The End-of-Life Nursing Education Consortium (ELNEC – For Veterans train-the-trainer program and curriculum was developed by the National ELNEC Project Team, a partnership between the City of Hope (Betty R. Ferrell, PhD, RN, MA, FPCN, FAAN, Principal Investigator) in collaboration with the American Association of Colleges of Nursing (Pam Malloy, MN, RN, FPCN, FAAN, Co-Investigator). Curriculum development and 6 national ELNEC-For Veterans train-the-trainer courses were generously funded by the US Department of Veterans Affairs (2009-2012).
This module builds on Module 2: Pain Management, by addressing other symptoms common in advanced disease and the role of the nurse in managing these symptoms.

Veterans requiring palliative care or experiencing terminal illness will most likely present with multiple symptoms. It is critical that the nurse understand the importance of symptom assessment and management. Symptoms can be managed effectively and the nurse plays a key role in communicating these symptoms to the team so that a plan of care can be implemented.

There are many physical and psychological symptoms common at the end of life. Optimum treatment of symptoms involves comprehensive assessment and use of pharmacologic and non-pharmacologic interventions. Nurses must work collaboratively with physicians and other disciplines in symptom management which will improve the quality of life for Veterans and their families.

Traditionally, symptom management research in palliative care has been related to cancer patients. Though more research is being done with other diseases/populations (i.e., care of older adults, children) further study is needed to ascertain symptom management across a wide-array of medical conditions and diseases.

This module explores several common symptoms that Veterans with life-threatening diseases and serious illness experience. A comprehensive review of all possible
symptoms is beyond the scope of this curriculum. Symptoms will vary depending on disease, treatments (past and current), and past history, as well as many other factors.

- This module is divided into five sections:
  - Sections I-IV: Physical Health Issues: Introduction, Respiratory Symptoms, GI Symptoms, and General/Other Symptoms
  - Section V: Mental Health Issues
Key Learning Objectives

At the completion of this module, the participant will be able to:

1. Identify common symptoms associated with seriously ill Veterans and for those at end-of-life.
2. Identify potential causes of symptoms necessitating palliative care.
3. Describe assessment considerations for common symptoms.
4. Describe interventions that can prevent or diminish symptoms while promoting quality of life for Veterans.
Assessment and evaluation of symptoms is an essential element in any care setting, requiring diligent ongoing assessment and evaluation of interventions.

Interdisciplinary care is central to symptom management. Chaplains, social workers and psychologists must be a part of the interdisciplinary team to assist in addressing suffering. The management of symptoms requires cohesive interdisciplinary teamwork to ensure that optimal care is delivered. Close collaboration among members of the healthcare team is essential.

Reimbursement and other financial concerns may be important factors for some families and should be considered in your overall care plan (Coyne et al., 2015).

Criteria for ordering diagnostic tests: Each test ordered should help determine an intervention. If no change in management will result, the test should be questioned for its appropriateness. The benefit vs. burden and the patient/family goals of care are paramount considerations.

Note: The National Consensus Project Clinical Practice Guidelines for Quality Palliative Care includes two Domains that are addressed in this module. Domain 2: Physical Aspects of Care emphasizes the assessment and treatment of physical symptoms with appropriate validated tools and management that is multidimensional (pharmacological, interventional, behavioral and complementary).
Similar to pain, other physical and psychological symptoms create suffering and distress. Psychosocial intervention is key to complement pharmacologic strategies.

Palliative approach to the relief of suffering is comprehensive and holistic. It addresses not only the physical, but also the psychological, social, and spiritual needs (NCP, 2013).

According to a 2015 report from the VA, the Veteran population has been declining since 1986, but the number of Veteran’s with service-connected disabilities (SCD) has been on the rise (NCVAS, 2015). There has been an overall 60% increase since 1990 with close to 4 million Veterans who have SCD. Many of these Veterans, who have suffered for years with their disabilities, will have unique palliative care needs. Nurses will play a critical role in assessing and managing these Veterans and their families as part of the interdisciplinary team.

Evidence-based research in symptom management in palliative and end of life care is evolving (Ferrell et al., 2015); as such, nurses and researchers are positioned to improve quality of life through nursing research and the application of research findings in practice.
The following symptoms have been chosen for review in this curriculum, because they occur frequently in patients with terminal illnesses, and they are extremely distressing to Veterans and families.

- **Physical Health Issues:**
  - Respiratory: dyspnea
  - Gastrointestinal (GI): anorexia/cachexia, constipation, diarrhea, nausea/vomiting
  - General/Systemic: fatigue, and skin disorders (i.e., wounds and pressure injuries)

- **Mental Health Issues:**
  - Post-traumatic stress disorder (PTSD)
  - Depression and suicide
  - Anxiety
  - Delirium/Confusion/Agitation

For each of the above-mentioned symptoms, we will present:
- Definition of the symptom
- Causes of the symptom
- Assessment of the symptom
- Symptom management, both pharmacologic and non-pharmacologic

**Note:** Many other symptoms exist which may be more concerning to your Veterans than the ones described here. Due to time constraints, we will just discuss these most common symptoms listed above.
Symptoms (continued)

Serious illness often includes a multitude of symptoms and as clinicians we should not assume things like lung disease is only associated with shortness of breath.


- Symptoms may occur singularly or in clusters, which is common at end of life (EOL) (Kelley & Morrison, 2015). Hypercalcemia is an example of a symptom cluster: nausea & vomiting, constipation, and drowsiness are typical symptoms. Symptoms can have a synergistic effect on each other and make it more difficult to identify the cause and treat appropriately (D’Arcy, 2012). In addition, some symptoms may be more common with select medical conditions or diseases, such as for patients with cancer or lung disease. The science and practice of symptom assessment and management in older adults is scant at best (Combs et al., 2013).

- Symptom burden refers to the number and severity of symptoms. These symptoms are distressing to patients. In patients with advanced cancer, the prevalence rates ranged from pain (89%) to vomiting (30%). Using systematic assessment, most palliative care patients demonstrate a median number of symptoms that is often tenfold higher than those volunteered by the patient (Homsi et al., 2006).

- It is important to specifically inquire with patients in detail about their symptoms for optimal palliation in advanced disease. Start with the question: “What is the hardest part of living with your COPD, CHF, etc.?” Then continue to ask: “What else makes it hard?” Many symptoms can be prevented or managed to promote comfort and decrease suffering. Recognizing the trajectory of dying with various conditions including likely symptoms, be prepared to discuss the expected path and proactively develop a plan for managing troubling symptoms with the patient and caregiver.
• Dyspnea is self-reported distressing shortness of breath and is frequently called breathlessness. The experience of dyspnea can be extremely frightening. Dyspnea is multidimensional in nature.

• The assessment of dyspnea is essential (Dudgeon, 2015). Approach dyspnea assessment like pain assessment - the subjective report of the patient is the only reliable indicator of this symptom.

• Many experience dyspnea: 10-70% with cancer, 11-62% with AIDS, 60-88% with heart disease, 90-95% with COPD (Dudgeon, 2015).

Dyspnea is prevalent in many end-stage medical conditions such as cancer, heart failure, COPD, chronic kidney disease, dementia and AIDS (Dudgeon, 2015; Kelley & Morrison, 2015).
There are many diseases and conditions commonly associated with this symptom (Dudgeon, 2015) and many patients may have comorbidities that cause and exacerbate dyspnea (Kamal et al., 2015).

