines nursing at its core: one of compassion, empathy, and understanding for patients. It is not that nurses who work in areas outside of palliative care do not provide these elements; rather, palliative care nurses are specifically trained to view and work with the whole patient, through all measures and abilities, helping them to function and deal with their emotions, and being a source of support through an incredibly difficult time. The compassion and caring given during this time is what sets palliative care nurses apart and what signifies the importance of the palliative team member in providing patient care.

In addition to the registered nurse as part of the palliative care team, the advanced nurse practitioner also plays a significant role in providing
palliative care. The nurse practitioner may play a clinical role in providing care, which may be closer to the work of the physician on the interdisciplinary team, or may have more experience in consultation and counseling of the patient and the patient’s family. Today, there are more nurse practitioners than ever who have undergone extensive study to further their education beyond the registered nurse role and to take on prescriptive authority. There are many specializations for nurse practitioners available, including pediatrics, geriatric care, oncology, or intensive care, and these nurses may take on palliative care roles within their specialties or they may focus their professional work entirely on palliative care only, meaning they work only with patients who receive palliative care and continue to provide assistance to this special patient population through symptom management and comfort measures.

The role of the nurse practitioner is important when providing palliative care because this position can provide all of the functions of the registered nurse as well as duties within an advanced scope of practice. The nurse practitioner is able to assess the patient and perform a physical exam to check for changes in medical status, certain medical procedures that may improve the quality of the patient’s life, such as lumbar puncture or paracentesis, and prescribe treatments or medications to follow up with the patient. Furthermore, the nurse practitioner also has the authority to make referrals to other types of specialties, transfer the patient to another facility if needed, and write discharge instructions and summaries to educate the patient and the patient’s family.

A nurse practitioner working with palliative care patients may consult with the patient to determine how the current method of symptom management is working and may make adjustments as needed. This might involve
prescribing new or different medications to manage symptoms that have developed as a result of illness, or recommending or prescribing certain types of therapy or surgery that would help to make the patient more comfortable. As with the physician and other professionals involved in the case, the nurse practitioner would maintain a position on the interdisciplinary team and continue to consult with others about the best course of treatment for the patient.

Another benefit of using a nurse practitioner for some palliative care services is the cost effectiveness of this type of care. According to Williams and Sidani in the Canadian Journal of Nursing Leadership, use of nurse practitioners for palliative care has been shown to result in beneficial economic outcomes for the patient and for the healthcare facility, resulting in increased patient satisfaction with care, improved patient access to care, increased adherence to treatment regimens, decreased morbidity and mortality rates, reduced length of inpatient hospital stays, decreased health services utilization, and overall reduced cost of care.\textsuperscript{28}

Although a nurse practitioner may spend a significant amount of time providing patient care when he or she is involved in this type of care, a nurse practitioner whose focus is primarily on palliative care can concentrate almost exclusively on the management of patient symptoms. In other words, when a nurse practitioner specializes in palliative care, he or she is more focused on providing comfort measures and managing the specific patient’s condition than if the nurse practitioner had a specialization in another area and was assigned to a palliative care patient. The use of a nurse practitioner as part of the interdisciplinary team benefits the palliative care patient, the patient’s family, and the rest of the team because the nurse practitioner has
the unique combination of prescriptive authority and advanced practice combined with the caring, practicality, and compassion of a registered nurse.

**Registered Dieticians**

As an interdisciplinary team member, the registered dietitian is the person who can speak to how the patient’s food intake and nutrition can affect all other aspects of the patient’s health. The dietitian knows that good nutrition is not the same as a cure and will not necessarily prolong a patient’s life. However, good nutrition is important for symptom control, for improving quality of life and comfort, and for preventing development of some other symptoms that may be related to malnutrition.

The registered dietitian has several functions when working with the patient who receives palliative care. The dietitian may assess the patient’s physical status as it relates to nutrition and fluid and electrolyte balance, such as by checking laboratory levels that measure blood chemistry or by monitoring the patient’s intake and output. The dietitian may also assess for changes or difficulties in the patient’s ability to eat and gain enough nutrition. For example, if a patient was once able to independently eat meals but then later developed difficulties with handling silverware and consequently had trouble getting food into the mouth, the patient is at risk of malnutrition from lack of food intake. The dietitian can assess for these types of complications and then make arrangements with the interdisciplinary team to help the patient overcome the setback or work around it so that the patient can still get enough food.

Other elements of assessment that the dietitian might measure include the patient’s environment where food is prepared, knowledge of food preparation to prevent food borne illnesses, access to food and an ability to
buy it, situation in which most meals are taken, such as whether meals are taken alone in the patient’s house, meets with friends, or has family dinners, and knowledge of what foods are healthy, should be included in the diet, and what should be limited or avoided entirely. The dietitian may also talk with the patient and family about what foods the patient eats regularly in order to get an idea of his or her typical diet. Sometimes, a recall of all of the foods eaten in the past 24 hours is helpful to determine if the patient’s intake is appropriate or if changes are necessary. The dietitian may also perform other assessment measures such as weighing the patient, calculating body mass index, measuring body fat percentage, taking blood pressure, checking blood glucose levels, or assessing for electrolyte imbalance.

An electrolyte imbalance or malnutrition can cause physical and psychological problems for the palliative care patient, yet this patient population is more likely to develop complications of inappropriate food or fluid intake. The best method of management of complications from malnutrition, dehydration, or other electrolyte imbalances is to prevent them from developing in the first place. The dietitian may serve as an educator to the patient to help him or her to understand what foods should be eaten and what should be limited. Information can be provided to the patient and family about how best to prepare food, how much fluid to take in, and what foods should be avoided while taking certain medication.

If the patient does develop dehydration or an electrolyte imbalance, the dietitian can work with other members of the palliative care team to ensure that the condition is corrected as quickly as possible and that further complications do not develop. The patient may need correction of certain minerals or substances through oral supplements or possibly through intravenous administration of supplemental electrolyte preparations. The
dietitian may monitor the patient’s laboratory results and assess for symptoms that would be associated with electrolyte imbalance or fluid loss, such as cognitive changes where there were previously none, difficulties with ambulation, and weakness or fatigue.

Malnutrition is a source of various complications that can worsen patient symptoms and can cause physical difficulties that require assessment and treatment. Malnutrition may cause an increased risk of pressure sores in an immobile client, it may lead to impaired wound healing, or it could cause poor psychosocial functioning. It is very important to assess for and manage malnutrition in a palliative care patient, and the dietitian who knows what signs or symptoms to look for and how to follow up can protect the patient from the consequences of poor diet and poor nutrition.

If the patient does develop malnutrition due to a lack of food intake, decreased intake of vitamins or minerals, or difficulties with chewing, swallowing, digesting, or absorbing foods, the dietitian can bring the situation to the attention of the team and can make recommendations to correct the situation. It may mean that the patient must choose different foods to eat, and the dietitian can help the patient with selection or preparation of such foods. Alternatively, a patient who has difficulty absorbing some nutrients may need supplements of other items or may need to avoid certain ingredients in foods altogether, which the dietitian can also provide counseling about.

The patient and the patient’s family may not know why complications of poor nutrition have developed, or they may fully understand how it developed but do not know how to correct the situation. Either way, the dietitian is
available to provide needed guidance and education to patients and families
to reduce further consequences of poor food intake.

In some cases, a patient may have lost the ability to eat food, whether due
to the progression of a condition or other factors associated with an illness.
When this occurs, the team may need to consider tube feedings or
parenteral nutrition for the patient to help the patient continue to get
enough nutrition to support health. Tube feedings require placement of a
feeding tube that either runs from the mouth or nose to the stomach or that
is surgically inserted through the abdominal wall and directly into the
stomach. This type of tube gives direct access to the nurse or caregiver to
be able to administer formula feedings and medications directly into the
patient’s stomach without requiring chewing and swallowing of food. It may
also be appropriate if there is an obstruction or some other measure that is
preventing the patient from eating, in which case the patient would benefit
from instillation of formula that contains the appropriate amount of calories
and nutrition for the patient’s condition.

Parenteral nutrition may take one of two forms: total parenteral nutrition or
peripheral parenteral nutrition. Total parenteral nutrition is designed to
make up the total amount of calories and nutrients that the patient needs so
that he or she does not have to take in food by mouth or use formula
through a feeding tube. It requires a central line for administration, although
it can be administered in this method over the course of weeks or months.
The physician must closely monitor this type of nutrition and the dietitian
and the patient will frequently need laboratory work to determine the effects
of TPN on the patient’s body. The amounts of certain electrolytes, vitamins,
proteins, or dextrose can be increased or decreased in response to the
patient’s reaction to the fluid. The dietitian may or may not administer TPN
but if he or she is involved in the case, the dietician will monitor its components and the patient’s response.

Peripheral parenteral nutrition (PPN) is another form of parenteral nutrition in which the patient receives intravenous fluid that contains vitamins, minerals, protein, and carbohydrates, but the amounts of these elements are less than TPN. This type of parenteral nutrition is not meant to replace all food intake in terms of calories and nutrient needs. Instead, it may be used to supplement the patient’s intake of food or it could be used to support nutrition when the patient must receive tube feedings. Parenteral nutrition is designed to be either a partial or complete form of nutrition that can prevent many complications in the patient and help to keep the patient healthy.

The palliative care patient may have to use PPN or TPN for a short period or it could last for quite a while, depending on the patient’s overall condition, food intake, and progression of the illness. In many ways, this type of nutrition therapy is lifesaving for affected patients, and provides a means of adjunctive therapy to support the other forms of therapy and treatment the patient receives through palliative care. Because the dietitian is involved in monitoring the patient’s nutrition status and communicating with team members about the patient’s response to nutrition therapy, he or she is an integral component of the team whose work can be considered life saving.

A registered dietitian who works with palliative care patients must be familiar and have experience working with this unique patient population and with their families. The dietitian must be aware of the effects of disease on the patient’s physical, psychosocial, and spiritual state, but must also know how to respond when altered nutrition does result in consequences in any of
these patient states. Palliative care is not always easy or pleasant, and it may be difficult for the dietitian to work with a patient who is progressing in a disease state and not responding to curative measures that patient had hoped to achieve. The dietitian should be prepared to reply to patient questions and inquiries about how health is affected by nutrition and what can be done to improve the patient’s health through appropriate nutrition intake.

A registered dietitian typically has a college degree in an area related to food and nutrition. The dietician may or may not have a college graduate degree in this same area, and, when working in palliative care, may have some credentials that provide a specialization to work with this particular patient population. In order to be considered a registered dietitian, he or she must take a licensing exam and may need to complete a certain amount of continuing education hours each year to stay current in practice. The dietitian may also work with patients in a number of settings, such as in the hospital environment, on an outpatient basis, or in home care. Regardless of the actual location where the dietitian provides patient care, her assessment of the patient’s nutritional status and professional input for the palliative care team is invaluable in supporting the patient’s health.

Social Workers

A social worker is a professional trained in helping people to manage mental illness, arranging financial or social resources, and supporting people as they cope with various situations, including chronic or debilitating illness that requires palliative care. A social worker offers much to a patient and to family members as they learn to cope with the struggle of the patient’s condition, symptoms, and complications of illness. Families may be wrestling with grief and may need emotional support; the social worker can provide
encouragement and resources for struggling families as they face potentially overwhelming circumstances.

Social workers are one of the largest groups of professional disciplines who work with palliative care patients. Because social workers provide a vast array of professional services and often have holistic health backgrounds, they are able to care for palliative care patients because this group also requires holistic health services. The situations that social workers encounter when working in palliative care can vary from patients suffering from acute illness that is life threatening to those who are struggling with chronic disease and are seeking cures, and who are nearing the end of life in hospice. The social worker is aware of cultural differences that may be present among different patients and that affect certain decisions and family relationships; he or she is then supportive of patient choices and understands that the patient needs to participate in cultural practices and uphold ethnic beliefs.

The patient and family members may face barriers in achieving adequate healthcare for the patient. Many people, when faced with a chronic or significant illness, must navigate not only the treatments and therapies related to managing the condition, but also the financial hurdles that accompany medical care. Patients may not have access to financial, social, or economic resources and may be in need of help.

One of the social worker’s jobs is to provide information about resources for patients. For example, a patient may be struggling with severe grief when he or she finds out that an illness is terminal. Because the patient will most likely not recover from a condition, he or she may stop going to medical appointments and cease cooperating with medical therapy designed to
promote comfort. After talking to the family, the social worker may determine that the patient is most likely responding in this method because of grief, which is an appropriate response but also one that could be harmful to the patient and may result in poor quality of life as death draws near. The social worker responds by providing resources for grief support, such as through counseling, support groups, and therapeutic intervention to help the patient manage this facet of the patient’s condition. By better handling grief, the patient may be able to participate in a palliative care plan again.

Communication is the core of the social worker’s time with the patient and family. Communication involves talking with the family about those ideas that are important to them, whether it is the progression of the patient’s illness or some other element that has occurred recently that is taking the family’s focus. The social worker uses his or her knowledge of medical, psychological, spiritual, and social health to discern what areas the family needs assistance and then provides that information to the family. The social worker also maintains communication with the interdisciplinary team; the information that is garnered through discussion and efforts with the family can be distributed to team members so that others may get involved in the patient’s care in specific areas. As an example, if the social worker determines that the patient requires more spiritual support, he or she may give the patient and family information for spiritual resources, but could also communicate with the team to bring in a spiritual advisor for the patient who will be a suitable source of help.

Because of the social worker’s psychosocial background, counseling may also be provided to the patient and family as they handle complex emotions and feelings throughout the palliative care process. The social worker can work with another mental health professional, such as a psychiatrist or counselor.
to provide therapeutic counseling through talk therapy or other methods of helping the patient cope with a difficult situation. Other means that the social worker might also provide include referrals to a psychiatrist for mood-stabilizing medication, or information about support groups that are specific to the patient’s condition.

The patient may be part of the interdisciplinary team that manages care for his or her condition. If the patient or family have issues with team decisions, or are otherwise unable to attend team meetings, the social worker may be the team member that is most likely to advocate for the patient and communicate for them. The social worker may also talk with the family about how other elements of patient care are going in relation to the work of team members and can help the patient to communicate with other members of the interdisciplinary team, if necessary.30

A social worker also educates the patient and family about resources available as part of health management. Whether the patient is seeking a cure for a condition, wants more information about how to manage symptoms, or is struggling with accepting the course of an illness, a social worker can be sympathetic and can provide support and information for the patient to help the patient remain informed. By continuing to provide this information and support, the social worker is upholding the patient’s autonomy to make decisions about the patient’s care. The social worker also practices other ethical principles that are essential to palliative care, including upholding the patient’s right to self-determination, and the standards of beneficence, non-maleficence, and social justice.

The social worker provides a classic example of a team member who fulfills many responsibilities for the patient and family. The social worker is often
there for the family at all times when other team members may be more likely to work as part of a schedule of care. The patient may call the social worker with concerns or questions and is often available by phone at almost all times to be able to step in to help when needed. If the family has questions or concerns about a number of issues, such as insurance coverage, advance directives, support services, or the work of other team members, the social worker if often the professional that they contact for help. The social worker is typically available to help the family with filling out and filing forms, teaching the family about their options to obtain care for the ill member, and basically helping the family to navigate the some times confusing aspects of the healthcare system.

**Psychologists**

Perhaps one of the more rare members of the interdisciplinary team, a psychologist contributes the essential work of supporting the patient’s emotional and psychological health, making him or her a very important member of the team when present. Because palliative care involves work with both the patient and family, the psychologist may also serve to meet the needs of the patient and family members. As with other specialties, psychologists who work in primary care are typically geared toward correcting and supporting those who have been diagnosed with mental illnesses. When a patient is struggling with feelings and has a mental health diagnosis, a psychologist may meet with the patient as part of prescribed therapy or treatment to help the patient to overcome illness and best manage a disease.

When a psychologist works in palliative care, however, the focus is somewhat different. A psychologist on the palliative care team still engages with patients and their families to help them through mental health crises if
they occur, and they provide emotional support and realistic interventions, which patients can implement into their lives to manage emotions and feelings. However, the focus within palliative care is not so much curative as it is supportive; the psychologist’s role is to improve the patient’s sense of wellbeing by helping the patient deal with emotions, and the patient’s mental state, rather than trying to manage or control the mental health condition.

It is well understood that illnesses and disease states that require palliative care can cause a flurry of emotions for the patient and family. Patients may be struggling with fear, anxiety, grief, anger, frustration, or guilt throughout the process and these feelings can change and fluctuate on a day-to-day basis. Furthermore, palliative care patients may be at increased risk of developing conditions that would lead to a mental health diagnosis, such as clinical depression or anxiety, as a result of the health condition and the difficulties with managing it.

The goal of the palliative care psychologist, therefore, is to help the patient learn methods of coping in the face of his condition and to find peace and an improved quality of life, regardless of what the patient’s ultimate health outcome may be. The goal of the psychologist-patient relationship is to support the continuation of living life to the fullest through various means so that the patient can find a sense of emotional stability, even if his or her health condition is not improving. This may mean that the psychologist utilizes psychoanalytical approaches to teach the patient about how to manage feelings, thoughts, and emotions to best handle the patient’s psychological state.
Kasl-Godley, et al., in the journal *American Psychologist*, stated that ideally, psychological care begins at the beginning of a diagnosis or at the point at which a patient begins palliative care. It is beneficial when it is delivered in combination with other disciplines and therapies provided by the healthcare team that is managing the patient’s condition. The psychologist may also work individually with the patient to help with decision making, particularly if the patient and family are facing difficult choices as part of healthcare. For instance, a palliative care patient who reaches a point where he or she determines that treatments are not helping the patient’s condition, and that what exists is a terminal illness with no hope of a cure, may struggle with acceptance and grief in this situation. The psychologist may work with the patient to help sort through many of the difficult decisions that must be made and help the patient to see the benefits and disadvantages of various choices so that informed decisions can be made.

The psychologist may meet with a patient and family in a number of situations, including in the patient’s home, in an outpatient clinic, or in the hospital. The patient may have regular sessions of counseling with the psychologist and may meet at his or her office for these sessions; alternatively, the psychologist may occasionally contact the patient for an update on how the patient is feeling or may check in to determine whether further treatments or interventions are required. The change in the patient’s routine, such as with increasing medications or therapy or adding a new intervention to the patient’s regimen to manage an illness may require a check in with the psychologist to see how the patient is handling the change and the possible progression of an illness.

The psychologist may perform an initial assessment of the patient’s psychosocial status, which includes a history of mental illness, assessment of
coping skills, evaluation of the patient’s relationship with family members and friends, self-esteem and self-care issues, history of substance use, current medications and treatments, the patient’s values, and any other pertinent information in the patient’s history that might apply to the situation. The psychologist may perform this assessment and gather information by interviewing the patient, often during an initial meeting, but the assessment could take place over several meetings or it could be ongoing. The psychologist and the patient may meet together and talk about any psychological, emotional, or spiritual issues the patient is experiencing; prominent family members who are involved in patient care may also be present at the meeting.

Based on the information garnered from the psychologist, a decision may be reached to continue to meet with the patient for therapy or counseling, or the psychologist may administer one of several tools that ask more questions of the patient and determine his or her level of distress and adjustment as well as psychological state and coping mechanisms. The psychologist uses the information gained from the tools and compares it with data gained through the patient assessment and interprets the data to determine what type of intervention is needed, such as whether the patient would benefit from a specific type of cognitive-behavioral therapy or from antidepressants or anti-anxiety medications. Because of the psychologist’s specific knowledge regarding psychosocial functioning and its effects on patient care, this team member adds yet another dimension of comprehensive and holistic care to the palliative care team.

**Massage Therapists**

A massage therapist may be part of the palliative care team to provide massage and therapeutic touch for the patient. Massage therapists recognize
the importance of touch and its healing powers; and, understand that to utilize massage therapy with a palliative care patient, they are helping the patient to achieve a certain amount of peace and comfort during a troubling time.

Massage therapy is delivered in a method that promotes patient dignity; it is respectful of the patient’s wishes for delivery of the therapy and it provides privacy and discretion throughout the process. The massage therapist may incorporate additional methods into a therapy session that promote relaxation for the patient. For example, in addition to performing massage on a palliative care patient, the therapist may also provide a setting that is comfortable and relaxing, with soft music or soothing sounds in the background.

A significant component of massage therapy is the provision of pain control for the patient. While massage is used for various purposes, such as to promote relaxation, or to enhance feelings of well being, many of these are also applied within the context of pain control. Because many patients who receive palliative care utilize methods of pain control, massage is a valid form of therapy that can help to promote comfort and quality of life during palliative care.

Pain is often complex and affects many different aspects of the patient’s well being, not simply the physical dimension. Massage therapy, when utilized for pain control, is delivered in a method that not only controls the physical aspects of pain, but may help the patient with accepting and managing other effects of pain as well, including the toll that pain takes on the patient’s psychological, spiritual, or emotional well-beings. In this method, massage therapy is a holistic form of symptom management for the patient because it
can address issues that are affecting various aspects of the patient’s quality of life.

When the therapist provides comfort measures through massage, he or she is helping to alleviate some of the physical pain that the patient is experiencing, but may also help the patient with controlling mood, feeling more positive about the experience and about the patient’s situation, or supporting a sense of spiritual well-being by helping the patient to be better able to see a sense of purpose or to have some hope in the current situation.

Most of massage involves manipulation of the muscles and soft tissues of the body. Although many people imagine a person receiving a massage as lying facedown on a table with the back exposed and the therapist kneading muscles, massage therapy may be administered in a number of methods that are very different from this situation. The patient may sit or lie down, may meet the therapist in the massage therapy office, in the hospital or healthcare facility, or in a private home, depending on circumstances. The therapist may massage the patient’s back and shoulders but could also include any other areas as well, including the neck, face, arms, legs, or feet.

Massage is effective because the act stimulates a physiological response in the patient’s body. The relaxation response is an involuntary reaction of the patient’s nervous system. It occurs when the patient’s heart rate and breathing rate slow down and blood pressure decreases; the patient’s body decreases production of stress hormones and increases production of the neurotransmitter serotonin. The patient’s body also undergoes a mechanical response during massage. There is an increase in blood and lymph circulation, and the muscles and soft tissues become more relaxed and are less likely to spasm or tighten.33
Massage stimulates the production of endorphins in the body, which have been shown to relieve pain and to produce a euphoric feeling. Massage has also been shown to enhance the patient’s sleep quality and may contribute positively to the immune system. In fact, the American Massage Therapy Association has issued a position statement saying that massage therapy can increase the quality of life for a patient in hospice or palliative care. The organization went on to say that massage is beneficial for the alleviation of many of the symptoms associated with hospice and palliative care, including pain, anxiety, sleep deprivation, depression, stress, nausea, and fatigue.

Massage is not only beneficial for the mechanical and relaxation responses it causes, the act of massage also supports the relationship between the therapist and the patient. The massage therapist takes the time to work with the patient and to provide one-on-one support delivered in a caring manner. The therapeutic effects of touch cannot be underestimated. When a massage therapist takes time to meet with the palliative care patient and to provide assistance through massage, he or she is also providing a listening ear, time, and focus and attention on the patient, which is beneficial to the therapeutic relationship and also helps the patient feel accepted and cared about.

The massage therapist acts as a healing presence for the patient, in which he or she is available and simply there for the patient during the difficult time of palliative care. A massage therapist may do more for the patient than provide soft tissue massage. Help with some other elements may also be provided that enhance physical comfort for the patient, such as offering assistance with turning or transitioning the patient, oral care, or helping with other activities of daily living. According to Catlin in \textit{Massage Today}, a massage therapist who is there for a person who is receiving palliative or
hospice care should be present to perform massage and bodywork, but should also be available and flexible to meet the unique needs of the patient in the moment. This may mean that instead of performing a prescribed massage, the therapist is simply there to hold the patient’s hand and to listen while the patient expresses his or her struggles. The therapist is adaptable and accommodating for what is happening with the patient and what the patient needs in the moment.

A massage therapist is someone who has been trained in providing massage through therapeutic touch and physical massage of muscles and soft tissues. The therapist has training in anatomy and physiology and is aware of the effects of touch on body tissues. Also, the therapist is familiar with and has some training in psychology and is cognizant of the effect of tissue massage on the patient’s psychological, spiritual, and social wellbeing. Massage therapists typically work in private offices designed to provide therapy services, as well as in patient homes, in hospitals and healthcare centers, long-term care facilities, specialty clinics, salons, spas, and resorts.

A licensed massage therapist has completed a training program at a school of massage therapy where the therapist has learned the techniques and benefits of massage. To become licensed as a practitioner, the massage therapist must then pass the Massage and Bodywork Licensing Exam, which is a minimum requirement to practice as a therapist. Further board certification is available from the National Certification Board for Therapeutic Massage and Bodywork. The therapist may also then receive additional training working with palliative care patients or providing care at the end of life for some patients. This training is offered through various programs and may consist of specific elements, such as providing end-of-life care or care working specifically with cancer patients. Based on the research and support
that states that massage is beneficial to a patient’s physical and emotional well being, the palliative care team would most likely benefit from inclusion of a professional massage therapist on the team.

**Chaplains and Spiritual Care**

Chaplains affiliated with varied faith traditions generally provide spiritual care to patients with a palliative care treatment plan. The chaplain is present to provide for the spiritual care and direction of the palliative care patient. The concept of hospice was founded on the tenets of spirituality, in which care was provided to patients as a selfless act of giving during a time of great need. The chaplain on the interdisciplinary care team upholds this spiritual component of care by meeting with the patient and attending to spiritual needs.

A patient who is utilizing palliative care services may be faced with significant or even terminal illness; through this process, the patient may become more focused on finding meaning in life. Talking with a chaplain can help the patient find direction, especially during times when the patient is feeling confused and seeking answers. A chaplain acts as a spiritual advisor for the patient; when meeting with the palliative care patient, the chaplain or religious representative should be of the same faith background as the patient. During such a time of confusion, the patient may have little to no comfort by meeting with a member of the clergy or spiritual advisor who does not share his or her same faith.

A chaplain may institute some religious practices as part of patient care. Religion differs from faith and belief in that religion describes the outward activities that are done in response to faith. A person may have faith in something but may not necessarily be religious. Nevertheless, if a patient
wants to perform certain religious rituals as an expression of faith, a chaplain or minister can be present to help during this time.

The chaplain may meet with the patient at various times and can be available in different locations of patient care. A patient’s personal minister, such as the officiating pastor at the patient’s church, may meet together at the patient’s home or may come to the hospital. Likewise, many healthcare facilities have chaplains on staff available at all hours to meet with patients. These men and women may also be on call at various times as well, particularly if the patient’s condition worsens to the point that he or she is reaching the end of life. Many families derive great comfort from having a clergy member or chaplain present during critical times and may want this person to be called when the patient’s condition has deteriorated.

The chaplain may meet with the interdisciplinary team on a routine basis to follow up with the team’s recommendations for patient care and to be aware of how the patient’s care is continuing or whether there have been changes made in the plan of care. The actual services of the chaplain, his or her level of education and experience, and amount of time spent with the interdisciplinary team may vary widely between locations. Some palliative care teams may utilize a clergy member who knows and works with the patient but they do not necessarily meet with the clergy member during team meetings. Alternatively, there may be some teams where the chaplain is recognized as being an integral part of the patient’s care.

Regardless of the assigned role of the chaplain, when the patient utilizes this service, great comfort and peace may be derived by talking to and spending time with someone who shares the patient’s beliefs and who is there to support a spiritual journey through palliative care.
Coordinating Palliative Care Treatments

Because many different members of the palliative care team exist, it is essential that team members communicate on a consistent basis when coordinating their efforts. The patient may be scheduled to receive treatment for a specific condition but without proper communication, the treatment may overlap in time with another type of therapy or may be unnecessary based on a change in the patient’s condition. When team members coordinate their treatments and communicate with each other, there is less potential for confusion and greater organization of patient care activities. Some of the main types of treatments utilized through palliative care include curative measures and analgesic treatments for comfort.

Curative

Not all palliative care patients are facing terminal illnesses or are receiving hospice care. Palliative care provides comfort measures, which may be needed if the patient is struggling with health issues that have set him back physically or emotionally. The patient may utilize palliative care services for control of symptoms and to keep comfortable but the patient may also continue to seek curative treatments for a condition.

Technically, palliative care is not curative care, although the two types of patient care may occur at the same time. The patient may seek curative treatments for a condition, and yet receive palliative care to combat symptoms of an illness or complications that have developed because of curative treatments. A classic example is of a patient who has been diagnosed with cancer and who undergoes chemotherapy treatments. The patient has a significant illness that may cause pain and discomfort for which palliative care is sought. However, the patient may also undergo
chemotherapy as an effort to control cancer and as a type of curative treatment. The chemotherapy is not considered a form of palliative care. Additionally, if the patient develops side effects from the chemotherapy, such as nausea and vomiting, palliative care may cover those effects as well.

Often, the combination of treatments needed as curative measures can take their toll on the patient’s health. Significant illness can cause stress and strain on family members and the loved ones of the affected patient. By working with the interdisciplinary team to develop a palliative plan of care, the patient and family members may be more likely to respond well to treatments and to be able to continue with the rigors of therapy needed for seeking a cure.

The holistic care provided as part of palliative care is designed to improve quality of life for the patient and family. Whether or not the patient seeks curative treatment is a matter of personal decision, based on the patient’s understanding of a condition, prognosis, and through conversations with the healthcare provider. When the patient makes the choice to try to find a cure for a condition, the palliative care team will still be available to provide comfort and compassion if difficulties are encountered during the course of care.

**Analgesic**

As stated, pain control is a significant part of palliative care. A majority of patients who utilize palliative care services suffer from some form of pain that would benefit from analgesia. The interdisciplinary care team may spend a portion of their time coordinating efforts to ease the patient’s pain by utilizing different measures and evaluating their success in bringing comfort.
Pain management is such a common component of palliative care, yet adequate pain control is a complex process that is fraught with challenges associated with maintaining holistic patient care. Further complicating matters is that a patient’s pain may be manifested in ways that are different from other patients, whether or not they share the same diagnoses. Some patients have chronic pain that is ongoing; it may be punctuated with episodes of acute pain that could indicate disease complications. Some patients have little to no pain until they reach a certain point in disease progression and their pain becomes constant. The varying clinical presentations of pain can make symptom control difficult.