- **Major pulmonary causes**
  - Tumor infiltration and metastatic cancer
  - Aspiration
  - Pleural effusion - may be blood, malignant or nonmalignant fluid
  - Superior vena cava syndrome
  - Pneumonia
  - Pulmonary embolism
  - Chronic obstructive pulmonary disease (COPD)
  - Thick secretions caused by an infectious process or dehydration
  - Bronchospasm
  - Ascites, which can impair diaphragmatic excursion

- **Major cardiac causes**
  - Congestive heart failure
  - Pulmonary edema and pulmonary hypertension
  - Severe anemia
  - Cardiovascular disease

- **Major neuromuscular causes**
  - Amyotrophic lateral sclerosis (ALS)
- Muscular dystrophy
- Myasthenia gravis
- Cerebrovascular disease and stroke
- Trauma as a result of physical injury

- Other causes may include
  - End-Stage-Renal-Disease
  - Anxiety
  - Metabolic disorder (e.g., alkalosis)
  - Obesity
  - Spiritual issues (e.g., feelings of guilt and issues of trust).
Complete a thorough assessment of the patient who self-reports dyspnea:

- The assessment should include: Effect on functional status, factors that improve or worsen this symptom, assessment of breath sounds, presence of chest pain and/or other pain that may compound the problem, and oxygenation status.
- The assessment should include history of acute or chronic dyspnea, history of smoking, heart disease, or lung disease, or concurrent medical conditions.
- Physical examination: crackles, respiratory rate and depth, use of accessory muscles, pain with respiratory movement, functional status.
- Use a 0-10 scale, as we use for pain, to assess intensity of dyspnea. Sensation can be subjective, particularly for patients with chronic conditions. “How bad is your shortness of breath today?” 0= no shortness of breath. 10= the worst imaginable. Use the Respiratory Distress Observation Scale (RDOS) for patients who cannot self-report (Campbell, 2010; Campbell et al., 2010).
- The patient's respiratory rate and oxygenation status do not always correlate with the symptom of breathlessness. The patient may report breathlessness in spite of good oxygenation status or limited disease state.
- The amount of dyspnea present may not be related to the extent of disease.
- Impact on function and quality of life: evaluate the individual's ability to sleep, get dressed, talk, eat, etc.
- Consider what, if any, appropriate diagnostic tests will be useful in treating the underlying cause. Diagnostic tests: Pulse oximetry (though even with a “normal” pulse oximetry reading, the Veteran may still be severely dysneic), chest X-Ray, EKG, PFT’s, ABG’s, serum K, Mg, phosphate, oxygen saturation, helical CT,
CBC, etc. The purpose of clinical assessment is to determine any underlying pathophysiology in order to develop the most effective treatment plan. The utilization of any test should be weighed on the risk/benefit ratio, patient's wishes, and prognosis.
In end-stage disease one should treat the symptom while assessing whether or not to treat the underlying cause. Attempts to treat an underlying cause could include treating infections or management of tumor progression.

Both pharmacologic and non-pharmacologic management should be initiated concurrently on a case-by-case basis.

Depending upon the medical condition and etiology, a wide range of medications may be considered. The dosages vary widely. Pharmacologic treatments include the use of opioids, bronchodilators, diuretics and other medications (Dudgeon, 2015).

Preferably use a spacer to assist debilitated and cognitively impaired patients in the efficient use of inhaled medications.

Oxygen therapy may be helpful for patients with COPD as it improves survival, pulmonary dynamics, exercise ability and neuropsychological performance (Dudgeon, 2015, p. 251). Usefulness in refractory breathlessness is less clear.

Consider using ventilatory assist devices (e.g., nasal intermittent positive pressure ventilation or NPPV) in patients decreased inspiratory effort (e.g., Amyotrophic Lateral Sclerosis) as is consistent with the patient’s goals of care.
There are many non-pharmacologic treatments/techniques available for dyspnea (Dudgeon, 2015; Kravits, 2015).

Oxygen use in non-hypoxemic patients may have limited benefit. A trial of oxygen should almost always be considered.

Counseling may include the use of interpersonal and complementary strategies.

Pursed-lip breathing slows respiratory rate and decreases small airway collapse.

Energy conservation techniques can reduce fatigue, and allow the patient to maintain control with lifestyle changes. Consult with an occupational therapist for assistive devices.

A fan aimed at the cheek can help relieve dyspnea by stimulating the middle branch of the trigeminal nerve on the side of the face.

Elevation of the head of the bed and sitting forward in the upright position reduces choking sensations and promotes expansion of the lungs. Placing the Veteran’s arms on pillows may promote air exchange.

Other methods include:

- Prayer can provide distraction to promote comfort.
- Education of patient/family reduces anxiety: explain how comfort interventions work
- Music as a form of relaxation and distraction also may reduce dyspnea.
- Calm room environment.

- Other techniques may include blood transfusions, thoracentesis, stent tube placement to open an occluded airway, endobronchial laser therapy, radiation therapy to shrink tumor, paracentesis—again, keeping in mind the Veteran’s preferences for treatment and goals of care.
The Gastrointestinal section includes the symptoms along with definitions, causes, assessment and treatments:

- Anorexia and cachexia
- Constipation
- Diarrhea
- Nausea and vomiting
Anorexia and Cachexia

- Anorexia: loss of appetite with decrease food intake
- Cachexia: lack of nutrition and wasting
- Decreased appetite and weight loss

- Anorexia and cachexia is a syndrome commonly found in advanced disease. Palliative care teams and clinicians must be prepared for these symptoms.

- Anorexia is:
  - A loss of desire to eat or a loss of appetite associated with a decrease in food intake (Wholihan, 2015).

- Cachexia is:
  - A general lack of nutrition and wasting occurring in the course of a chronic disease
  - A result of metabolic abnormalities
  - Increases distress, impacts negatively on self-concept and body image, is associated with decreased survival, and serves as a constant reminder of the disease process and impending death
  - Etiology is rarely reversible in advanced disease

- Weight loss is present in both conditions. Decreased appetite can occur very early in some diseases.
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- **Disease-related:**
  - Oral or systemic infection, such as candidiasis, may cause discomfort when eating.
  - Pain associated with eating can occur in certain disease states, such as pancreatitis.
  - Chronic nausea and vomiting can be caused by treatment, medications, or disease progression.
  - Constipation may be caused by medications, decreased fluid intake, and inactivity.
  - Delayed gastric emptying and ulcers may decrease a person’s desire to consume food.
  - Diarrhea causes increased weakness, and food intake may worsen the symptom.
  - Malabsorption may be a result of medications or disease process.
  - Bowel obstruction may be a result of tumor/disease process.
  - Raised intracranial pressure can be a frequent cause of chronic nausea in terminal illness (Fearon et al., 2010).

- **Psychological:**
  - Depression exhibits many somatic symptoms which includes anorexia (Wolihan, 2015; Pasacreta et al., 2015).

- **Treatment-related:**
  - Taste changes are often a result of treatments such as chemotherapy.
 Radiation therapy effects, including bowel strictures and fistulas, can be problematic for patients long after radiation has been completed.
Physical examination includes the assessment of weight loss, muscle wasting, gastric stasis, loss of strength and decreased fat. Edema may mask some wasting (Wholihan, 2015). Additional factors to consider include:

- Pain that is associated with eating.
- The risk or presence of skin breakdown.

- Ascertain the impact of anorexia and cachexia on function.
  - Evaluate if there is an increase in weakness and/or fatigue.
  - Evaluate for signs and symptoms related to depression or confusion.
  - Impact on self/family – Discuss the patient’s/family’s perception of and response to this symptom and on quality of life.

- Calorie counts/daily weights may be of value (though may not be appropriate in last months of life).
  - Evaluate if the patient has experienced decreased food/fluid intake (Note: The use of these assessments will need to be continuously evaluated, as late in disease they may be unnecessary and may create burden and distress).