Fortunately, caregivers have various resources available for pain management. The most common element is administration of pain medications, including opioid and non-opioid analgesics. These drugs each have their own benefits and side effects; they may provide pain relief and comfort to the patient when given but they may also place the patient at greater risk of some other types of complications.

The physician determines the type and amount of pain medication to give, but many team members are involved with ensuring that the patient stays comfortable while utilizing the analgesic regimen. The nurse may be the one to administer the prescribed drugs and may monitor for side effects or ensure that the medication is working appropriately. The physical therapist may request that the patient receive a dose of pain medication 30 minutes before starting therapy since the process can be painful. The social worker might note that the patient seems drowsy during their meeting about financial resources since a recent dose of opioid narcotic administration. All of this information must be coordinated and brought together when the team meets to ensure that pain control and analgesia is at the right balance for
the patient; enough to allow the patient to remain comfortable but not so much that complications are suffered.

Patient caregivers may administer analgesia through a variety of methods, depending on the patient’s ability to take the drugs. Analgesic medications are typically available through oral, sublingual, intramuscular, topical, or intravenous preparations. When considering the type of drug to administer based on the patient’s condition, the nurse can take into account the World Health Organization’s (WHO) analgesic ladder, which considers the amount of pain the patient is experiencing and offers suggestions for pain control methods based on the pain level. For example, a patient who is experiencing mild pain (Step 1) may be adequately treated with non-opioid analgesics and adjuvant medications. As the level of the patient’s pain increases, he or she will need a stronger drug in response to continue to keep him comfortable. If he reaches the point to where he is in severe pain (Step 3), the provider should administer a combination of a strong opioid with a non-opioid analgesic, as well as an adjuvant drug.

Pain control is complex. It requires continuous communication and coordination of efforts among all caregivers. Because pain can impact so many facets of the patient’s life, there is not one team member who is impervious to dealing with pain control for the patient. Rather, it must be recognized that all of those on the team work together to provide analgesia as part of acknowledging the importance of patient comfort and symptom relief.

**Benefits**

The diagnosis of a serious illness often leads to many more questions than answers for patients and their families. People in these situations may feel
overwhelmed with their choices for care or may wonder if palliative care is the right decision. Some patients may need further education about their options for palliative care, what it means to receive this type of care, and the benefits to utilizing it under difficult circumstances.

Palliative care seeks to support and assist patients with achieving care goals, including pain and symptom control, improving feelings of patient independence, supporting continued patient functioning, and planning for contingencies in the event of an unforeseen occurrence. Engaging in palliative care has been shown to improve patient quality of life and studies have shown that it may slightly lengthen the lifespans of some patients with terminal illness.\(^\text{100}\)

Patients may be misinformed about what palliative care is and whether they have this option for their care. They may confuse palliative care with hospice or reason that they since they do not require late-stage or end-of-life care, they are not eligible for palliative care. Furthermore, some care teams may form to provide palliative care but only do so at much later stages of care or when the patient is in the final stages of illness. While the patient may still benefit even by receiving palliative care during a later stage, if he or she could benefit from the coordinated efforts of the team to improve quality of life, then the patient should receive palliative care as soon as it is feasible.

\textit{Pain and Symptom Control}

One of the most important benefits to the patient is the focus on pain and symptom control as part of caregiving. The patient may need education and guidance for how to best manage an illness and symptoms. The patient is a member of the palliative care team and should work with team members to come up with a plan of care that will help to control symptoms, but can also
be taught about the things that can be done to manage the patient’s care as well. For instance, the patient’s family may not be aware of the person to call if they find that the patient is suffering breakthrough pain from an illness. Through education and instruction, the family can learn how to continue to provide caregiving measures to the patient that is in coordination with the team’s plan of care.

Control of pain and uncomfortable symptoms also promotes quality of life, which is central to palliative care. When a patient does not understand the tenets of palliative care or is misinformed about what it means to receive this type of care, he or she could miss out on the opportunity for better symptom control and thorough management and coordination of care services. When symptoms are under control, the patient can experience more joy, greater freedom from stress, and improved feelings of well-being. The patient may have been living with a condition long enough that he or she does not know any other way of living except for one full of pain or discomfort. By working with the palliative care team, the patient will learn that it is possible to control negative symptoms from an illness and to experience more freedom and independence.

*Communication*

Because of its holistic nature, palliative care seeks to assist patients and families in a multi-dimensional manner, utilizing various disciplines. Professionals from these different backgrounds work together as a team and review the patient’s care needs on a regular basis, making adjustments as needed. The team may determine that the patient would benefit from a certain type of therapy aimed at reducing treatment side effects and it would be implemented into the patient’s plan of care. By the next meeting,
however, the priorities of patient care may have changed, based on the patient’s health status and response to prescribed therapies.

Coordination across the various disciplines involved in patient care requires effective communication between all team members and the patient and family. Team members must regularly check in with each other or meet together to discuss the patient’s care and stay up to date on the patient’s status. The patient also benefits in that he or she may have access to all of the patient’s care providers at or near the same time, resulting in less fragmented care.

This type of care coordination has been shown to result in greater patient satisfaction with care, as the patient and family may be more likely to feel listened to and cared about. Team members are available to answer questions and provide support, which improves the patient’s sense of well being but the patient may also be more willing to participate and cooperate with care measures.

Regular communication between patients and palliative care members will promote establishment of appropriate patient goals for care and will outline the interventions needed to help the patient reach care goals. This communication is essential for the patient to best convey personal preferences and desire for care.

*Emotional Support*

Emotional support for the patient and family is a key element of palliative care. By providing emotional support, the patient’s needs are met on more than one level of care. For instance, a patient may struggle with depression and feelings of sadness because of the serious nature of an illness. He or she
may find comfort in talking with the psychologist on the palliative care team who can help the patient to understand that these are normal feelings. Together, they come up with coping mechanisms that the patient can utilize whenever he or she starts to feel depressed and continues to work on a self-acceptance of the situation.

This emotional support is beneficial in reducing the patient’s level of distress, which can be detrimental to overall health. A person who suffers from depression and who has little emotional support is more likely to have poor physical functioning and poor quality of life. Depression is associated with increased length of stay in the hospital, a higher mortality rate, and increased utilization of healthcare services. Because depression is a common response that develops among those struggling with serious illness, the palliative care team must recognize the importance of emotional support for these affected patients and deliver care that is appropriate and timely, and that addresses fundamental issues that are impacting the patient’s emotions and causing psychological distress.

Caregiver Support

The family members of the palliative care patient may suffer greatly during the time of the patient’s illness and associated treatments. Unfortunately, when much of the focus is on the patient and his or her needs for care, the needs of family members and patient caregivers are often overlooked. The holistic nature of palliative care recognizes the importance of family members in the patient’s life, their role as caregivers, and the potential strain they are experiencing during the patient’s illness.

Caregiver support involves attending to the needs of those family members and loved ones who are engaged in-patient care activities. Patient caregivers
also experience stress and strain as a result of the patient’s illness and their caregiving duties, which can lead to detrimental health outcomes. The palliative team must recognize the importance of providing caregiver support and helping involved family members to have time for rest and to take a break from their duties from time to time. The caregiver who does not take time away from constant patient care activities is at greater risk of becoming exhausted and experiencing burnout, which will ultimately cause negative consequences for both the patient and the caregiver.

Another benefit of caregiver support is that after the family member takes some time away from patient care duties, he or she may return to working with the patient with renewed energy and a sense of purpose for the patient’s care. The caregiver will be less likely to suffer the physical and psychological effects of stress that would otherwise develop without support from others or the palliative care team. Ultimately, support and assistance for the caregiver results in better quality patient care, less pressure on the patient and the family, and improved relations and communication between team members and the family of the palliative care patient.

**Hospice Care**

Although death comes to everyone at some time or another, many people remain fearful of the subject and do not wish to discuss it with those close to them. People frequently walk around most of each day without giving their death much thought; yet it will happen eventually for each and every person.

For the person who has been diagnosed with a terminal disease, or for someone who has reached a point in managing his or her disease, where attempts at treatment have become futile, the thought of death is much
more prominent. The terminal patient may think about death all the time, knowing that it is approaching soon, and yet may still be filled with fear and dread. Hospice care is designed to support and coordinate care for a terminal patient through the times of fear and worry about upcoming death and to approach it with dignity and grace.

In a time when death is inevitable and will occur soon, hospice care provides an element of peace and comfort for the patient and family. Hospice care is a program designed to care for terminally ill patients and their families. This contrasts to the potential for dying alone or in great discomfort. Most people prefer not to spend their final days or weeks in an unpleasant, noisy, or cold environment of the hospital, going through treatments that may be painful or ineffective. Instead, hospice care makes it possible for patients to spend their final time in the presence of loved ones and with support and warmth from friends and trained hospice caregivers. Because of this, choosing hospice is not about giving up at living life; instead, patients and their families who choose hospice care in the final weeks and months of life do so to make the most of the life that they have left.

The concept of hospice dates back hundreds of years; the word "hospice" comes from the Latin word *hospes*, meaning "host."² The term has been used to describe the concept of hospitality and the mindset that sick or traveling persons were given shelter and rest and were given a warm welcome and kind treatment. The modern concept of hospice care was developed by Dame Cicely Saunders, an English physician who originally trained as a nurse and who began working with terminally ill patients in 1948. Saunders eventually went on to found St. Christopher’s Hospice in London in 1967, which was designed to give specialized care to dying
patients and was based on the knowledge and experience that Saunders had obtained from providing holistic care to terminal patients.³

The first hospice center in the United States, the Connecticut Hospice, was started in 1974 by Florence Wald of Yale University, along with two physicians and a chaplain, in Branford, Connecticut.³ Wald had spent time working with Saunders in the United Kingdom, learning about the concepts of holistic care for dying patients and studying the importance of supporting dignity for terminal patients. Since that time, more hospice facilities opened their doors across the country after also seeing the importance of holistic hospice care. Through legislation and ground breaking political action, hospice care has received funding and benefits to provide support and comfort care to dying patients who receive this special kind of service. As of 2007, there were approximately 4,700 hospice programs operating in the United States.²

Although there have been many advances in the concepts of hospice in recent decades, many people are still fearful about entering a hospice program. Reasons for this vary but they are often related to the difficulties of accepting a terminal condition and recognizing that death is inevitable, and there is reliance on modern medicine for hope of a cure for their condition instead of accepting death. Some patients fear the effects that entering hospice care will have on their family members. For instance, a dying patient may not want to place a financial burden on family after the patient is gone because healthcare services for palliative care had been utilized until the time of death. Another patient may realize that family is in denial about the extent of his or her condition and that hospice is imminent as an option because the family members are unable to face the patient’s diagnosis of a terminal condition.
In reality, hospice is designed to manage the patient’s condition so that the transition into death is smoother for the patient and family. While it requires that involved patients and family must at least recognize that death is a possibility that does incur healthcare costs, hospice supports the patient’s emotional comfort and upholds those values that are important to the patient and to family. The basic concepts of hospice care include the idea that death is understood and that it must be accepted, the hospice patient and family will be cared for by an interdisciplinary team who can provide comprehensive and holistic care, and that the family and the patient will be supported through painful and uncomfortable symptoms as well as through grief and bereavement throughout the process.

Delivery of hospice care varies by situation and there are often few restrictions as to who can receive this type of care. A dying patient does not need to be of a certain age or have a certain terminal condition, with the exception of whatever illness or condition the patient has developed, and be expected to eventually not survive. Some patients use hospice care for only a few days before their deaths, while other patients may receive this special care for months.

The course of hospice care is designed and managed by an interdisciplinary team made up of professionals from varying backgrounds. These professionals support planning for comprehensive patient care during hospice care so that the patient will be comfortable and well cared for until death. The exact patient criterion that determines eligibility to enter a hospice program will vary between programs. However, most hospice programs require that patients utilizing their services have been diagnosed with a terminal illness and that they are choosing to seek palliative care and
comfort measures for their symptoms, rather than seeking a cure for their condition.

As a general rule, a patient who enters hospice care must:

- Have a terminal and progressive condition that involves a limited life expectancy
- Choose to receive palliative and comfort cares rather than focus on finding a cure for a condition
- Have a life expectancy of six months or less (although in some locations, the patient may have a life expectancy of one year or less)
- Have a diagnosis from a physician on record that states that an illness is incurable

Programs vary in their criteria to accept patients according to their health conditions and life expectancies. When hospice programs receive funding from Medicare, though, their patients often are required to have certain eligibility criteria to be considered as part of the program. Most patients have at least one family member who is available as a support person, although there are some programs that are specifically designed for those who live alone or who do not have family support.

If a patient enters a hospice program and survives longer than six months, he or she will generally not be released from the program. Often, as long as the patient’s physician can certify that the patient has a terminal and progressive illness that will shorten life, the patient can remain under hospice care.
Criteria And Goals Of Hospice Care

Hospice care is typically designed for those who have a prognosis of six months or less to live. Hospice often includes elements of palliative care, which keeps the patient comfortable so that the final stages of life are in comfort. Unlike traditional forms of medicine, the goals of hospice care are not to find a cure for the patient’s condition or prolong life. Instead, treatments are often aimed at controlling symptoms, and improving or maintaining quality of life for as long as possible instead of slowing or eliminating the disease process.

Quality of Life

Hospice care is holistic care in that it focuses on all aspects of the patient’s life. Hospice care is not just directed at one element of the patient’s condition, such as providing pain control or support for emotional health. Instead, hospice considers all aspects of the patient’s care needs, including the physical, emotional, spiritual, and social factors that make up the patient’s unique situation.

Quality of life describes a concept in which an individual experiences a feeling of wellbeing and comfort. It does not necessarily mean an absence of discomfort or of difficult feelings, but rather an ability to cope and contend with the situation at hand in a positive manner. The elements that make up an individual’s quality of life are exclusive to his or her particular case; what one person deems to be valuable in determining care quality may not be as effective to another person. For example, a patient may feel positive and have a healthy sense of wellbeing when the patient knows that family and friends surround them, even if the patient is unable to get up out of bed. Alternatively, another patient may place a higher value on body movement...
and the ability to get around, suffering reduced quality of life with increased periods of immobility.

The palliative care team works with the patient to determine what factors are most important and what would support quality of life. Obviously, there are some factors that are common to almost all patients; for example, keeping the patient comfortable and managing pain is a universal concept and factor that promotes quality of life for anyone. The provision of care is done by keeping the patient’s values and preferences in mind to achieve the best possible level of quality of life appropriate for each patient.

**Pain and Symptom Control**

A second goal of palliative and hospice care is to relieve patient suffering, regardless of the patient’s stage of life or severity of the illness. Symptom control may need to be aggressive for some patients, particularly, in cases where the patient is experiencing negative symptoms that do not otherwise respond to conventional treatment. An example lies in the administration of pain medication for the patient suffering from severe pain and discomfort as a result of the disease process. The doses appropriate for pain management as a standard of care for patients, *i.e.*, those in the hospital recovering from surgery or recuperating from another type of illness, may not be enough to control the pain of advanced disease. The patient may need much larger doses of pain medication, more frequent administration of drug doses, and pain medication given around the clock instead of as needed or prn.

Symptoms of life-limiting disease may vary between patients, which is why it is important to continue to assess the patient’s condition as the disease progresses. Disease symptoms and side effects of medications may cause transient effects that are prominent during one assessment but then change by the time of the next interaction. Alternatively, some symptoms develop
and are unchanged and unresponsive to caregiver attempts at comfort measures. The hospice care team must continually assess patient symptoms so that they can understand what management measures are working and controlling discomfort and what needs to be modified.

It is important to note that some patients, particularly those with advanced disease, may have difficulty communicating their levels of pain and are at risk of being undertreated for pain. A person with advanced dementia or a patient with an altered level of consciousness would be at high risk of suffering from pain and uncomfortable disease symptoms that may be difficult to control. It is therefore important to establish regular communication between team members and the patient’s family to determine the best course of care for ensuring that the patient is kept comfortable. Often, family members can provide insight into the patient’s state; the hospice team should work with the family to come up with a system of symptom control that will sufficiently manage the patient’s pain in cases where the patient is otherwise unable to communicate needs.

Common symptoms may include pain, nausea and vomiting, dyspnea and increased work of breathing, constipation, anorexia, and cognitive changes. The effects of these symptoms, as well as the success in their management, impact the patient’s wellbeing in other areas of life beyond just the physical component. Although providing symptom control will increase the patient’s comfort levels, it has also been shown to cause other positive effects in the patient’s life, including increasing positive feelings and supporting spiritual beliefs about being cared for and attended to while ill. This holistic provision of comfort is the cornerstone of palliative and hospice care.
Location of Hospice

The location of hospice care refers to the place where the patient will receive services. This may change throughout the course of the patient’s care. For instance, a hospice patient may start out in a private home being cared for by family members and home health nurses and therapists who visit the patient there. As the patient’s condition progresses, however, he or she may choose to move to an inpatient facility where care is provided on a 24-hour basis. There are several different options of location for where patients may receive hospice care and this often requires some decision making on the part of the family when making plans for the patient and when considering their financial abilities. Ultimately, patients and their families have a choice about where they should spend their time through hospice care.

Patient’s Home

The most common location of hospice care takes place in the patient’s home. Patients choose this option because home is a familiar environment where family or friends can surround them. In a typical hospice situation that occurs in the home, a family member or spouse cares for the terminal patient, but a hospice nurse and other members of the hospice care team provide guidance and direction for the patient’s care. Healthcare providers from different disciplines who are caring for the patient and who make up an interdisciplinary hospice team may make home visits to help with some patient care activities or to plan strategies for patient care.

In the U.S., hospice care is usually focused in the home, and this location is typically supported by the industry as a whole, as it is recognized that the home is often the center of the patient’s life and that dying at home prevents a patient from spending final days and hours in a sterile environment filled with medical equipment and technologies. Because death
can be frightening, many people who are facing the end of life want to hang on to something that is familiar and comforting; for many, this is their home.

If the patient develops short-term complications as a result of a medical condition and requires more intensive care, a registered nurse may provide continuous care on a short-term basis during the time of the crisis. Continuous nursing care in the home involves nursing care on a constant basis where the nurse provides ongoing support and care for the patient’s condition until it has stabilized. For example, if a patient develops severe nausea and vomiting that causes dehydration as a result of a condition, a nurse may provide continuous care in the home by administering medications, providing additional fluids, and supporting the family until the patient’s condition stabilizes. The patient would then revert to routine home hospice care as before the crisis occurred.

Although hospice patients who stay at home are frequently cared for by family members or loved ones, they may still use the services of home health aides to assist with some caregiving tasks, such as bathing. The addition of a home health aide for help with these personal care services not only assists the patient with these tasks, but also gives family members a little time off from regular caregiving duties.

The hospice care team may make modifications to the patient’s plan of care that provides allowances for the patient to remain at home as long as possible, even until death. For instance, the team may make arrangements for a hospital bed to be brought in to the patient’s home and for the patient to be able to use patient controlled analgesia (PCA), a self-administered method developed for pain control while the patient remains at home. For
some, the desire to be at home is so strong that they want to make accommodations to accomplish it; this location is one of the most common choices for care because of what it signifies. Home is often a safe and comforting place that can give the patient an opportunity to die in a place of peace and rest.

**Hospice Center**

Approximately 20 percent of hospice programs are affiliated with hospice centers, which are designed to provide care and comfort to dying patients. This type of facility often has a home-like setting that is comfortable for the patient and that allows family members to either stay with the patient in a room or to be nearby at all times. In many cases, the use of a stand-alone hospice center is reserved for end-of-life care and support during the final days or weeks of the patient’s life, rather than being used on a long-term basis.

A hospice center offers several advantages that other locations may not be able to provide. Because it is a designated hospice center, all of the staff are familiar with and have experience working with dying patients and know the challenges associated with this care. People who are inexperienced or unsure about what to do in the patient’s situation will not care for individuals that choose this type of facility. There are nursing staff available at all times to provide care measures and administer medications at a hospice center so that the family is not alone to provide caregiving duties. Additionally, the staff is made up of hospice team members, so those who work in the facility are able to communicate relatively easily with each other and can coordinate their care efforts.
Finally, the hospice center, because the staff understands the associated difficulties for the patient and family, typically has created an environment that is comfortable, quiet, and peaceful. Family members may be able to stay with the patient and may have access to their own care measures within the facility, such as a comfortable bed in the room with the patient so that they can be nearby during the final hours. The type of services offered vary between facilities, but a freestanding hospice center is usually designed to provide support services for the patient and family so that he or she will be comfortable and well cared for during the final days of life.

*Skilled Nursing Facility*

A skilled nursing facility is an organization that provides care around the clock for residents. It may vary in terms of the type of structure it provides: some skilled nursing facilities are similar to long-term care centers and a hospice patient may be cared for in one section of this residential facility. The skilled nursing facility may also resemble a short-term nursing center or rehabilitation facility, where hospice patients receive services such as medical care, pain control, physical or occupational therapy, or other services as part of palliative care during hospice.

A skilled nursing facility is a location that provides medical care for patients who may be unable to stay at home for their care. A hospice patient may have few sources of support or no family members available to help with care and may choose a skilled nursing facility for help with medical care. The skilled nursing facility may not necessarily be focused on hospice patient care and the patient may be cared for within an area where other residents live, all of whom may have varying degrees of abilities and care needs. Some skilled nursing facilities have a wing designated for inpatient hospice care, in which hospice nurses and staff care for all patients in that area.
The skilled nursing facility is beneficial in that nursing staff is available 24 hours a day. As the name implies, the nurses and staff are skilled in patient care and are able to provide comfort care, help with activities of daily living, and assistance with transfers and repositioning. Another advantage is that the patient may reside in a skilled nursing facility for a longer amount of time when compared to a stand-alone hospice center. The facility is designed to accommodate residents who may stay for months or years and who require skilled nursing care.

The hospice patient may already be a resident of the facility and may transition to hospice without needing to move or may enter the facility when a decision is reached to have hospice care. If the patient develops complications or dies while in the nursing facility, the staff will be with the patient and provide care moment by moment until the end of the patient’s life.

Hospital

When the patient receives hospice care in the hospital, he or she is often given specialized care. The patient in this situation has access to the various resources and different types of equipment that is available in the hospital but that may not be accessible in the home. This can be particularly beneficial if the patient develops complications as a result of a condition. For example, a patient who is in hospice because of cancer who develops seizures may be able to undergo diagnostic testing to determine if the cancer has metastasized or if there is another reason for the seizures. This enables the healthcare provider to offer better symptom control and reduces the need for the patient to attend appointments or to go into the hospital to have the testing done.
There are many other benefits of hospice care in the hospital as well. As with skilled nursing facilities, the hospital has nursing staff and other support staff available 24 hours a day to be near the patient and to provide support whenever necessary. The nurses who care for hospice patients in the hospital have access to prescribing providers that they can call at a moments notice, if necessary. If the patient requires more intensive care than the family can give, the nursing staff in the hospice department can perform procedures and be available right away to administer medications or provide comfort measures.

Families may reach the point that they feel overwhelmed by caregiving duties. A family member may feel love for the patient but the requirements of providing end-of-life care can reach a point that they become very taxing. The caregivers at the hospital, including nursing assistants and volunteers can help to provide some of the tasks of activities of daily living for the patient, which serves as a form of respite for some family members who feel overwhelmed. Many of the members of the interdisciplinary team may work at the hospital or may be closely affiliated with the facility, making it easier for team members to meet together.

When the patient reaches the end of life, the hospital staff is there at all times to provide care and comfort, to pronounce the death when it occurs, and to provide post-mortem care for the patient's body. The hospital may have easier access to contact with the mortuary or funeral home to take care of the patient's body and prepare for a memorial service. Some hospitals have programs in place that they provide ongoing care for a certain period of time for the family during bereavement. Based on these and many other benefits, some patients choose hospice in the hospital to have the advantage of specialized and immediate care.
Alternatively, some patients do not want hospice care in the hospital because they associate it with a sterile environment that is cold and indifferent. They do not want to spend their final days and hours surrounded by medical equipment and being cared for by people they do not know well. Time spent in the hospital may be too expensive for some patients, particularly if they require services from an acute care unit such as the Intensive Care Unit where they may be high acuity requirements of the staff. Fortunately, those who participate in care planning of hospice patients and administrative staff at the hospital tend to focus on maintaining hospice patient care at a lower level of acuity — in step-down units, transitional care, or even in a specific low-acuity area of the hospital designed specifically for hospice patients. Using lower acuity services will allow more focus on family members helping the patient with many tasks rather than relying on nursing staff, and the costs are lower and hospice care in the hospital may be more affordable. Furthermore, many private insurance plans cover some inpatient services for hospice care, and inpatient care is included in some facets of Medicare coverage.

Some nurses and hospital caregivers may not be comfortable providing hospice care if they have little experience in this area. They may not be aware of the unique needs of hospice patients when the majority of their previous care has been focused on providing treatments and curative therapies. For example, a nurse who has cared for inpatients in the hospital may be accustomed to providing pain medication to control acute pain but with the goal to eventually help the patient wean off of intravenous pain medications so that pain can be controlled at home. When caring for a hospice care patient, the same nurse may not be familiar with the sometimes greater amounts of pain medications required to manage a
terminal patient’s needs and may fear that the patient will become addicted to the pain medication.

The hospital offers benefits and disadvantages for those who choose this type of end-of-life care. Certainly, the hospital is one facility that has access to almost all of the acute care measures that the hospice patient might need, and staff are available at all times. There may be areas of the hospital that are designated for hospice patients, as well. Because of the skilled nursing care available, some patients and their families see the hospital as the most suitable option for hospice care.

### Death As A Stage Of Life

Hospice is looked upon as a concept, in which all members of the team, as well as the patient and family members are aware that the end of life is coming. Death is viewed as a stage of living and of being, rather than being viewed as an end to an individual’s purpose.

There is a misconception that by entering hospice, a patient is choosing death instead of trying to fight to live; or that hospice ultimately accelerates the dying process. While starting hospice generally involves recognition by the patient that death is coming, it may not always be easy to accept. A patient who is in a hospice program may still vacillate back and forth between accepting death and hoping for a cure. However, most patients do come to recognize that the hospice program allows them to live well and that death is inevitable.

The hospice program also helps patients and their families to understand that it is okay to have mixed feelings about death and dying and that sometimes it is difficult to accept. The caregivers on the interdisciplinary
team may spend some time working with patients to help them understand the finality of death and to work through some issues that may be preventing them from accepting their death, such as saying good-bye to loved ones or fearing the unknown.

Because the team works together to coordinate their caregiving efforts, the patient receives comprehensive care that covers a multitude of services. The hospice patient does not simply receive basic medical care or emotional support. Instead, care is full and inclusive, attending to various patient needs, from physical and practical solutions for caregiving to emotional and psychological support for both the patient and family.

**Basic Medical Care**

Because hospice treats the whole person, one of the most significant tenets of hospice care is the provision of basic medical care for the patient. When the patient has reached the point of hospice, he or she is no longer seeking curative treatments for a condition. However, the patient still can receive palliative care to maintain quality of life and control some symptoms of illness. Basic medical care involves providing the patient help with basic needs for daily living, medications and therapies to control symptoms, and utilization of medical equipment and supplies.

The state of the hospice patient’s health may vary between patients, depending on the patient’s condition and the time at which hospice is entered. Some hospice patients remain active for weeks or months until they reach the end of life, while others may enter the hospice program very close to the end of life and are inactive.
The type and amount of basic medical care is tailored to meet the needs of the patient and will change and evolve as the patient’s condition changes or deteriorates. A caregiver may provide some assistance with basic medical care at the beginning when the patient enters hospice; as time elapses, however, the patient often needs more help as the end of life approaches.

Basic medical care may be considered as help with activities of daily living and assistance with pain and symptom control. The nurse or caregiver may help the patient with basic medical care through activities of daily living by assisting with transfers, helping with walking or getting around using assistive devices, assisting with bathing and grooming, or helping with eating and getting enough nutrition. Again, the amount of assistance with basic medical care depends on the patient’s abilities and condition.

Basic medical care utilizes many members of the interdisciplinary team. A home health aide, occupational therapist, or nursing assistant may assist with activities of daily living by helping the patient with oral care and to brush teeth, bathe or shower, or get dressed in the morning. The patient may need help getting into and out of bed, which may require help from a nurse or nursing assistant who can utilize transfer devices. A physical therapist may work with the patient to help with ambulation, fit the patient for a walker, or assist with range-of-motion exercises that maintain muscle tone and flexibility.

Other team members are also involved in providing basic medical care that the patient needs, including the registered nurse, dietitian, respiratory therapist, pharmacist, and physician. The nurse, when providing direct care to the patient, is able to give medical care and support for the patient’s needs, which could consist of a range of activities. The nurse may provide
such types of basic medical care as applying supplemental oxygen when needed or performing dressing changes. Other team members are involved in providing care that helps to regulate the patient’s breathing, ensure that the patient gets enough dietary nutrients, and has the correct medications needed.

Pain and symptom control is another tenet of basic medical care provided for the patient during hospice. This may come in the form of pharmacological or non-pharmacological measures. The physician, after receiving input from the interdisciplinary team, prescribes medications and therapeutic interventions that would best help the patient with controlling symptoms. The type of drugs needed and their route of delivery depend on the patient’s unique situation. One hospice patient may suffer from intractable pain that requires PCA and prn medications for breakthrough pain, while another hospice patient may require little to no pain medication at all. The team will decide what medications would be most helpful for the patient based on his or her condition and reports of symptoms.

Non-pharmacological therapies are also implemented as part of basic medical care to control many of the patient’s symptoms. Non-pharmacological therapies do not utilize drugs, but instead work to control the patient’s symptoms through other methods. Various team members are also involved with utilizing non-pharmacological methods of pain and symptom control for patients, including the nurse, physical therapist, occupational therapist, and nursing assistant. Some types of non-pharmacological interventions that may be included as part of symptom control involve deep breathing exercises, relaxation techniques (hypnosis or massage), distraction, hot or cold therapy (warm packs, gel packs, or cold cloths placed on certain areas to control pain), pet therapy, in which a
patient spends some time petting and interacting with a service animal, and aromatherapy, which is used to promote relaxation and enhance feelings of wellbeing.\textsuperscript{39}

It is important to note that the patient may want to incorporate some elements of complementary or alternative care while managing health needs. As with mainstream medicine, complementary and alternative medicine (CAM) in this situation would not necessarily be designed to treat the patient’s condition or to find a cure. Instead, its focus would be on keeping the patient comfortable and improving his or her quality of life while utilizing hospice services.