- Laboratory tests – Serum albumin concentration decreases as nutrition status decreases; however, this laboratory value is a last marker. Hence, if low albumin is noted, this problem has existed at least 2 to 3 weeks.
Exercise - Stop and Consider:
You are caring for a terminally ill Veteran who does not feel like eating because he experiences extreme epigastric pain after each meal (diagnosed with stage IV liver cancer five months ago). He has diarrhea that is poorly controlled and experiences frequent bouts of nausea. His family insists that he eat and is worried that he will certainly die soon if he does not take some nutrition. He has lost 30 pounds in the past five weeks. The Veteran’s daughter tells you that she believes the institution is killing her father because they are not feeding him. She insists that a feeding tube be inserted immediately and that an IV be started now. The Veteran is awake, alert, oriented, and is capable of making his own decisions about his healthcare.
- How would you respond to the daughter?
- How would you proceed?
- What other disciplines would be available to assist you?
Interventions regarding anorexia and cachexia must be individualized (Wholihan, 2015). Eating for pleasure should always be the goal. Referrals to a dietician may be appropriate. Patients should be encouraged to:
- Eat favorite foods.
- Dietary restrictions are typically eliminated to optimize quality of life. High calorie foods, in small frequent meals, may improve intake.
- Food presentation is important - small quantity; smaller more frequent meals; serve on a large plate (less overwhelming).

Problem odors that inhibit eating can be addressed by separating cooking times from eating times or moving the patient away from the kitchen. If the Veteran is an in-patient, removing the cover of the food out in the hall, before bringing it into the room can allow for some of the odors to dissipate. Odors from wounds may also affect appetite.

Medications:
- Appetite stimulants may be useful (such as megestrol, though not always effective and can increase the risk of blood clots).
- Steroids may increase appetite and energy level, especially in depression
- Olanzapine or mirtazapine (in lower doses such as 7.5mg to 45 mg at bedtime may be helpful in increasing intake, improving sleep and treat depression.
- Prokinetics (e.g. metoclopramide) may be helpful in increasing gastric emptying.
• In some institutions the leading referral to palliative care consult teams is related to the issues surrounding nutrition. In some cases parenteral or enteral nutrition may prove useful in patients who cannot swallow but continue to have an appetite, such as in esophageal cancer.

• Artificial nutrition is a medical procedure requiring serious consideration as it can incur significant morbidity and financial cost. Artificial nutrition can lead to nausea, vomiting, or diarrhea. This therapy can sometimes provide a false sense of hope to the patient/family, that this therapy will allow them to “get better.” Caring for the Veteran and family as they deal with the real and symbolic meaning attributed to feeding, requires much reassurance, support, and education by the nurse.

• Unfortunately aggressive nutritional treatment does not improve survival or quality of life and may actually create more discomfort for the patient (HPNA, 2011; Prince-Paul & Daly, 2015). Artificial nutrition may become a burden to patients and families. Informed decisions and consents are vital to obtain. Remember to educate and communicate continuously.

• Counseling:
  ➢ Overall the problem of cachexia may prove to be one of the most distressing symptoms for patients and families. Some patients may try to eat to gain weight and strength, so they can continue treatment(s). Constant evaluation is appropriate with support and guidance regarding this symptom.

**Note:** Anorexia and cachexia may not be reversible and are often a normal part of the dying process.
• Constipation is defined as the infrequent passage of stool. While constipation occurs in approximately 30% of the general population, its incidence can be as high as 30-100% in palliative care (Economou, 2015). Associated symptoms may include:
  ➢ Rectal pressure
  ➢ Straining
  ➢ Cramps/distension/bloating
  ➢ Hemorrhoids/fissures

• Constipation may be a highly embarrassing issue for the patient and this situation can frequently evolve to a severe problem. Talking frankly and openly regarding this symptom and encouraging discussion (with appropriate privacy of setting) helps prevent significant distress (Economou, 2015). Ask the patient how he/she wants this issue addressed.

• Prevention is key to avoiding constipation!
• Disease-related:
  - Intestinal obstruction, whether partial or complete in nature, is related to presence of tumor in or compression of the bowel. This is most commonly seen in mesothelioma, ovarian, and gastrointestinal cancers (NCI, 2016c).
  - Hypercalcemia and hypokalemia.
  - Spinal cord compression or transection will slow transmission of food via the intestines.
  - Concurrent disease, such as diabetes, can affect the neurological stimulation of gastrointestinal motility. Other diseases such as colitis, hypothyroidism, diverticulitis, or chronic neurological states, can also impact bowel motility.
  - Surgical adhesions can cause scarring.
  - Dehydration can affect stool consistency, resulting in dry, hard stools.
  - Inactivity, weakness, and loss of privacy can change daily bowel habits.
  - Pain, especially if associated with bowel movement, can also lead to constipation.
  - Decreased abdominal muscle tone.
  - Depression and resultant inactivity can be a contributing factor that leads to constipation.

• Medication-related:
  - Opiates can impair effective peristalsis, increase sphincter tone, increase electrolyte and water absorption, and insensitivity to rectal distention, and decrease the need to defecate.
  - Antidepressants can slow motility, which can precipitate constipation.
  - Antacids cause hardening of stool, making defecation more difficult.
Chemotherapy drugs such as vinca alkaloids have a neurotoxic effect on the bowel, which increases colonic transit time. Cisplatin, oxaliplatin, and thalidomide cause autonomic nervous system changes.
Assessment of Constipation

- Bowel history
- Abdominal assessment
- Rectal assessment
- Medication review

Bowel history: The assessment of constipation should include a bowel history (i.e., characteristics [appearance and consistency] and frequency of stool, history of use of bowel medications and preferred bowel interventions, fluid intake, anorexia, presence of nausea and vomiting associated with constipation, presence of concurrent medical conditions, constipation problems prior to disease). The nurse should be aware that the definition of constipation varies significantly from patient to patient and the goal is to establish what is normal for each patient. The Constipation Assessment Scale, ranking 8 symptoms on a 0-2 scale, may be helpful as an objective measure of the severity of constipation (Economou, 2015).

Abdominal assessment: Perform an abdominal assessment to rule out obstruction, which includes: examination for bloating, tenderness, bulges, bowel sounds (i.e., hyperactive, hypoactive or absent – listen for a minimum of 5 minutes), percussion, and rectal assessment for impaction. Abdominal x-ray may be necessary to rule out bowel obstruction.

Rectal assessment: The digital rectal exam should be initiated in the neutropenic patient only after careful consideration. The exam may reveal stool, tumor, or perhaps rectocele. A visual inspection should be accomplished examining for hemorrhoids, ulceration or rectal fissures. Their presence may make defecation painful and/or may be the site of infection.

Medication review: Review all prescribed and over the counter medications, vitamin supplements, herbals.
- Dietary review: typical foods, amount of fiber, and average fluid intake. Increased fiber with insufficient fluids may worsen constipation.
The treatment of constipation is multi-faceted (NCI, 2016a).

- **Medications:**
  - Maintenance usually requires a prophylactic stool softener and stimulant.
  - An array of laxatives may be considered (e.g., stimulant, bulk, lubricant, surfactant/detergent, combination products).
  - If the cause cannot be eliminated then treatment should include a bowel regimen. A minimum goal for a bowel movement is at least every 72 hours regardless of intake.
  - Prior to beginning any treatment, the presence of bowel obstruction should be ruled out.

- **Dietary and fluid interventions:**
  - Patients should be encouraged to drink plenty of fluids and increase their activity as able.
  - Many patients have their own bowel regimens and these should be encouraged as long as they prove effective. Give oral agents before trying rectal agents. (Economou, 2015).

- **Additional approaches:**
  - Suppositories and/or enemas should be considered when the patient is no longer able to tolerate oral medications or they have become ineffective. Enemas should be avoided as part of a routine bowel regime but may be necessary in some cases.
  - The opioid antagonist methylnaltrexone (Relistor) is useful for severe opioid induced constipation in palliative care patients.
Complementary approaches:
- Herbs (mulberry, rhubarb constituents, megavitamins, etc. (Kravits, 2015)
- Use of a foot stool to elevate legs into a squatting position on the commode
- At the same time every day, serve a hot drink 30 minutes before a meal to stimulate peristalsis and help produce regular BMs. Works best if patient goes directly to the bathroom following the meal.
Diarrhea is the frequent passage of loose non-formed stool. While this problem is much less common in the palliative care setting than constipation, it remains a common symptom (Economou, 2015).

Diarrhea may:
- Dramatically affect a person's quality of life.
- Cause fatigue, electrolyte abnormalities, and depression if diarrhea continues for long periods of time.
- Cause patient and family to become more homebound.
- May be embarrassing, time consuming and lead to several problems such as skin breakdown and dehydration.
- May cause breakdown of home care giving.
• Disease-related: Multiple bacterial and parasitic infections, which can be the causative agents of diarrhea. Partial bowel obstruction or fecal impaction can lead to diarrhea that sometimes alternates with constipation. Diarrhea may be especially problematic in HIV patients.

• Malabsorption may occur in the presence of pancreatic tumors or following gastrectomy. Alcohol and carbohydrate malabsorption also contribute to diarrhea.

• Concurrent diseases, such as hyperthyroidism and irritable bowel syndrome.
  ➢ What appears to be diarrhea may be bleeding out.

• Psychological: The occurrence of diarrhea can be caused by or increase anxiety on the part of the patient, particularly in public situations and this can have a negative psychological sequela. Fear of loss of control may cause patients to become isolated and homebound. The use of adult absorbent briefs may enable some patients to participate more fully in activities.

• Treatment-related: Chemotherapy causes mucositis and immunosuppression, which makes the individual more susceptible to infections, viral, fungal and parasitic pathogens (NCI, 2015a).
  ➢ Radiation therapy to the abdomen, pelvis, and spine.
  ➢ Graft vs. host disease is a result of immunosuppression.
- Dumping syndrome can also occur after surgery.
- Infections such as clostridium difficile may occur after receiving antibiotics. This is a result of overgrowth of bacteria in the gut.
- Medications (i.e., herbal remedies, over-the-counter medications & overly aggressive bowel regimen can cause diarrhea).
• Bowel history: Assess the nature and frequency of stools, as well as the presence of dehydration and weight loss. The onset/suddenness of a bowel movement is also an important part of assessment. A rapid onset may indicate fecal impaction with overflow. If diarrhea occurs once or twice a day it may be due to anal incontinence. Typically watery stools in large amounts are consistent with colonic diarrhea, while foul smelling, fatty, pale stools are associated with malabsorption. Evaluate for presence of dumping syndrome, carcinoid, and other syndromes. Evaluate/monitor occurrence of incontinence (Economou, 2015). Ascertain number of loose stools per day and accompanying symptoms (e.g., cramping, incontinence, nocturnal, etc.)

• Medication review: Indications of laxative overuse include cramping, urgency, or fecal leakage. Check over-the-counter medications or herbal supplement usage.

• Infectious processes: Laboratory values which may be considered include evaluation of stool for blood, fat, mucous and pus, culture and sensitivity.
Early treatment for diarrhea is essential, as people can die from dehydration and/or loss of electrolytes. Treat the underlying cause as appropriate.

Dietary modifications: Initiate a clear liquid diet. Eat smaller size meals (NCI, 2015a). Avoid milk, proteins, and fats, alcohol, hot spices, and gas-forming foods, such as broccoli, cauliflower, cabbage, sauerkraut, corn and beans.

Promote hydration, suggesting fluids that may improve electrolyte status (i.e. sports drinks, juices). Consider IV fluids if consistent with goals of care.

Medications such as loperamide, scopolamine, cholestyramine, clonidine and pancreatic enzymes may be considered (Economou, 2015). Treat infections as nonspecific antibiotics can make diarrhea related to *C. Difficile* worse.

Diarrhea related to antibiotic therapy may be prevented by starting probiotics within two weeks of the initiation of antibiotics.
The incidence of nausea and vomiting is quite common in advanced disease

- Nausea occurs in up to 70 percent of terminally ill patients (Chow et al., 2015).
- Vomiting occurs in approximately 30 percent of terminally ill patients; but unfortunately, this symptom has not been well-researched in those with advanced disease.

The pathophysiology of nausea and vomiting is extremely complex, requiring careful assessment of etiology, and therefore, appropriate treatment.

- Nausea/vomiting can be acute, anticipatory or delayed.
- Nausea and vomiting can be exceptionally frustrating, painful and exhausting for the patient and family/caregivers. These symptoms clearly increase suffering and require immediate intervention in ensuring patient comfort (Chow et al., 2015).
There are many causes of nausea and vomiting (Chow et al., 2015). Etiology is often multi-factorial.

- Physiological:
  - Gastrointestinal causes – The following causes of nausea and vomiting include gastric irritation and stasis, constipation, intestinal obstruction, pancreatitis, ascites, liver failure, intractable cough, and radiation effects. All cause visceral disturbances by stimulating vagal and sympathetic pathways.
  - Metabolic causes – Hypercalcemia, uremia, infection and drugs cause stimulation of the chemoreceptor zone within the brain, causing nausea, with or without vomiting.
  - Central nervous system causes – increased intracranial pressure, pain.

- Psychological:
  - Emotional factors can lead to nausea and vomiting as a result of stimulation of emetic receptors in the brain.
  - Anticipatory nausea can be a response to treatment that could result in nausea/vomiting.

- Disease-related:
  - Chronic organ failure
  - End stage renal disease

- Treatment-related:
  - Radiation
- Chemotherapy

- Other:
  - Vestibular disturbances, including motion sickness, toxic action of certain drugs (i.e., aspirin and opiates).
  - Local tumors within the brain stimulate the vestibular apparatus causing nausea/vomiting.
Clinical assessment of nausea and vomiting should include past history and effectiveness of treatment of nausea/vomiting, medication history, frequency of episodes of nausea and any correlation with vomiting, identification of those activities that may precipitate or alleviate nausea/vomiting (Chow et al., 2015). Obtain the following history:
- Consistency, frequency and volume of emesis
- Emesis associated with position changes
- Presence of contributing factors (i.e., vertigo, blood sugar levels, and medications)
- Relationship to food intake
- Evaluation of the presence of constipation or impaction
- Presence of uncontrolled pain or infection
- Presence of anxiety and other emotional symptoms

Physical examination should include:
- Abdominal examination and evaluation to include bowel sounds
- Possible assessment of the rectal vault.

Lab values as indicated:
- Renal and liver function tests
- Electrolytes, calcium, serum drug levels
- Radiologic tests to include abdominal X-rays and/or head CT or MRI
• Treatment of nausea is dictated by the presumed cause so treat any underlying cause if possible and try interventions that have worked in the past (Chow et al., 2015).