There may be a range of complementary or alternative therapies that the patient would like to use. Complementary therapy describes a treatment or measure that is used in addition to mainstream medicine. An example might be that a patient uses a PCA for pain medication but also incorporates aromatherapy to help with relaxation and distraction to manage pain as well. Alternative therapy is that which is used instead of mainstream medicine. A patient may use alternative therapy in some areas of health care while using mainstream medicine in others. For example, the patient may take medicine for pain associated with a cancer diagnosis but may choose to use herbal supplements to control nausea that is caused by the pain medication.

Complementary and alternative therapies used among palliative and hospice patients may be grouped into four different areas, including mind-body interventions, manipulative therapies, biologically based therapies, and whole medicine systems.\textsuperscript{32,38} Mind-body interventions seek to connect the body and the mind through practices that involve focus and concentration.
Examples of these types of interventions include meditation, yoga, prayer, and biofeedback.

Mindfulness meditation is a concept that helps some patients to overcome suffering by focusing on the present moment and what is happening at that exact point in time. Mindfulness meditation does not seek to change the person practicing it; instead, it focuses on accepting what is happening, being present in the moment, and acknowledging the situation, regardless of its outcome. The process started through Buddhist traditions, but has evolved into a common type of mind-body intervention that can be used by hospice patients to help them accept and live with their current circumstances, which can bring them peace.

Manipulative therapies are those that involve body movement and adjustment of muscles and tissues to bring pain relief and promote relaxation. Examples of some of the most common manipulative therapies used in CAM include massage therapy, chiropractic care, Reiki, craniosacral therapy, and healing touch.

Massage therapy is one area that has been growing in use for hospice patients. It has been shown to improve pain and promote quality of life in patients, including those who receive hospice and palliative care. The act of massage is beneficial for improving blood flow, release of endorphins, and promoting relaxation, which can help the patient to feel better physically. Because the focus of hospice is on quality of life that remains, rather than curative factors, massage is one type of complementary therapy that may help to promote a patient’s greater sense of wellbeing during the last months of life. The massage therapist who works with a hospice patient promotes quality of life by being present for the patient, providing comfort.
through touch, which is essential to life and wellbeing, being empathic to the patient’s unique condition, and providing focused care that concentrates on the patient’s needs and helps the patient to feel valued and accepted.

Biologically based therapies utilize natural products such as botanicals or herbal medicines to manage symptoms of the patient’s condition. The patient may use such therapies as vitamin and mineral supplements, botanical components, or therapeutic diets. Botanical medicine is a type of therapy that uses plant-based products to control symptoms and to help the patient to feel better. Some botanicals have pharmacological properties that may be used to control certain symptoms, such as pain or depression. Some types of botanical products a patient may use include ginseng, black cohosh, or valerian.

Whole medicine systems are those that comprise an entire method of thinking and living; these may utilize some of the principles of mind-body interventions or biologically based therapies. Examples of whole medicine systems include Traditional Chinese Medicine, homeopathy, Ayurveda, and naturopathic medicine. Some patients may utilize some of the principles of Traditional Chinese Medicine (TCM) for symptom relief; acupuncture is one of the most common elements of TCM that is used. It involves insertion of thin needles into the body along certain lines, called meridians, which are said to carry the flow of energy. Placement of these needles can stimulate the flow of energy or relieve blockages in energy flow that may be causing the patient pain, discomfort, or fatigue.

**Medical Supplies and Equipment**

Although a patient who utilizes hospice is no longer seeking curative treatments, he or she may still benefit from the use of some types of
medical supplies that can be used to deliver therapies or treatments of certain symptoms. Medical supplies and equipment are often classified as being durable medical equipment, self-care supplies, diagnostic equipment, and treatment equipment. As with medications and basic care interventions, the amount and types of medical equipment and supplies needed for each patient will vary.

Durable medical equipment (DME) is equipment that a patient uses for therapeutic benefits and that is used for managing a patient’s symptoms or illness. According to the Centers for Medicare and Medicaid Services, DME consists of items that are:

- used for medical purposes
- not useful for someone who does not have an illness
- prescribed by a physician
- reusable
- able to tolerate repeated use
- appropriate for use in the home

Durable medical equipment is called “durable” because it is designed for use on a long-term basis, or reused as needed. Examples of DME include such items as walkers, wheelchairs, commodes, dressing aids, bath chairs, hospital beds, artificial limbs, and oxygen concentrators. The hospice patient can use these items as needed for help and support with managing an illness. For instance, if a patient develops difficulty with walking because of the progression of illness, the patient’s physician may prescribe a walker or wheelchair for use so that the patient can still get around when needed. The physician prescribes the necessary item based on input from the interdisciplinary team; if the nurse or physical therapist assesses the patient
for ability to walk or transfer, the physician will have a better idea of what types of DME this patient would most likely need.

Patients who have Medicare Part B can have the costs of their DME covered when a physician prescribes it. A physician must write a prescription for DME in a similar way that a prescription is written for medication. With a prescription, the physician can deem that the medical equipment is medically necessary. The social worker on the interdisciplinary team may be able to help the patient and family determine what coverage they are eligible for to be able to pay for using DME, whether it is through Medicare or their private insurance company.

Self-care supplies are those that are most likely needed for the patient’s personal use but are still incorporated into the patient’s care. Many of these items are disposable or are only designed for short-term use, but they still benefit the patient’s needs and help to manage symptoms of the patient’s illness, or to perform activities of daily living. Examples of these types of products include incontinence pads, denture cups, and washbasins. Personal care items can usually be purchased through medical supply companies or through drugstores that sell these items; they typically do not require a prescription from the physician but caregivers and other staff on the interdisciplinary team, such as registered nurses or nursing assistants, often utilize them.

The nurse or caregiver who provides direct care of the hospice patient may use certain supplies and medical equipment that include diagnostic tools. These products do not necessarily diagnose a health condition that would warrant treatment while the patient is undergoing hospice; rather, they are often used on a routine basis or occasionally as the patient’s condition
warrants. As an example, when the nurse notes a change in the patient’s condition, he or she may utilize some kinds of diagnostic equipment for assessment and evaluation of the patient’s state. Examples of diagnostic medical equipment that may be used include blood pressure cuffs, thermometers, stethoscopes, and ophthalmoscopes.

Treatment equipment is yet another category of supplies that may be used for some types of patient care. Treatment equipment is used to manage the hospice patient’s symptoms and to improve quality of life, rather than being designated as curative equipment. If the patient develops complications as a result of illness, the nurse or caregiver may use treatment equipment to ease the discomfort of symptoms or to prevent the condition from rapidly worsening. As an example, if a hospice patient develops a pressure ulcer due to immobility, the nurse would utilize skin protectants and dressing supplies to manage the wound and to prevent infection. This is not considered curative for the patient’s condition, but it does prevent potential pain, deformity, and infection when this type of complication develops. Examples of other equipment that may be classified as treatment equipment include syringes and needles for dispensing medications, skin creams and barrier products, feeding tubes, oxygen tubing, and nebulizers.

**Counseling and Social Support**

Hospice and the process of dying can cause emotional turmoil for the patient and family; these situations require ongoing counseling and support. This can be provided through any member of the team during informal discussions and interactions while providing care. For example, a nurse may talk with the patient and provide support while caring for an ostomy appliance, as the patient expresses not liking the stoma and how it makes the patient feel inadequate as a person. This type of informal counseling can
occur at any time and caregivers should be prepared to provide comfort, counseling, and encouragement when needed.

The patient typically also benefits from formal counseling, in which a specific time has been set up for a caregiver to meet with the patient and possibly family. Counseling sessions can be ongoing and meetings may take place on a routine basis; alternatively, the counselor may assess the patient during an initial meeting and could determine that frequent counseling sessions are not necessary. Most people that utilize hospice would benefit from some amount of counseling, whether it occurs in an official setting or not. It may take place in a counseling office, at the inpatient care unit where the patient is staying, or in a location such as the patient’s home. A nurse, mental health therapist, or psychologist may provide the counseling. Many people also gain from spending time talking with friends or meeting with others in support groups that offer relaxed sessions to get together and talk about moods, feelings, and ongoing struggles associated with hospice care.

Counseling is the process of meeting with someone to provide guidance, education, and support. Some counseling situations involve the patient meeting with a counselor and the two have discussions about the patient’s current state. The counselor may offer information about how the patient can handle feelings, such as by developing coping skills or determining if he or she has any positive activities that may be engaged in to help with the patient’s outlook on the situation. Some forms of counseling involve specific types of therapeutic treatments that are designed to help patients with specific issues. Examples include cognitive-behavioral therapy (CBT), which involves taking note of how thoughts influence behavior and then working to change these thoughts to promote more positive behaviors. Eye-movement desensitization and reprocessing (EMDR) is a form of therapy in which the
patient undergoes activities that cause the eyes to quickly move back and forth; during the process, the patient thinks about certain memories or events that could be causing painful feelings and then works to develop new associations for those thoughts so that when they reoccur, he or she will have a different association with them. EMDR is often used among patients who struggle with traumatic histories and who have difficulty functioning emotionally because of memories or events that have occurred and that can be too difficult to overcome.

Effective communication through counseling has been shown to improve patient symptoms and to reduce overall distress. Counseling is focused on building a relationship between the caregiver and the patient and family, rather than instructing the patient about care or telling the patient what to do. A study by Ellington, et al., in the Journal of Palliative Medicine demonstrated that nurses who provide direct care for patients often have times for dialogue and discussion during the physical aspects of care, which is a process that provides opportunities for positive interactions, and discussion of a range of topics that can all be beneficial and supportive for the patient and family.41

It is important for the counselor to provide help and support for the patient and family by recognizing that people grieve differently and that they can accept their own method of dealing with grief in their own way. Hospice involves feelings of grief because the patient is dying; whether the patient and the family members accept this as a fact during the time of hospice or whether they struggle with it after the patient is gone can somewhat depend on the amount of counseling they receive during hospice. While it is inappropriate for the counselor to force people to recognize and accept their feelings, it is important to help these patients to understand that they may
be feeling a number of different emotions and that the counselor will be there to help them handle whatever feelings are there.

The counselor may also help the patient with activities that can assist with recognizing and dealing with some of the patient’s feelings. The counselor may encourage the patient to write a letter to him- or herself, to important people in the patient’s life, or to God to describe how he or she is feeling and experiencing at that time. The patient may be encouraged to journal and then the patient and counselor can talk about some of the topics brought up in the journal during the time between sessions. The patient may develop a scrapbook or collection of meaningful items to leave after he or she is gone, and write stories or poems that help to describe feelings. The counselor may provide the patient with books or reading materials that further talk about the patient’s situation, or may engage in activities such as role playing to help the patient talk about difficult topics.

The social worker of the interdisciplinary team often provides a great deal of social support to the patient during this time. Although other team members are also involved in this element of the process, it is the social worker that is a recurrent figure in helping the patient and family continue with social functioning. The social worker may provide resources and information about community services that the family can utilize. Some of these services are specifically designated for families and those caring for hospice patients in that they recognize the level of support required and the difficulty associated with this time. Some types of services or information that social services can provide include setting up home health care services for personal care for the patient while at home, arranging for a housekeeper to come in and help maintain the home or run errands, arranging for Meals on Wheels or another form of meal delivery service.
Setting up transportation for the patient and family, if needed, is also needed so that they can get to appointments or to the hospital for services, arranging for the family to have handicapped signage in their vehicles for preferred parking. Additionally, the social worker may coordinate respite care for the patient’s caregivers, and planning for a caregiver to tend to the patient while the family is taking time off through respite. The social support needed during the time of hospice is varied and extensive. Although it is one element of hospice care, it may take a substantial amount of time for the providers to work with the patient and family to meet these specialized needs.

**End-Of-Life Guidance**

End-of-life is the term used to describe patients who are not only suffering from a terminal condition that requires hospice, but that also have reached the point where death is close. There is not a specific point for everyone in hospice where this stage occurs; it depends on the patient’s condition. Some hospice patients may go through stages of illness so that their caregivers may better understand that they are closing in on the end of life. An example might include the stages of Alzheimer’s disease, in which the patient has lost most awareness of his or her surroundings, has become medically fragile, and requires constant care. Alternatively, there are many conditions in which it is unknown when the patient will enter the end-of-life stage.

Because each case is different, many families may not know or understand when their loved one has reached a point in hospice in which end-of-life care is needed. A physician can usually dictate as to when a patient has reached this point, but there are also some signs that will signify that the patient needs end-of-life care. Some signs or symptoms that the patient has
reached this stage include a repeated need for medical care or recurring hospitalizations because of infection or complications associated with the illness, a change in the patient’s cognitive status that is different from a normal level, even while receiving hospice care, a significant decrease in activity, an inability to perform activities of daily living as once done, and/or an inability to eat and take in adequate food and fluids.

During this late stage of life, the patient often requires much more extensive care. While care is palliative in nature and focuses on keeping the patient comfortable, the caregiver may have to perform many more tasks for the patient than ever before and the patient may become totally dependent on caregivers for performing any tasks at all. It is important for the interdisciplinary team to discuss the situation with the patient’s main caregivers to determine where the patient should be to receive the best care, while respecting the patient’s wishes for care and providing respectful care that continues to uphold dignity. This may mean that the patient should be moved to an inpatient hospice facility where the patient can receive care around the clock from nursing staff. Alternatively, the patient may remain at home to die with family nearby; keeping in mind that the family members providing most of the caregiving to this point may need a break or to have other caregivers step in to take over some of the demands of patient care.

Family members, while they love the patient and want to help, may not be aware of the toll that continuous care at the end of life can take. They most likely want to be present when the patient dies and they often want to show love and care for the patient during even the most difficult times, but it can also be exhausting and draining for family members to perform each and every task. It is therefore essential that interdisciplinary team members have ongoing discussions with family members to best determine the course
of the patient’s care by providing help and allowing for family members to rest.

Not all patients exhibit the same symptoms as they near the end of life but there are some symptoms that are commonly seen and that the caregiver or nurse must help the patient through to keep comfortable and to preserve dignity. This includes bowel and bladder care, as incontinence becomes more likely during this stage; the nurse should work to keep the patient as clean and dry as possible. The patient may be unable to eat or drink adequately and could become dehydrated; the caregiver can provide care to keep oral mucous membranes moist and offer sips of water if tolerated. If the patient becomes disoriented and confused, the caregiver can gently re-orient the patient to the date and time and take measures to keep the patient safe. Other signs or symptoms that also require ongoing and gentle care that often occur toward the end of life might include poor circulation that results in cold and clammy skin, dyspnea and labored breathing, and drowsiness or a change in level of consciousness.

The end-of-life period may last hours, days, or weeks for a patient. Some patients are able to die peacefully and some do not. At times, the patient may have reached the end-of-life stage and then may die in an unexpected manner as a complication of illness, not allowing the family to say good-bye in the final moments. Whatever happens that eventually takes the patient’s life, family and caregivers should be allowed to spend as much time with the patient as they need and take time to talk to the patient, hold the patient’s hand, and even provide reassurance to the patient if he or she expressed fear of dying or leaving others behind.
Respite and Support for Caregivers

In many cases, family members of the hospice patient are the primary caregivers. Although it is important to many family members that they are present with the patient and are there to provide care, family caregivers must take care of themselves as well or they will be of little benefit to the patient. The members of the hospice care team may need to remind family members on a routine basis that they take some time for themselves to recharge and so they do not experience burnout when caring for a hospice patient.