• Medications include:
  ➢ Prokinetic agents, such as metoclopramide, can treat gastric stasis or ileus.
  ➢ Dopamine receptor agents such as butyrophenones (haloperidol) and phenothiazines which are also categorized as antipsychotics but given at a lower dosage.
  ➢ Antihistamines are commonly used in intestinal obstruction, increased intracranial pressure, or peritoneal irritation, and when vestibular causes exist (e.g., cyclizine). Use with extreme caution in older adults.
  ➢ Selective 5HT3 receptor agonists are used for post-operative nausea and vomiting and chemotherapy-related emesis. These include ondansetron and granisetron.
  ➢ Steroids, given alone or with other agents for nausea and vomiting, are appropriate for cytotoxic-induced emesis (e.g., dexamethasone).
  ➢ Anticholinergics, such as hyoscine hydrobromide, treat motion sickness, intractable vomiting, or small bowel obstruction. Use with extreme caution in older adults.
  ➢ Others include: benzodiazepines, such as lorazepam, are most effective in treating nausea exacerbated by anxiety. Use with extreme caution in older adults.
  ➢ In the setting of intractable nausea and vomiting, rectal or parenteral routes may be needed in the first 24 hours
  ➢ Review meds/doses every 24 hours. If insufficient relief, seek new orders.
Anticipatory nausea can be treated by the use of distraction or relaxation techniques, acupuncture, music therapy and hypnosis (Kravits, 2015).

Dietary and environmental modifications:
- Serving meals at room temperature with clear fluids.
- Avoiding strong smells may be beneficial.
- Encourage the patient to eat slowly, avoiding large, high bulk meals.
- Patients who are weak should be positioned to avoid aspiration.

Invasive therapies include:
- A nasogastric tube may need to be inserted to relieve pressure.
- In rare cases, such as unresectable obstruction, a draining peg tube may be placed.
- IV hydration in severe nausea/vomiting needs to be carefully considered. TPN and peripheral nutrition have a very limited role in palliative care. Some may argue it has no role in end-stage disease. Be aware of patient’s goals of care.
- Surgery to remove obstructions if patient’s life expectancy permits.
This section will provide an overview of fatigue and wounds as well as assessment, causes and treatment modalities.
• Fatigue is described as a “multidimensional, is not easily relieved by rest, and has a profound impact on the dimensions of quality of life (QOL) including physical, psychological, social and spiritual well-being. Fatigue is influenced by the cultural context of the individual and is associated with a reduced capacity to carry out expected or required daily activities” (Ferrell et al., 1996).

• Fatigue may be a reminder that the disease is progressing, that one is helpless, useless, and no longer capable of doing previous activities. Although the disease may be progressing, nurses can encourage patients to reconsider how they approach tasks and activities to enhance quality of life.

• Many approaches to assessment and management of fatigue exist, so consider the presence of many different factors and their impact on the individual.
Cancer related fatigue is reported in as many as 60% to 90% of patients (O’Neil-Page et al., 2015). Fatigue in cancer is associated with anorexia/cachexia; however, improving intake has not been shown to alleviate this symptom (NCI, 2014).

Disease-related:
- Coronary artery disease (CAD)
- HIV/AIDS
- Rheumatoid arthritis
- Advanced renal disease
- Anemia
- Electrolyte imbalances
- Malnutrition
- Infection
- Hyperglycemia/hypoglycemia
- Fever
- Pain
- Organ failure (heart/lungs/kidneys/liver)
- Adverse environment (heat or cold extremes)
- CNS injury disrupts the electrical pathway within the nervous system
- Hypoxia

Psychological:
- Fatigue in cancer patients can affect mood, social interaction, sense of self, and work performance (NCI, 2014).
- Inactivity/immobility resulting from disease process, medical intervention, or psychological response to illness can lead to impaired ability to participate in activities of daily living (e.g. sense of loss, loss of role).
- Assess for asthenia—weariness or exhaustion without physical or mental exertion.

- Treatment-related:
  - Inadequate rest, unrelieved symptoms, medications, psychological and spiritual distress, and multiple/additional factors.
  - Treatment effects can be from drug therapy, radiation, and surgery.
  - Unrelieved symptoms, (such as diarrhea, constipation, and vomiting).
Subjective data:
- Are you feeling weak, tired or wiped out?
- How long does the fatigue last? Is there a pattern? Hours, days, weeks?
- Are you able to complete activities of daily living?
- What, if any, part of your body is the most fatigued?
- What makes this better or worse?
- Do any of your medications improve or worsen this problem?
- Are you anxious or depressed?
- Are you experiencing difficulty in concentrating?
- Are you having difficulty sleeping?
- How does fatigue affect the way you live your life?

Objective data:
- Monitor vital signs to determine if fever, rapid or weak pulse is present.
- Observe patient's ability to move about without experiencing dyspnea or nausea.
- Evaluate hydration status and daily diet
- Test muscle strength, symmetry and endurance of upper and lower extremities to determine if neurological changes are present.
- Evaluate medications, especially sedating medications, all over the counter medications, and herbal preparations

Laboratory data:
- Oxygenation status
- Hemoglobin, CBC and differential
- Thyroid function
Pharmacologic interventions include the possible use of:
- Corticosteroids
- Stimulants
- Antidepressants
- Recombinant human erythropoietin

Non-pharmacologic interventions (O’Neil-Page et al., 2015) include:
- Take frequent rest periods and use energy conservation techniques, such as the use of appropriate assistive devices as needed (i.e., commode, wheelchair, and/or walker).
- Pace activities, alternate physical activity with rest and try to reduce demands. Set priorities to ensure that valued activities can be continued and “letting go” of less important activities.
- Provide assistance that helps the person to maintain independence and functional abilities for as long as possible.
- Physical and occupational therapy may offer valuable input in the evaluation of potential interventions.
- Participating in an exercise program may decrease the severity of this symptom.
- Initiate blood transfusions as appropriate. The goal of transfusion therapy should be scrutinized prior to each treatment session, and should be directed toward improving the patient's overall quality of life.
Wounds can be described as skin drainage of varying degrees causing inflammatory pain and being a potential site of infection. The most common wound seen in palliative care patients is the pressure injury (Bates-Jensen & Petch, 2015).

In April, 2016, the National Pressure Ulcer Advisory Panel updated the term of pressure ulcer to pressure injury (NPUAP, 2016).

Risk factors include:
- Patients at higher risk include patients with breast, lung, kidney, stomach, gynecologic, bladder, head and neck cancers; frailty, and dementia.
- Intrinsic – sensory impairment, tumor growth or vascular disease.
- Extrinsic – pressure, friction/shearing, chemotherapy extravasation, radiation, urinary and fecal incontinence.
- Risk factors are increased due to poor functional status, decreased activity, poor nutrition, and/or advanced age.

The Department of Veteran’s Affairs Amputation System of Care (ASoC), initiated in 2008, provides holistic and care coordination for Veterans with amputations that result from any etiology ranging from the effects of war (Veterans of Operation Enduring Freedom, Operation Iraqi Freedom and Operation New Dawn) to older adults experiencing the effects of vascular disease with access to Regional Amputation Centers, Polytrauma Amputation Network Sites, Amputation Clinic Teams and Points of Contact (Webster et al., 2014).

Prevention is key and requires:
- Early intervention
- Maintaining mobility as possible
- Decrease moisture
- Maintaining nutritional status, as appropriate
• Evaluate the characteristics of the wound to include:
  ➢ Odor
  ➢ Location – anatomic description
  ➢ Size – length, width, depth
  ➢ Color – pink, black, or yellow
  ➢ Drainage – amount, consistency, source
  ➢ Periwound status of intact, inflamed, or macerated. Note: some pressure ulcers are considered unavoidable (Edsberg et al., 2014).
  ➢ Staging: (NPAUP, 2016)
    – Stage 1: non-blanchable erythema of intact skin
    – Stage 2: partial thickness skin loss with exposed dermis (a shallow crater or blister)
    – Stage 3: full-thickness skin loss (adipose tissue is visible in the ulcer and granulation tissue is often present).
    – Stage 4: full thickness skin and tissue loss with extensive destruction, necrosis or damage to muscle, bone and supporting structures.
  ➢ Note: Kennedy Terminal Ulcers are sudden and fast progressing wounds due to skin (organ) failure, not pressure injuries, and may occur despite meticulous care of the skin, as the patient approaches the actively dying phase. Educate caregivers that these wounds cannot be prevented as they are due to organ failure, not pressure injuries or shear.
• Pain: Assess and determine effectiveness of interventions
• Psychosocial issues:
- Wounds may keep Veterans more isolated. Doing frequent dressing changes can add to the fatigue a Veteran may already be experiencing.
- Assess for body image issues associated with amputations, etc.
- Impact on caregivers related to management of wound and impact on relationships.

• Obtain a diagnostic evaluation as appropriate to the patient-family goals of care:
  - Transferrin and albumin
  - Creatinine
  - Hemoglobin and complete blood count
  - Blood and wound cultures
Meticulous wound assessment and treatment is important in addressing goals of care. Goals of caring for wounds in palliative care include controlling odor, bleeding, pain, and exudate (Seaman & Bates-Jensen, 2015).

- Wound cleaning to decrease exudates needs to be gentle to prevent trauma, bleeding and pain.
- Appropriate dressings to absorb exudates may prove useful. Use appropriate cleansing and dressing, such as moist dressings or collagens to decrease risk of bleeding.
- Topical metronidazole may decrease infection while improving odor
- Debridement may be necessary

Ensure appropriate analgesic treatment for all wound care (before turning or dressing changes). Enterostomal nurses or wound care teams should be utilized as appropriate.

- Continue to evaluate impact of wound on the Veteran’s body image and self-esteem.

**Note:** Veterans may come into an acute care setting from home or other facilities with a pressure injury. At this point, your goal of care will be to minimize the wound, preventing the wound from increasing in size. Healing may not take place, due to the poor nutrition and skin quality of the Veteran. However, nurses can focus on excellent pain management, documentation, and prevention of the wound from becoming more pronounced.
Veterans who utilize the VA system may have mental health diagnoses and other complex psychosocial issues requiring palliative care interventions. Conditions most frequently seen among Veterans:

- Post-traumatic stress disorder (PTSD)
- Depression, with the possibility for suicide
- Anxiety
- Delirium/confusion/agitation
- Substance abuse

Note:
“The Mental Illness Research, Education and Clinical Centers (MIRECC) were established by Congress with the goal of researching the causes and treatments of mental disorders and using education to put new knowledge into routine clinical practice in the VA. Specialized Mental Health Centers of Excellence (MHCoE) are an essential component of VA’s response to meeting the mental health needs of Veterans.” Retrieved February 25, 2016 from: http://www.mirecc.va.gov/index.asp
Post-Traumatic Stress Disorder (PTSD) is a disorder that is characterized by a persistent and severe reaction to a traumatic event and has specific symptom clusters (e.g. avoidance, re-experiencing, and hyperarousal). It is characterized by recurrent distressing memories (Koenigs & Grafman, 2009). PTSD can affect not only Veterans but others who have endured a traumatizing event. PTSD is associated with events such as:

- Combat
- Terrorist attacks
- Sexual, physical/violent assault
- Accidents
- National/natural disasters
- Life-threatening illness

Prevalence rates vary based on several studies indicate the following:

- National Vietnam Veterans Readjustment Study: The estimated lifetime prevalence of PTSD among these Veterans was 30.9% for men and 26.9% for women. Of Vietnam Theater Veterans, 15.2% of males and 8.1% of females were currently diagnosed with PTSD during the study.
- Gulf War Veterans: The prevalence of current PTSD in Gulf War Veterans is 12.1% and for the total Gulf War Veteran population is estimated to be 10.1%
- Operation Enduring Freedom/Operation Iraqi Freedom: the prevalence of current PTSD is estimated at 13.8%.

• Very little research, if any, has been done in addressing PTSD and terminal illness. The unique stresses that Veterans experience may influence their response to serious illness and at end of life (Periyakoil, 2016; Grassman, 2015):
  ➢ Terminal illness (threatening of one’s life) may mimic the original trauma, and this can exacerbate previous PTSD symptoms leading to more distress
  ➢ When a patient (Veteran) has vital memories that are related to trauma, life review can cause anxiety, sadness, guilt, anger
  ➢ Avoidance symptoms are key to the diagnosis and so they may avoid/ignore the problems, which leads to difficult doctor-patient communication
  ➢ A distrust of authority can lead to many questions about what the provider is doing. The Veteran may refuse medical care.
  ➢ Those with PTSD may not have developed a community of family and friends and may lack caregivers.

Further information on PTSD, DSM-IV™ Diagnosis and Criteria can be found at http://www.mental-health-today.com/ptsd/dsm.htm (last accessed February 24, 2016).
Veterans may experience many terrifying and life-threatening ordeals that can precipitate PTSD (Koenigs & Grafman, 2009). It is important that the healthcare team caring for a Veteran with PTSD is aware of this diagnosis. Causes include:

- Various fears, including fear for their own life or another’s
- Witnessing horrific events in wartime
- Feeling helpless in being able to respond to the horrific event(s) (Veterans Advisory Council, 2009).

Scientists in the neuroscience field are looking at areas of the brain that can provide answers to the pathophysiology of PTSD (Koenigs & Grafman, 2009).

Some terminally ill Veterans may never have been diagnosed/treated for PTSD until they are seen by the palliative care team. Veterans may have PTSD, but it is unknown to him/her upon admission.
Screening and assessment of symptoms common to PTSD is a necessary component of palliative care. Symptoms are important for nurses to assess (Periyakoil, 2016):

- Persistent re-experiencing and reliving the trauma or “flashbacks” thus reliving the trauma and feelings of intrusion.
- Persistent avoidance of the thoughts and feelings, places and people that are connected with the trauma. They may have feelings of detachment (e.g. unable to have loving feelings, etc.) and a sense of not seeing a future (e.g., not able to think of marriage, children, career, etc.).
- Negative changes in beliefs and feelings such as guilt, shame, or fear. The Veteran may not be interested in doing activities that in the past brought enjoyment.
- Persistent hyperarousal (e.g., hypervigilance, difficulty going to sleep and staying asleep, outbursts, difficulty in concentrating, startle response that is over exaggerated).
- Functional impairment may emerge in social and/or occupational settings or other areas.
- Duration of symptoms are present for one month and can occur right after the trauma or later in life.

Risk factors for PTSD include:

- History of child abuse
- Chronic mental illnesses
- Females
- Ethnic minorities (e.g. Hispanics and African Americans)
- Combat Veterans or those who have had dangerous duty assignments: These symptoms may begin within three months of the traumatic event, though may not begin until many years later (Periyakoil, 2009). PTSD may surface initially at the end of life and it can be frightening at a time when the Veteran is already vulnerable (Grassman, 2009). The palliative care team must work closely with the mental health professionals to identify the best plan of care for Veterans in their final days.

- All Veterans, especially those admitted for end-of-life care, should be screened for PTSD, just to obtain a baseline.