The family members of the hospice patient are also usually involved in developing the patient’s care plan. They may receive services themselves that differ from direct patient care but that are nonetheless important. Family members of the hospice patient might be attended to by the hospice care team and may receive counseling, referrals for support groups, information about financial resources, reading materials and print resources with guidance for patient care and self care, or prescriptions for medications that may help with emotions or as mood stabilizers, such as antidepressant medications.

The hospice team can initially assess the family’s priorities and the level of support available. The care team can provide support to the family when members of the team talk to family members, make visits just to spend time with the patient and family without including education or instruction, or make phone calls to check in with family to see how they are doing. One of the activities that the hospice care nurse or another member of the healthcare team might engage the patient’s family in would be to make a list of activities or items that would promote relaxation for the person. This may mean collecting a list of activities that the family member enjoys doing that
does not involve patient care, such as reading books for pleasure, gardening, or going to a restaurant with friends. Unfortunately, family members can become so caught up in patient care that they feel enormously guilty for taking time alone or for not being there with the patient. A family member of a patient may feel guilty for taking time to do pleasant activities when he or she knows that a loved one is suffering. When this scenario occurs, it may be helpful to remind family that they are more helpful to the patient when they are rested and not facing burnout from caring too much.

Respite provides a method of allowing the family member of a high-need patient to have time to rest and recharge. Respite is available as a program so that the main caregiver is able to take a certain amount of time away while someone else stays with the patient to provide care and to be present to meet the patient’s needs. The respite provider is usually someone who has been trained in patient care and who is informed about the patient’s needs so that the patient will continue to receive competent care. Knowing that the respite provider is capable also allows the family member to be more comfortable with taking time off, knowing that their loved one is in good hands.

Respite is most often provided when family in the home cares for a hospice patient. In these cases, respite is also provided in the home but the patient may also go to an inpatient healthcare facility for a short time to receive respite as well. During the period of respite, the patient typically receives the same types of services that he or she normally would under a family member’s care. For instance, if a family member spent time with the patient and a physical therapist came in to perform range of motion exercises while a nurse provided direct nursing care, the patient would still receive all of
these services during respite care except that the family member might be replaced by a volunteer or another caregiver who could sit with the patient.

As with many other services provided for hospice care, some amount of respite is covered by Medicare services, and specific conditions apply. This can be another reason why the family might choose respite care if they otherwise fear that they cannot afford it. Respite care is beneficial to allow the family member to take a break from caregiving duties and may be used to allow the family member to have time to simply step away and rest.

Additionally, respite may also be used for certain purposes, such as to provide caregiving coverage during a special event or if the caregiver herself becomes ill and cannot take care of the patient. For example, a family member who has been providing near-constant care for a hospice patient may want to attend a wedding of a close friend but may feel that she is unable to take the time off. In this situation, she may be able to take some time off and utilize respite so that she can have a break, attend the wedding, and know that her loved one is being well cared for.

After the patient dies the family members will need continued support during their bereavement. The social worker or other members of the hospice team may help family members as they prepare for the funeral or memorial service, including providing guidance for decisions that must be made for the service, the care and preparation of the body, whether an autopsy will be performed, and what to do to notify other family members or friends of the patient that he or she has passed. Hospice team members should also be available and willing to talk with family and follow up with them to check in on how they are doing in the weeks and months after the patient’s death. This may mean making phone calls to check the emotional state of the
family member or stopping in for visits to determine how well the family is coping with the patient’s death.

Many hospice programs offer bereavement counseling for a certain period of time following a patient’s death. This may include counseling, frequent visits, or transition to a support group to help family members as they learn to live without the patient and without providing regular caregiving to their loved one. For example, a certain hospice program may provide follow-up counseling and support for grieving loved ones for a year after the patient’s death, which may include regular phone calls, visits, or letters to family members, or even scheduled counseling sessions with a mental health provider as they learn to manage their feelings and deal with their grief.

Hospice Care Team

The interdisciplinary team is a central aspect of hospice care: this core group of people works together to provide care that covers the various aspects that patients and families need. As with the palliative care team, the hospice care team is an interdisciplinary group made up of professionals from various disciplines that bring their skills and expertise to the team. When the group meets together to discuss the patient’s condition, each member of the team can contribute insight and advice from their professional background. When taken together, all of the input from the various disciplines forms a comprehensive approach to patient care and the group recognizes the importance of meeting the patient’s physical, psychological, spiritual, and emotional needs, as well as other important needs, such as those for financial support, help with using medical supplies and equipment, and support for family and friends of the hospice patient.
The team of hospice workers presents a patient-centered approach that includes the patient and family members in decisions for care. The patient is also a central part of the team and may attend some of the team meetings or participate in decisions made as part of the group. Because the patient knows his or her own preferences and abilities during this time, the patient is an important member of the team and can say whether certain treatments are effective or if the plan of care should be changed. The team is responsible for arranging services, including obtaining medical supplies and equipment for the patient to use, making appointments for various forms of therapy that can help with some of the patient’s symptoms, and prescribing and arranging for comfort and pain-relief measures, such as through analgesics and non-pharmacologic measures.

Hospice care covered under many private insurance policies and services are also covered under Medicare and Medicaid, according to the Medicare Hospice Benefit, which was developed in 1983. Participating hospice programs must agree to provide care according to specified conditions of participation in order to receive financial coverage for their services. The Centers for Medicare and Medicaid Services have listed the services provided under hospice care that are considered to be covered benefits. These include:

- Nursing care or supervision by a registered nurse
- Therapeutic services, including speech, occupational, or physical therapy
- Medical social services that are directed by a physician
- Personal care services by a certified home health aide
- Homemaking services
- Medical supplies, medications, and medical appliances
• The services of a physician
• Counseling, including bereavement counseling and dietary counseling to help the patient to adjust to the idea of impending death
• Inpatient hospitalization for symptom management, such as pain control, which does not last longer than five days and is on an intermittent basis

Because death can occur on any day or at any time, there is typically a member of the interdisciplinary team who is on call to be available when complications arise or the patient dies. In this way, there is always someone available for support that the patient’s family can call when needed. Hospice is a frightening prospect for many people; there are also many who feel ill equipped to navigate the circumstances of using this type of care. They may not know what to expect for care or they may not understand how decisions are made. The threat of death may be so overwhelming for some that decision-making becomes very stressful and confusing. The interdisciplinary team works to provide essential guidance for patients and families, with each member of the team being available in their role and being there every step of the way.

**Social Workers**

The role of the social worker as part of the hospice team may vary somewhat between clients. The duties of the social worker, as with other members of the team, are focused on meeting patient needs for social services, but these needs will obviously differ between patients. Most social workers that become part of hospice care teams have experience working in other fields and with patients who are dying so that they can provide care and support during the time of hospice.
The hospice social worker operates off of the plan of care developed for the patient through the interdisciplinary team. The social worker may further work with the family to develop a plan of care for the patient that is specific to the social services the patient and the family requires. Then, the social worker functions according to this plan of care to provide services for the family. This may mean a variety of tasks, which are based on the identified needs of the family.

For example, a family of a patient in hospice may need support and extra information about accessing healthy food for the patient. The family may have always relied on their own abilities to access food and meals by grocery shopping and participating in meal planning and preparation, but with the development of the patient’s illness, they realize that they need more information about healthy meals that are easy for the patient to chew and swallow while providing enough nutrients. The social worker may help the family to set up services such as Meals on Wheels or other forms of food delivery systems, provide information about shopping and meal preparation of specific foods that the patient needs, or may help the family to find financial resources that will pay for specialized dietary planning and preparation. By working with the family, the social worker can help them to meet their specific goals that are needed for the patient’s unique situation.

Other tasks that the social worker may be involved in include helping families and caregivers to learn more about the caregiver role for a dying patient through educational offerings, providing information about times and locations of grief support groups, helping the patient and caregivers to fill out forms regarding advance directives, arranging for tours or informational meetings with different hospice facilities available in the area, assessing home safety concerns if the patient is being cared for in the home, and
helping the family access medical equipment or devices needed as part of patient care.5

The social worker can also provide information about financial benefits and resources that are available to the patient and family and that may be helpful for some of the economic difficulties the family could be facing during this time. Additionally, the social worker can help the family to determine if they have certain employment allowances through their jobs that could offset some of the costs, such as through sick leave, short-term disability, or bereavement allowances. Some employers may provide a benefit that covers the costs of time off for the patient’s funeral and that pays some of the expenses of the funeral service.

A social worker that works with a family during hospice requires specialized skills and experience in working with dying patients. End-of-life care may involve some ethical dilemmas, and the social worker could be in a position where he or she must help the family to make some difficult patient care decisions. This requires that a hospice social worker have experience with recognizing his or her own values and morals for decision making but also being able to be a third party outside of the decisions that the family must make. Further, the social worker must have enough social skills and must possess a certain amount of empathy for the families worked with so that the social worker can inform patients about their options for care in a personal, rather than detached manner.

While the social worker is part of the interdisciplinary team, he or she spends much time working independently to meet with the family. The social worker must be an independent worker and have the knowledge to be able to provide information to families without requiring constant supervision.
During team meetings, the social worker brings important information about the family’s social service needs to inform other members of the team. This may also be a time when other team members could step in to meet some family needs that the social worker does not. For example, if a family who uses hospice finds that they need some respite time and more help with the patient’s personal cares, the social worker can take these concerns back to the team who can implement the family’s concerns into the plan of care and make arrangements for a skilled nurse or home health aide to assist the family.

Hospice programs that participate in Medicare and Medicaid funding must employ social workers that fit certain requirements in order to receive reimbursement. Hospice social workers employed by these organizations must have either a Master’s degree or Bachelor’s degree in social work or a Bachelor’s degree in another, related discipline, such as psychology or sociology. Prior regulations stipulated the all hospice social workers must have a Master’s degree in social work to work in this setting, but the Centers for Medicare and Medicaid Services changed these requirements in 2008.6 Bachelor’s prepared social workers must be supervised by another social worker that has a Master’s degree. Those who work in hospice must have at least one year of experience in a healthcare setting first.

The hospice social worker will be assigned to one or more hospice patients at a time. The role of the social worker is to be available as a resource to assist patients and their families during this most vulnerable time. They may meet with families for scheduled visits to talk about patient care concerns or to follow up on previous conversations. They may also visit the family without advance notice if the family contacts the social worker with questions or if they need further help.
When the patient dies, the social worker is a resource for helping the family with making funeral arrangements or other service arrangements as a memory to the patient, depending on family preference. The family may need assistance with making decisions, even if much of the arrangements have already been made in advance. The social worker may provide further information about payment for these arrangements or may help the family to meet with a pastor or spiritual counselor.

The social worker’s role continues after the death of the patient, as he or she typically follows up with families to check on their wellbeing and adjustment to life after the patient has passed away. The social worker can assess for signs of dysfunctional grieving among family members and can make arrangements for therapy or other types of counseling or group meetings for family members who need support with managing their pain. The needs of the family do not necessarily end with the death of the patient; the social worker’s role is to attend to both the patient’s and the family’s needs during the time of hospice, and after the patient is gone, the family may still need continued support for a while. The comprehensive work of the social worker attends to family needs in an ongoing manner to help them achieve closure and to manage their grief in a healthy manner.

**Medicine Specialists**

Medicine specialists are physicians who have completed advanced training within a specific area of care. A physician may become a specialist in the field of hospice; if he or she is a member of the hospice care team, then the medicine specialist can provide much information and guidance to the rest of the team regarding patient care because of the added training in this particular area of patient care.
The hospice specialist carries out the duties of a physician on the team by prescribing medications and therapies and performing some palliative care procedures. The advantage of having a specialist on the team is that this type of physician is familiar with and has experience working with hospice patients and understands the unique needs and challenges of this population. Hospice patients are not being cared for through curative measures, which is often how many mainstream physicians approach caregiving. Instead, the hospice physician’s focus is to provide treatments that control the patient’s symptoms and that make the patient comfortable as death approaches.

The hospice physician works with the interdisciplinary team to guide decisions and to be a source of information regarding the patient’s care. If team members bring issues forward during team meetings about the patient’s condition, the hospice physician can direct how the care will be delivered or changed, as needed. For example, a physical therapist might relay to the team that the patient is no longer able to get out of bed because of the progression of a disease. The hospice physician may then prescribe an increase in physical therapy treatments to perform range-of-motion exercises and may also direct other team members to increase vigilance with patient care to monitor for complications of immobility.

In addition to working with the team to direct patient care, the physician may visit the patient to follow up about how the patient is feeling and to ensure that the patient remains comfortable and that needs are being met. The physician will periodically assess the patient and perform a physical exam; this may occur as a regularly scheduled event during routine health maintenance visits, but the patient will also need to be examined and checked if complications develop or the physical status changes. In the
example above that described the patient who could no longer get out of bed, the physician would need to see the patient and examine the patient to determine what factors are causing the change in physical status.

The patient’s health may have deteriorated to the point that he or she is too weak to move, or another condition could be present that might mean the change in condition is only temporary. Although the physical therapist in this situation might relay information to the team about the patient’s condition, it is the physician’s role to assess the patient and actually diagnose what has occurred that is causing the change in condition.

The hospice specialist will also need to be on call for care during “off” hours. Hospice patients need care around the clock and although a physician is not always at the bedside providing direct care, he or she does need to be available on call for consultations if complications arise. The hospice specialist may take phone calls at any hour of the day or night to consult with the caregiver about the patient’s condition and to make changes in the patient’s orders as needed. If the patient dies, the physician will need to be contacted and may need to be present to pronounce the death.

A physician who is a hospice specialist undergoes the training and education to become a physician, including attending medical school and going through residency training. After becoming board certified, the physician may then become specifically certified as a specialist in hospice and palliative care. Currently, there are two organizations that offer specialty certification to physicians in the areas of hospice and palliative care: the American Board of Medical Specialties (ABMS) and the American Osteopathic Association (AOA). Additionally, the American Academy of Hospice and Palliative Medicine has developed a certification board that administers a certification to qualified
physicians that is specific to hospice care. This type of certification not only qualifies a physician to be a medical specialist and to serve on a hospice care team, but he or she would also be qualified to act as medical director of a hospice organization or facility.

Although a medical doctor can provide many elements of hospice care, a hospice medical specialist is an important person to have as a member of the interdisciplinary team. This specialty physician brings a certain amount of expertise to the group that comes from experience and care for multiple hospice patients and their unique needs.

**Spiritual Advisors**

Part of the holistic care of the patient during hospice is to recognize the spiritual dimension of health. Spirituality is the idea that there is something beyond what a person can see, touch, or feel; something that exists outside of the normal senses. Religion is the practice of spiritual beliefs. A person may be spiritual or may look for peace in a spiritual dimension, but may not necessarily be religious if his or her spiritual beliefs do not line up with a particular faith system.

Whether or not a hospice patient has an affiliation with a particular religion, a spiritual advisor may be part of the hospice interdisciplinary team. The spiritual advisor is a person who can assess the patient’s spiritual needs and can provide care and comfort for this area of the patient’s needs.

A patient may recognize the need for spiritual guidance and support when entering hospice, and a spiritual advisor is someone who can provide that support in various ways. By talking with the patient and family, the spiritual advisor becomes aware of their feelings and beliefs. Many people associate
death with being an end to living on Earth in their current state, but then moving on after death into another state. A patient may have particular beliefs associated with his religion, such as a belief that he or she will go to Heaven after death, or may want to be more attuned to spiritual beliefs.

For the patient who has a pre-existing belief system in place, a spiritual advisor may be someone from church or a religious institution who is able to meet with the patient and family to pray or talk about topics that are meaningful. For example, a hospice patient who is Catholic may meet with a priest from the patient’s diocese to talk about the death, a relationship with God, and the patient’s life after death. The priest may perform a religious ritual called Anointing of the Sick or may deliver the sacrament of Last Rites to the patient as death nears. These discussions and activities provide comfort for the patient and family when they are in line with their religious beliefs.

In other cases, a patient and family members may meet with a spiritual advisor, even if they do not ascribe to a particular religion. They may want to talk further about the patient’s death as it approaches; sometimes, this is done as affirmation about the patient’s life or questions about what might happen after death.

If the patient is experiencing a disruption in his or her belief system because of illness or impending death, the patient may be feeling spiritual distress. This can be particularly upsetting to the patient or the family, and a spiritual advisor can help to relieve some of this distress by talking and connecting with the patient. The hospice patient may feel spiritual distress for a number of reasons. Illness may isolate the patient from a normal routine, which includes regularly meeting with other believers. This isolation may prevent
the patient from participating in normal activities that support his or her religious beliefs. The patient may also question God, self, or others about why he or she developed an illness.

The spiritual advisor must be flexible in assessing the patient’s beliefs and needs for spiritual support. Being in hospice causes mixed emotions that can affect a patient’s spiritual health and the advisor should be prepared to discuss various topics based on the patient’s feelings, provide guidance and help to the patient and family according to their religious beliefs, and listen to patient and family concerns about the situation and their feelings surrounding it.

There is much religious diversity among patients, and the interdisciplinary team who is working with a specific patient should first avoid making assumptions about the patient’s religious preferences. Even within specific religious beliefs, there may be variations between practices; for instance, the Anabaptist and Eastern Orthodox Churches are both considered Christian believers, yet they practice very different religious rituals among their parishioners. Furthermore, some people are more conservative and some are more liberal with their religious beliefs, even within a specific group. It is always best for the team to assess the patient’s religious beliefs and ask the patient and family what type of spiritual advisor would be most helpful. The spiritual advisor should then talk further with the patient about his or her specific beliefs. A person who was once healthy may have marginally accepted a form of religion but then may have become much more serious about its importance after a diagnosis. Through careful listening and talking with the patient about personal beliefs, the spiritual advisor can determine what factors are important to the patient and what should be avoided, in order to be sensitive to the patient’s needs during this time.
Watson, et al., in the *Oxford Handbook of Palliative Care*, recommend that spiritual advisors who do not necessarily garner all important information about the patient’s desires for spiritual care should at least follow the orthodox method of the religion.\(^\text{32}\) For example, if a patient has stated that he or she is a Buddhist, the advisor may be less likely to offend the patient and remain sensitive to the patient’s Buddhist beliefs by following practices that are central to this belief system. The spiritual advisor would also avoid introducing aspects that are not part of the belief system as well; for instance, the spiritual advisor would not necessarily bring a Bible to a meeting with this patient because the general belief system associated with Buddhism is not associated with this item. The practice to support a patient to maintain a religious belief system would be the same if the patient had another religious background as well.

Based on their training, experience, and person convictions, spiritual advisors provide essential spiritual care and support for patients struggling through hospice. The comfort provided during this time supports the concept of holistic care, making spiritual advisors a valued member of the hospice care team.

**Nursing Assistants**

Central to providing patient personal care, a nursing assistant is an important member of the healthcare team who assists the registered nurse with performing many care activities. The HPNA officially recognized nursing assistants as essential members of the hospice care team, acknowledging them as professionals who are commonly involved in patient care.\(^\text{47}\) Many organizations do not necessarily recognize the importance of nursing assistants as part of the team; they are often seen as simple caregivers with less importance when compared to the registered nurse or other professional
team members. The HPNA recognized that day-to-day provision of care of the patient’s personal needs and activities of daily living is essential patient comfort and symptom control. It is nursing assistants who provide much of this type of patient care.

A nursing assistant does not diagnose a patient’s condition, nor does the nursing assistant make decisions about the patient’s plan of care. He or she works under the direction of the registered nurse to perform tasks as delegated. The nursing assistant does not administer medications, but is responsible for reporting the effects of medications and other therapies to the nurse if untoward effects occur. The nursing assistant may spend a significant amount of time providing direct patient care and can report to the nurse or to other team members the elements of the patient’s condition that have changed so that team members will remain informed.

The nursing assistant is educated about how the signs and symptoms that may indicate a change in the patient’s physical status and when to report these items. For example, the nursing assistant may help the patient to use the bathroom and may note that the patient’s urine output has declined significantly in the last 12 hours and that urine is dark and cloudy. He or she would then report these findings to the nurse, who can further investigate the cause of the changes in the patient’s urine output.

The nursing assistant must observe for any signs and symptoms that would affect patient care or that would indicate a change in condition, such as labored breathing, changes in the patient’s skin temperature, color, or moisture levels, reports of increased patient pain, dry mucous membranes, or weight loss. The nursing assistant can take the patient’s vital signs and then reports these results to the nurse.
The nursing assistant may spend a significant amount of time with the patient providing direct care, and works within a specific scope of practice. He or she is able to help the patient with many different tasks and responsibilities. Physical tasks include assisting with activities of daily living, such as bathing or showering the patient, providing oral care, brushing and cleaning dentures or brushing the patient’s teeth, applying skin lotion, brushing and combing the patient’s hair and clipping fingernails. The nursing assistant can also help the patient to pick out clothing to wear and get dressed or apply makeup if this is important to the patient.

There are many other physical tasks that the nursing assistant could provide to help with the patient’s care, and the job description could vary between patients. Such tasks may also include light housekeeping or helping with errands if the patient still lives at home, assisting with meal preparation or feeding the patient, providing light massage, turning the patient while in bed or transferring from the bed to the chair, or helping the patient during ambulation. Through every care process, the nursing assistant provides consistent and compassionate care that signifies a caring attitude and one of respect for the patient.

The nursing assistant is also present to be with the patient and to talk to him or her and to the patient’s family. This may mean that at times, the nursing assistant sits and spends time with the patient while he or she engages in certain activities, such as watching television or listening to music. The patient and family may need to talk about topics that are important to them or they may want to discuss day-to-day items. The nursing assistant can be present to listen and talk with the patient and family as needed, which is an essential part of patient care in this role because it provides ongoing support and encouragement for the patient and family.
The nursing assistant can provide patient care where the hospice patient is living, including as a home care nursing assistant where he or she meets the patient in the home, as well as in the hospital, long-term care facility, or hospice inpatient facility. The nursing assistant may be employed directly as a caregiver of hospice patients because he or she has experience and certification in palliative care. Alternatively, some nursing assistants who work in medical hospital units or long-term care facilities may end up caring for hospice patients as part of their routine work or assignments.

Most nursing assistants who are trained as caregivers and are certified nursing assistants (CNAs) can perform the duties needed for hospice care. To become a nursing assistant, a student goes through a specific class that teaches about how to provide caregiving activities, how to respond to emergencies, and what elements need to be reported to the nurse. These types of classes are often available through community colleges, hospitals, and healthcare facilities that employ nursing assistants. Once the student has completed the course and received certification, he or she is eligible to work as a CNA providing general patient care, which may include care of some hospice patients. There is also a specialty certification available for this job that some nursing assistants may want to achieve.

The Hospice and Palliative Nursing Association offers certification as a hospice and palliative nursing assistant (CHPNA) for those who have experience working in hospice care. Each nursing assistant who achieves this certification will have demonstrated that he or she has devoted at least 2,000 hours in the work of caring for hospice and palliative care patients and has passed the certification exam. When a nursing assistant has experience in the field of hospice care, he or she brings comfort to the patient through the personal care provided.
Trained Volunteers

The concept of hospice as it has developed today started through the work of volunteers. At a time when hospices were first developing and there was no funding for this important type of patient need, hospice volunteers provided their services and help to patients in need. The people who volunteer their time to care for hospice patients and to support them are correctly trained so that they can provide competent care. Trained volunteers dutifully provide compassionate care to hospice patients, understanding that the job is important and necessary, even if they do not receive pay for their services.

The volunteer who works with a hospice patient and family may be able to connect closely with the family and may be one of the most likely images of love and support because volunteers are not paid workers. Hospice employees can and do provide compassionate and empathic care and they offer a great deal of support in these situations. However, when the patient and family knows that a volunteer is working with them simply as a service and to serve in a selfless manner, they may connect with the volunteer because they know that the person is caring for the patient without receiving any financial reimbursement for doing so.

A hospice volunteer could be utilized in a number of methods to provide patient care. A volunteer’s job can range from assisting patients and families with paperwork needed for admission to a healthcare facility, helping the patient to get settled in home or in an inpatient facility if transferred there, or running errands and performing practical duties that would help the patient in daily activities. Practical activities are some of the most common actions performed by the volunteer, and while this may not sound as important as providing direct care or being present during critical times in
the patient’s life, it is still necessary and is supportive of the patient’s basic needs.

A volunteer will often perform duties according to the training received; this training may or may not be extensive, depending on the duties performed. For instance, a volunteer may be trained in providing basic comfort care for the patient or he or she may learn how to respond to emergency situations to be available to care for the patient during a time when the family is using respite. Other elements of the volunteer’s work do not necessarily require much training, such as performing light housekeeping duties, preparing meals, purchasing groceries and supplies, running errands, babysitting small children, or transporting the patient to and from clinic visits. However, each of these activities requires a basic knowledge of safety measures to protect the patient and may require a little more education or training to be performed correctly; for example, a volunteer might drive a patient to a doctor’s appointment but the organization would want to know that the vehicle is clean and equipped for patient transport and that the volunteer has a good driving record.

Another duty often taken on by the volunteer is sitting with the patient and spending time with the patient and family. This could take many forms, including simply being present while the patient sleeps or has reached a state of unconsciousness, eating a meal with the patient and family, playing games or cards together, watching television, or simply spending time talking. The volunteer does not need to have a counseling background to be a source of support and encouragement for the patient and family. Often, the volunteer is most helpful by simply being present and most patients enjoy having someone who will listen to them if they need to talk.
A director of volunteers who supports hospice or other types of patient care may guide trained volunteers in their work. Volunteers may communicate with the interdisciplinary team, particularly if he or she becomes aware of information about the patient’s condition that would warrant a change in care delivery or if complications develop in the patient’s condition.

Anyone who wants to be a volunteer can apply to work in the hospice role; a person who applies may have a background check and may need to interview to determine if he or she is a suitable candidate for providing hospice care. The volunteer will then undergo training for various care measures, depending on the type of care provided. All volunteers should at least have a basic understanding of safety practices and should know what to do to get help for the patient or the family when needed.

**Additional Support**

Beyond the most well-known members of the hospice team, there lies a group of team members who play important roles in patient care and hospice care management but who may not be commonly thought of as hospice team members. Despite this fact, these team members are vital; they may provide supportive services and assist those who provide direct patient care, or they may be directly involved with caring for the patient and family members. Additional support members may include such personnel as pharmacists, respiratory therapists, and physical and occupational therapists.

**Pharmacists**

Pharmacists are specifically trained in knowledge of medications: including their appropriate use, side effects, dosages and indications, interactions, and
how they are absorbed and distributed in the body. A pharmacist dispenses medications based on patient prescriptions and is a source of advice and knowledge for the patient so that the patient can take the drugs safely and correctly.

A pharmacist is an important member of the hospice team. While the patient may not be undertaking any curative measures in response to an illness, the patient may still take several different kinds of medications to manage the symptoms of illness and to keep comfortable. The pharmacist on the team is aware of the different drugs prescribed for the patient and understands the drugs’ effects and interactions. The goal of pharmaceutical care during the hospice period is to provide and manage medications that will improve the patient’s quality of life.

The pharmacist’s role on the team is focused on palliative care for the patient, as the medications provided to the patient are typically used for comfort measures. One of the goals of hospice care is to provide palliative care to patients, which focuses on management of symptoms such as pain, nausea and vomiting, or psychological symptoms, such as depression. Many medications are essential for controlling these symptoms. Pharmacists play a key role in managing and dispensing medications that are used to control these and other symptoms.

The pharmacist on the hospice team typically focuses on providing medication information for the patient. This differs somewhat from other members of the team, who focus on providing emotional and spiritual support to the patient and family members. Because the patient is the main person utilizing the medications during the hospice period, the pharmacist’s role is often focused on the patient. If other family members develop a need
for medications, the pharmacist may be involved as well if the drug prescriptions are regulated through a physician on the team. For example, if a family member of the hospice patient develops depression as a result of increased stress and grief related to the patient’s death, the physician on the team may consult with a psychiatrist and may recommend antidepressants for the family member. These drugs may be further regulated through the pharmacist, but the ultimate goal is to meet the medication needs of the hospice patient first.

Because medications are commonly used for patient care during hospice, it is important to have a pharmacist on the team. This professional can coordinate medications and ensure that the patient remains comfortable by taking the medicines as prescribed, which ultimately supports the goal of hospice care.

*Mental Health Professionals*

The decision to start hospice care is not taken lightly. Many patients and their families wrestle with their circumstances, vacillating between hope for a cure and the idea that the patient is not getting any better. Making the choice to start hospice can be incredibly frightening and many patients and families feel lost between not knowing what to expect through the course of the disease or how long they will need to use hospice. Additionally, many people struggle with feelings of fear, anxiety, sadness, guilt, or anger during this time.

Hospice and end-of-life care may cause some patients and their families to struggle through these various mental health issues that could require further treatment through therapy or medication. The thought of death and the experience of living with someone who is dying is often enough to cause
feelings of sadness, grief, depression, or anxiety. If these feelings become overwhelming, they can significantly limit a person’s ability to function and may require further assistance through a psychologist or psychiatrist.

The psychologist or psychiatrist on the hospice team is there to provide support for the patient and family when mental health issues arise. Although all team members recognize the emotional impact that hospice can have on a patient or loved ones, the mental health practitioner’s role is to work with the patient or associated family members and help them to manage potentially intense feelings that can hamper the ability to function well during the time of hospice.

For example, a patient may be aware that he or she is dying and may be suffering from intense emotional pain because of a terminal condition. The patient could be experiencing various feelings, such as unfairness that this situation occurred to him or her and not to someone else, feelings of regret over not completing more tasks during life, and fear for the future and what will happen to loved ones after the patient is gone. A mental health practitioner who works on the hospice care team can be a valuable resource for providing help through talk therapy, or even medications such as antidepressants to help the family members or the patient through this difficult time.

It can be extremely difficult for a patient or family members to come to the point of accepting death. Although people grieve in various ways, some of these methods are not necessarily healthy and may contribute to unhealthy methods of coping with the situation. Kübler-Ross has identified several stages of grief that have been shown to be common among people experiencing the pain that comes with losing a loved one or knowing that
death is imminent; however, although people may progress through these stages while grieving, not all people progress through the stages in an orderly fashion and overcome feelings of grief in a healthy way. Instead, a person may feel denial and anger associated with the situation and then may progress to intense feelings of depression that do not resolve with time.