- The PTSD Checklist for DSM-5 (PCL-5) is a self-report tool with 20 items that assesses the 20 DSM-5 symptoms of PTSD (Weathers et al, 2013). The PCL-5 has a variety of purposes, including: monitoring symptom change during and after treatment, screening individuals for PTSD, making a provisional PTSD diagnosis. The gold standard for diagnosing PTSD is a structured clinical interview such as the Clinician-Administered PTSD Scale (CAPS-5). When necessary, the PCL-5 can be scored to provide a provisional PTSD diagnosis. Note: the PCL-4 is now obsolete and PCL-5 is currently in use. The change in the rating scale, combined with the increase from 17 to 20 items and suggested cut score means that PCL-5 scores are not compatible with PCL for DSM-IV scores and cannot be used interchangeably. The PCL-5 is a self-report measure that can be completed by patients in a waiting room prior to a session or by participants as part of a research study. It takes approximately 5-10 minutes to complete. Interpretation of the PCL-5 should be made by a clinician. For more information, visit the VA PTSD Checklist for DSM-5 (PLC-5) website with more details; retrieved March 31, 2016 from http://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp

- There also exist PTSD screening instruments which are short and brief questionnaires that may identify people who are more likely to have PTSD and may have possible problems. A positive response to the screen does not necessarily indicate that a patient has Posttraumatic Stress Disorder (PTSD, 2016a). However, a positive response does indicate that a patient may have PTSD or trauma-related problems, and further investigation of trauma symptoms by a mental health professional may be warranted with a structured interview by a trained mental health professional. For additional details and specific screening instruments, visit PTSD Screening Instruments; retrieved March 30, 2016 from http://www.ptsd.va.gov/PTSD/professional/assessment/screens/index.asp
• Nurses must be aware of Veterans who have PTSD during the end of their lives. Currently, there are no evidence-based guidelines to address the psychosocial management of PTSD at the end of life (Feldman & Periyakoil, 2006).

• Nurses’ thorough assessments are important to report to the entire healthcare/palliative care team.
  ➢ In one study, there were four important findings about the impact PTSD-related symptoms have on Veterans at the end of life (Alici, et al., 2010):
    ♦ Families of Veterans believe that PTSD-related symptoms are common near the end of life. These symptoms should be assessed along with depression, anxiety and other psychological distresses.
    ♦ PTSD-related symptoms may be difficult to predict, especially when a formal diagnosis of PTSD has never been made.
    ♦ Near the end of life, PTSD-related symptoms are not as common as pain and dyspnea. However, families have reported that PTSD causes more distress than dyspnea.
    ♦ During the last month of life, families whose loved one had PTSD-related symptoms reported negative perceptions of care.

*Important:* Those who received palliative care consults were associated with less PTSD-related discomfort. This suggests that PTSD-related symptoms and their management near death is amenable to intervention and that palliative care teams may be used to reduce some of the burden that these symptoms cause.
• The Institute of Medicine (IOM) recommends that the VA and other government agencies promote and support research on early intervention in PTSD. Additional research is essential to review every treatment modality (IOM, 2014).

**Note:** Nursing care considerations when caring for Veterans who have PTSD or who have a history that suggests risk of undiagnosed PTSD:
- Avoid using bed alarms.
- Avoid touching them unless you call their name out first and and/or they see you coming.
- Avoid keeping curtains closed around their bed, where they cannot see what is going on in the room.
- Tucking linens around their feet may give them a sense of being “closed-in” without a way “to escape.”
- If experiencing PTSD at home, contact the Veteran Center so they can follow up with the Veteran and/or his/her family.

• For further resources on PTSD:
  - Department of Veteran Affairs: [http://www.va.gov/](http://www.va.gov/)

In addition, as mentioned previously, very little research, if any, has been done in addressing PTSD and terminal illness. More research is needed in this area. Because PTSD can complicate the dying process in many ways, it is vital that research continue so that the patient can die with dignity (Feldman & Periyakoil, 2006; Periyakoil, 2009, IOM 2014). Families will always remember those last moments of their loved one’s life. It is critical that every effort be made to assess and manage these patients carefully.
Delirium is an acute change in cognition or awareness. These diagnoses can be challenging to nurses as they care for Veterans. They can be difficult for nurses to manage and can be agonizing for family members to witness.

- Terminal delirium is common in patients near death. Early detection and assessment may lead to resolution of delirium if cause is reversible but in all cases patient and family support is essential (Heidrich & English, 2015).

- Agitation is a common symptom accompanying delirium (hyperactive delirium), although withdrawn behaviors (hypoactive delirium) can also occur. Individuals may also experience a mixed delirium (hyperactive and hypoactive), making the diagnostic process even more challenging.

- Confusion refers to disorientation, inappropriate behavior or communication and/or hallucinations. Note: Distinguish from Nearing Death Awareness: patient uses transportation imagery (“the train is coming), may have conversations with people who have died as though they are present; asks to go home when they are already home.

- Agitation of PTSD needs to be distinguished from delirium, confusion, or agitation. Agitation is sometimes a sign of PTSD, which can become exacerbated at end of life as cognition wanes and unwanted memories surface unbidden (Grassman, 2009).

**Note:**
There may be predisposing and precipitating factors that contribute to delirium (Heidrich & English, 2015).

- Predisposing factors may include, but are not limited to: demographic characteristics (older age, male sex); cognitive status (dementia, history of delirium, depression); compromised functional status (immobility, history of falls); sensory impairment (visual, hearing); decreased oral intake (dehydration, malnutrition); drugs (multiple psychoactive drugs and anticholinergic drugs); and coexisting medical conditions (severe illness, renal or hepatic diseases, history of stroke, terminal illness, metabolic derangements).

- Precipitating factors may include, but are not limited to: drugs (sedatives, hypnotics, alcohol withdrawal, opioids); primary neurological disorders, intercurrent illnesses (infections, severe acute illness, dehydration), surgery (orthopedic, cardiac, prolonged cardiopulmonary bypass), prolonged sleep deprivation, and environmental (ICU, use of restraints, pain, emotional distress, PTSD).
Assessment for delirium/confusion/agitation is multifaceted. Careful assessment is needed to distinguish the many, often related symptoms of anxiety, depression, confusion, delirium, agitation, and PTSD.

History:
- To determine onset and distinguish delirium from related symptoms such as anxiety, depression, and/or PTSD.

Physical assessment:
- Common signs include disturbed sleep/wake cycle, agitation, restlessness, moaning. Assess for potential underlying causes as identified above.

Assess for spiritual distress:
- Consult with chaplain services, etc.
- A person’s sense of spirituality is often the key to transcending losses and finding meaning in life (Borneman & Brown-Saltzman, 2015). Many search for the meaning of suffering, for forgiveness and/or for acceptance. This can cause anxiety and depression that can further lead to delirium, confusion and agitation.
- Forgiveness issues, including acts they might have committed during combat.
- Spiritual distress may be seen as agitation among patients who view God as a punishing judge, and less among people who view God as a loving parent.
• Use of pharmacologic agents has shown mixed results in literature while non-pharmacologic interventions have been shown to provide benefit with delirium/agitation/confusion.

• Pharmacologic treatments (use with caution in older adults) include:
  ➢ Evaluate current medications to eliminate any nonessential drugs.
  ➢ Neuroleptics, which have historically been the first line pharmacologic treatment, may worsen symptoms (e.g., haloperidol, risperdone) while other neuroleptics such as chlorpromazine have not been studied as extensively.
  ➢ Benzodiazepines have been shown to worsen delirium symptoms and should be used with caution when needed to treat associated anxiety.
  ➢ Monitor closely for potential side effects of these agents

• Non-pharmacologic interventions include:
  ➢ Presence of family or staff to reorient as needed.
  ➢ Institute relaxation/distraction therapy, massage (Kravits, 2015).
  ➢ Limited course of hydration may be indicated based on assessment of potential benefits or burdens (i.e., to prevent a build-up of metabolites from certain medications or infection).
  ➢ Spiritual support to heal the patient’s image of God from an angry judge to a loving parent welcoming him/her home.
• The true incidence and prevalence among Veterans is unknown. Depression is often a dual diagnosis with PTSD and may lead to suicide.