It is normal for a person to progress through the various stages of grief, but when a person becomes stuck in one stage and is unable to move on, or is acting in an unhealthy manner, the patient would most likely benefit from meeting with a mental health practitioner to help him or her through some feelings. Both psychologists and psychiatrists treat people with mental health issues, and both utilize psychotherapy to treat patient illnesses in regards to mental health issues. Psychiatrists are medical doctors who have the ability to prescribe medications, while psychologists utilize psychotherapy and focus more on the theory behind a patient’s mental condition.

One of the roles of the mental health practitioner while caring for hospice patients is to be a source of support to assist families with managing some of the very complex issues associated with dealing with terminal illness. The psychologist on the team upholds the concept of promoting quality of life by providing psychosocial support for the patient and family and by promoting autonomy with their decisions. Haley, et al., in the journal Professional Psychology: Research and Practice, point out that psychologists already play key roles in managing patients who are struggling with chronic illness, including chronic physical diseases, such as chronic obstructive pulmonary disease or diabetes; as well as chronic mental illnesses and neurodegenerative disorders. Psychologists are already actively involved in care of these patient populations to assist with the psychological and
emotional responses that often accompany diagnosis of a chronic illness. They may provide interventions such as counseling and support to adjust to the disease, and help with anxiety or grief related to the diagnosis.\textsuperscript{8}

Because of the already strong association between psychologists and patients who suffer from chronic illness, it makes sense that these professionals would be further involved in hospice care when chronic illness progresses to a terminal condition. Psychological intervention can take place at any time during a chronic illness or hospice care. The psychologist can provide counseling and support as the illness progresses, and may be most likely to offer services at key points during the progression of the disease, such as just after diagnosis of a terminal condition and the decision to use hospice care, during the time that the patient’s physical condition is deteriorating, during the dying process and end-of-life period, and after the patient is gone to provide bereavement support to families.\textsuperscript{8}

A patient who has made the decision to use hospice care may face a number of emotional responses that would benefit from psychosocial support. The psychologist could meet with the patient and the family in the home, in a private clinic, at the hospital, or in another agreed-upon location to discuss the feelings and emotions that develop with understanding the significance of hospice. They may also discuss other options, such as treatment preferences for upcoming care or finding the best way to ensure that the patient receives care that helps to keep comfortable.

During this time, the psychologist has the chance to assess the patient and family’s coping skills and to determine the areas of support available. Some hospice patients have large networks of friends and family who are available to provide support and who can be present to talk, spend time with the
patient, or help with practical living matters. Alternatively, there are some hospice patients who may have very little support outside of family, or they may have few or no family members who are available to help with the patient’s care. The psychologist could help the patient and family members to recognize areas of support in their lives that would help with adjustment during this time. They would benefit from developing and using coping skills during this challenging time and the psychologist can work with them to help them recognize their areas of strengths.

A psychologist who works with hospice patients should be one who has experience working with dying patients or who has helped patients who struggle with grief because of death. The psychologist should also have resources to appropriately respond to patient needs and potentially have extra certification or training in the areas of grief and dying.

**Physical and Occupational Therapists**

As noted when describing members of the interdisciplinary palliative care team, physical and occupational therapists play distinct roles in patient care activities that are essential with helping the patient maintain quality of life and to gain control over some illness symptoms. Physical and occupational therapists may not be members of every hospice team but when they are involved in patient care, they bring a new dynamic to the patient’s care that is not necessarily provided through other disciplines.

A physical therapist takes part in patient rehabilitation, often to help recover from physical injuries or from illnesses. While it may seem pointless to incorporate rehabilitation into a hospice patient’s plan of care, the principles of rehabilitation may still be applied as part of patient care, even if the patient is not going to recover.
Rehabilitation is designed to promote the patient’s quality of life, which is the same goal in hospice care. The physical therapist can provide patient care to maximize quality of life and to help remain as active and functional as possible for as long as possible. By helping the patient maintain functional abilities, the physical therapist is also providing for the emotional, social, and spiritual needs of the patient, as these elements can be significantly affected if the patient lacks physical functioning abilities.

The physical therapist provides physical care measures to the hospice patient that are therapeutic in quality. Because hospice care is aimed at symptom control, the work of the physical therapist can assist with reducing the frequency and severity of patient symptoms. Although pain is one of the most common symptoms encountered during hospice and the physical therapist does utilize many measures to control the patient’s pain, the patient may also be involved in managing other symptoms as well, including nausea, depression, insomnia, anxiety, or labored breathing.

According to Jeyaraman, et al., in the *Indian Journal of Palliative Care*, physical therapy services during hospice care are multiple and varied. They include aspects, such as:

- pain management
- positioning to prevent pressure ulcers and contractures
- endurance training and energy conservation
- gait training and transfers
- therapeutic exercises
- management of edema
- medical equipment modification
- home safety modifications
The physical therapist also functions as part of the interdisciplinary team to provide input to team members about patient care modalities. Although the physical therapist may not be a traditional member of the hospice team, the recognition of the role of the physical therapist is growing and the use of physical therapy among hospice patients is becoming more widespread. The role of the hospice physical therapist differs from a standard physical therapy role in that the goal of care is not to cure the patient’s condition. Instead, this compassionate level of care seeks to meet the hospice patient where he or she is at in terms of physical functioning and to help the patient to maintain as much independence for as long as possible during the transition toward end of life.

As with a physical therapist, an occupational therapist is also a non-traditional member of the hospice care team, but this role has also seen recent growth because of its importance in supporting patient functioning and upholding the patient’s dignity. The occupational therapist knows the importance of the patient’s ability to continue participating in activities of daily living for as long as possible. By being able to perform these types of tasks, the patient maintains some of functional status and can feel productive and respected. The occupational therapist works with the patient to help the patient to achieve these tasks or to utilize adaptive equipment that may make performing these tasks easier. For example, a patient may have lost the ability to adequately grip a fork to bring food to the mouth. The occupational therapist may help the patient to utilize adaptive silverware devices that allow the patient to continue to feed despite the loss of a handgrip.

All people have the need to continue to engage in certain roles or occupations that are important to them. The ability to participate in these
activities gives people a sense of purpose. Without being able to continue to function in important, everyday activities, the patient is at greater risk of feeling lost, hopeless, frustrated, and sad. The occupational therapist supports the patient’s self-esteem and abilities for as long as the patient is able to continue to participate. This is provided through a multitude of activities that are part of the job of the occupational therapist, including:56

- assessment of the patient’s living skills
- provision of adaptive devices and living aids
- energy conservation
- social skills development
- therapeutic activities, such as crafts or music
- time management skills
- patient education about developing coping skills

Essentially, the occupational therapist promotes patient quality of life through many methods. The patient may participate in activities that not only improve functioning, but that may also be enjoyable. Depending on the patient’s situation, he or she may work with the occupational therapist during group sessions as part of rehabilitation so that the patient can meet others, work together, and find support during this critical time.

Respiratory Therapists

The respiratory therapist is another member of the hospice team whose goal is to bring the patient through the transition of passing between life and death. A respiratory therapist often plays the role of assisting a patient with breathing and ensuring adequate oxygenation; he or she may administer medications and nebulizing agents, perform chest physiotherapy, and help the patient perform activities that decrease the risk of his developing pulmonary complications.
A respiratory therapist may work under the direction of the hospice physician for the ongoing assessment and monitoring of the clinical status of the patient. He or she may check the patient’s oxygen saturation levels and determine if the patient would benefit from additional supplemental oxygen to help feel more comfortable. If the patient needs further respiratory support that is not necessarily curative in nature but that would help to make the patient feel more comfortable, the respiratory therapist can help to set up equipment and instruct the patient and the family about how to use it. As an example, a patient may have obstructive sleep apnea that significantly impacts his or her ability to achieve adequate sleep and may be struggling with fatigue and depression. The physician may order that the patient use CPAP at night while sleeping to prevent obstruction and to promote sleep. The physician would give the orders for the CPAP machine and its parameters for use, but the respiratory therapist would most likely be the team member who sets up the CPAP machine and instructs the patient about how to use it.

The respiratory therapist also communicates with team members about the patient’s condition based on the assessments made while providing patient care. He or she may recommend certain respiratory care interventions believed to help the patient to be more comfortable, such as by changing the patient’s oxygen delivery methods or administering respiratory medications in a different route than the one currently in use. The RT provides further education, not just to the patient and family members but also to other team members who provide patient care about how to perform respiratory interventions, such as appropriate methods of suction and oxygen delivery, how to administer nebulized medications, methods for using and maintaining oxygen canisters, and how to perform tracheostomy care.60
Dyspnea is a common symptom seen among hospice patients. It is all too often distressing for the patient when difficulty breathing is experienced. The patient may also exhibit other respiratory symptoms, particularly as the end of life becomes closer, including wheezing, lung rales, increased effort to breath, increased sputum production, and periods of apnea. The RT is present to provide respiratory care interventions for the patient that are comforting during this time and that decrease or eliminate the patient’s distress because of breathing problems. The RT also talks to the patient and family about the changes in breathing patterns and provides guidance and education about how best to care for the patient and promote calmness and comfort.

A hospice patient may be discharged from the hospital to home using a ventilator. When a ventilator is ordered, the RT is often the person who manages the ventilator settings, suctions the patient, and monitors for changes in respiratory patterns because of its use. The RT also instructs the patient’s family about the use of the ventilator and what some of the alarms might mean. Many patients do not use a ventilator at home. Indeed, its use could be considered controversial in that it may be seen as extending the patient’s life. However, a patient may use a ventilator for a short period even when it is understood that he or she will not recover from a condition; this situation is known as placement of a terminal ventilator.

Use of this type of respiratory support in the home often allows patients to be at home when they die, surrounded by loved ones, rather than being in the hospital environment because they otherwise needed ventilator support. The physician determines the time and circumstances of discontinuation of the ventilator with input from the family and the rest of the hospice team.
The respiratory therapist may be present to discontinue the patient’s breathing tube at the last stage of life when the ventilator is discontinued.

A respiratory therapist is a non-traditional member of the hospice team, yet the role of this profession is important to support other measures performed by the many team members and their patient care tasks. Although many respiratory therapists work in acute care settings, such as with caring for patients in critical care units, they often successfully transition into hospice care and become effective team members when they recognize that although the goals are somewhat different, the patient care required is no less compassionate and respectful.

**Summary**

Patients who face serious illnesses may experience many emotions and feelings as they struggle with making care decisions. Hospice and palliative care services have been developed to specifically work with this unique population of patients and their families to provide holistic care and to manage varying levels of discomfort, pain, and confusion during a critical or terminal illness. By improving quality of life for these patients, the hospice and palliative care teams provide support, reassurance, and compassionate care throughout the time of caregiving as the patient makes the final transition from life into death.

Often, palliative and hospice care patients may wonder why an illness has happened to them and the circumstances surrounding death. There is generally a struggle in the patient seen by the health team and family members involving factors that undermine the patient’s normal self-image, outlook on life and spirituality because of having a terminal illness. When a patient develops a sense of hopelessness and despair because a cure is not
imminent, and an illness worsens, the patient will experience a range of emotions and fear, including being angry about dying and with God, or a higher power, and avoidant of those nearest to help them. Fear of losing independence and of burdening loved ones accompanies the patient’s sense of hopelessness.

Being present, communication and listening, with patients during times of evaluating patients’ care needs is a never-ending task of the palliative or hospice nurse. Communication and listening are interventions that are at the core of the health team’s role while interacting with the patient and family. Communication involves talking with the family about those ideas that are important to them, whether it is the progression of the patient’s illness or some other element that has occurred recently that is taking the family’s focus. Various members of the palliative and hospice care team uses knowledge of medical, psychological, spiritual, and social health to discern what areas family members needs assistance, and then provides that information to the family. Information that is garnered through discussion and efforts with the family can be distributed to team members so that others may get involved in the patient’s care in specific areas.

Based on the training and experience of the different health team members caring patients and families of patients at the end of life and who are dying, each team member contributes to holistic care and ongoing support to help alleviate physical, emotional and spiritual distress and to find peace. The comfort provided during this time makes each specialized team member valued in the area of palliative and hospice care.

Please take time to help the NURSECE4LESS.COM course planners evaluate nursing knowledge needs met following completion of this course by completing the self-assessment Knowledge Questions after reading the article. Correct Answers, page 152.
1. **Palliative care is distinguishable from hospice care because**
   a. it is designed to manage the patient’s physical symptoms of suffering, but not psychological, spiritual, social, and emotional impacts that a serious illness can have.
   b. it is curative care, whereas hospice care is not.
   c. palliative care, unlike hospice care, is not limited to those with terminal conditions.
   d. it provides holistic care that improves the patient’s sense of well-being.

2. **Dyspnea describes a condition in which a patient suffers**
   a. from a chronic illness that progressively worsens at the end of life.
   b. from breathlessness and difficulty breathing.
   c. an upset feeling in the stomach, the abdomen twisting or churning.
   d. from a lack of appetite and subsequent failure to eat.

3. **True or False: 71 percent of patients in the final days of life suffer from nausea and vomiting.**
   a. True.
   b. False.

4. **When spending time talking to a palliative or hospice patient, a nurse should**
   a. avoid difficult conversations, such as the patient’s failure to respond to treatment.
   b. talk to the patient about his terminal situation if the opportunity arises.
   c. engage in small talk, pretending that the treatment is working.
   d. leave the difficult conversations to other team members, such as the psychologist.
5. **Hospice is designed to manage the patient’s condition**
   a. while the patient waits for a potential cure or treatment for his condition.
   b. until he receives a diagnosis from his physician stating that his illness is incurable.
   c. when the patient has no family members to care for him.
   d. so that the transition into death is smoother for the patient and his family.

6. **The skilled nursing facility is beneficial in that**
   a. it may provide holistic care that a stand-alone hospice center cannot.
   b. it provides the best possible level of quality of life that is appropriate for each patient.
   c. the patient may reside in a skilled nursing facility for a longer amount of time when compared to a stand-alone hospice center.
   d. it provides a better level of care for severe illnesses.

7. **Respite is available as a program so that**
   a. the main caregiver is able to take time away while someone else cares for the hospice patient.
   b. family members of a high-need patient may have time to rest and recharge.
   c. a patient in hospice home care may go to an inpatient healthcare facility for a short time.
   d. All of the above.
8. When managing pain for the palliative patient, the nurse
   a. may be asked to administer much larger doses of prescribed drugs
      than what he or she is used to giving.
   b. should be careful not to administer larger amounts of pain medication
      for fear of the patient becoming dependent on the drug.
   c. should leave it to the doctor to advocate for higher doses of pain
      medication if the current dose is not effective enough.
   d. All of the above.

9. Hospice care is a program designed
   a. to care for terminally ill patients and their families.
   b. to provide support and warmth from friends and caregivers for the
      terminally ill patient.
   c. so that the patient may make the most of the life he or she has left.
   d. All of the above.

10. True or False: Family members of the hospice patient should
    not be attended to by the hospice care team and should not receive
    counseling.
    a. True.
    b. False.

CORRECT ANSWERS:

REFERENCE SECTION

The reference section of in-text citations include published works intended as helpful material for further reading. Unpublished works and personal communications are not included in this section, although may appear within the study text.


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