• Depression can be described as a broad spectrum of responses that range from “expected, transient, and nonclinical sadness to extremes of major clinical depressive disorders and suicidality.” For many who suffer from terminal illness, little, if any attention is paid to assessment and treatment of depression and anxiety. Because of this, dysphoria, family conflict, noncompliance with treatment, increased length of hospitalization, persistent worry, and suicidal ideation, etc. may be on-going (Pasacreta et al., 2015).

• Early diagnosis can improve outcomes and allow individuals to feel better while having more energy to achieve their goals.

• Persistent feelings of helplessness, hopelessness, inadequacy, depression and suicidal ideation are not normal at the end of life. These symptoms should be aggressively evaluated and treated.

• Further information on depression can be found at:
http://www.cancer.gov/cancertopics/pdq/supportivecare/depression/healthprofessional


- For more insight, read this New York Times article: *Stalked by Suicide, Veterans Try to Save One Another*. Members of a Marine battalion that served in a restive region in Afghanistan have been devastated by the deaths of comrades and frustrated by the V.A. by Dave Philipps, September 19, 2015. Retrieved April 26, 2016 from http://www.nytimes.com/2015/09/20/us/marine-battalion-veterans-scarred-by-suicides-turn-to-one-another-for-help.html?r=0
- Disease-related:
  - Uncontrolled pain and other associated symptoms (i.e., constipation, anorexia, and sleep disturbances) are factors that may exacerbate depression.
  - Altered physiologic states that can cause anxiety and contribute to depression in the cancer patient include: sepsis, abnormal metabolic states, delirium, organic mental disorders, drug reactions and drug withdrawal syndromes.

- Psychological:
  - Psychological or existential factors related to impending death such as fear, loss of independence or control, changes in body image, also affect patients' emotional responses.
  - Family and personal history of pre-existing psychological conditions, such as major depressive and anxiety disorders, can place the patient at greater risk of experiencing these disorders when facing cancer or other life-threatening illnesses. Other factors (i.e., financial, social, safety issues), may contribute to distress and exacerbate depressive symptoms.
  - Unresolved grief may also be a factor that is associated with depression.

- Medications:
  - Numerous medications and substances associated with depression include the antihypertensive, analgesics, antiparkinsonian agents, steroids, hypoglycemics, chemotherapeutic agents, hormones, antimicrobials, L-Dopa, benzodiazepines, alcohol, phenothiazines, amphetamines, cimetidine, and others.
- Treatment-related:
  - Additional causes are brain radiation, and metabolic and endocrine abnormalities (Pasacreta et al., 2015).
• Situational factors:
  ➢ Evaluation of depression requires a careful interdisciplinary team assessment, keeping in mind that time may be limited for the patient.
  ➢ After basic physiological needs are assessed and managed following a diagnosis of a life-threatening illness (i.e. pain, nausea, vomiting, fatigue, etc.), patients then have the opportunity to begin exploring psychological needs. After long months or years of treatment and seeing their quality of life decrease with a small chance of a positive outcome, patients may be forced to think about their lives and reprioritize (Borneman & Brown-Saltzman, 2015; Chovan et al., 2015).
  ➢ Nursing has a unique opportunity to communicate with patients and their families about this stage and the meaning illness has for them.
  ➢ Which relationships bring you the most joy and meaning?
  ➢ Which activities bring you the most joy and meaning?
  ➢ Are you able to define a new purpose for your life? (Chovan et al., 2015)

• Previous psychiatric history/treatment:
  ➢ Work with interdisciplinary team to assess for suicide risk (see next topic).

• Presence of risk factors:
  ➢ Other predictors include male gender, over age 45, living alone, lacking a support system.
  ➢ Uncontrolled pain, presence of multiple deficits, including inability to walk, loss of bowel and bladder control, amputation, inability to eat or swallow, sensory loss, and exhaustion are risk factors.
Culture affects presentation of symptoms and responses to depression, i.e., complaints of “nerves” and headaches in Latino and Mediterranean cultures, and “imbalance” in Chinese or other Asian cultures (Pasacreta et al., 2015).

- Nurses must ask the right questions and listen to the answers. Examples of questions that you could ask include (Chovan et al., 2015):
  - Which relationships bring you the most joy and meaning?
  - Which activities bring you the most joy and meaning?
  - Are you able to define a new purpose for your life?
  - Do you feel depressed?
  - Are you having difficulty in sleeping or do you sleep too much?
  - Are you experiencing trouble concentrating?
  - Do you feel your life still has meaning and/or worth?
  - Have you had any thoughts about harming yourself?
  - What can I do to make your day better?
  - What do you know and what do they want to know about their illness?
  - Do they have fears of what is to come?
  - What are your goals and what do you want to accomplish (life plans)?

**Example of follow up to the screening questions:** “We have found that in other patients with an illness like yours they sometimes feel the way you do. “Please tell me when you began to feel this way.” “Was there any significant circumstance that caused these feelings?”
Various scales are available for depression screening (Chai et al., 2014).

**PHQ-2:** A brief initial screening tool that can be used in busy clinical settings. Can be completed orally or in writing. Considered “first-step” in screening for depression. There are two questions: Over the past 2 weeks, how often have you been bothered by any of the following:

1. Little interest or pleasure in doing things?
2. Feeling down, depressed or hopeless?

Both questions are scored as follows:

- 0 = not at all
- 1 = several days
- 2 = more than half the days
- 3 = nearly every day

Total score can range from 0-6. Many suggest that a score of 3 or higher is the optimal point for further screening. For more information, go to: [http://www.cqaimh.org/pdf/tool_phq2.pdf](http://www.cqaimh.org/pdf/tool_phq2.pdf); retrieved March 30, 2016).

**PHQ-9:** Follow-up positive responses from the PHQ-2 with using the PHQ-9. Developed specifically for primary care and can detect changes over time. Good for monitoring treatment responses. The two components of the PHQ-9 include assessing symptoms and functional impairment in order for a physician or psychologist to make a tentative diagnosis of depression and deriving a score that will assist in selecting and monitoring treatment. Examples of questions used on the PHQ-9 include:
Ask the following questions and score each question 0-3, as with PHQ-2:

- Little interest or pleasure in doing things
- Feeling down, depressed, hopeless
- Trouble falling or staying asleep or sleeping too much
- Feeling tired or having little energy
- Poor appetite or over-eating
- Feeling bad about yourself – or that you are a failure, or have let yourself or your family down
- Trouble concentrating, such as reading the newspaper or watching TV
- Moving or speaking slowly or being fidgety and restless
- Thoughts that you would be better off dead, or of hurting yourself in some way.

- Work with your team’s physician or mental health provider to review the score and next steps in regards to palliative care (Chai et al., 2014).

**Note:**
For further information see:
Twenty percent (22%) of suicides in the US are Veterans (Kemp & Bossarte, 2012). Gender (female) and age (younger) Veterans are at greater risk for suicide. Those working with Veterans must be aware of this prevalence so that every effort can be made to properly assess and manage these Veterans so that suicide can be prevented. The nurse plays a key role as a member of the interdisciplinary team in asking the right questions of Veterans and documenting/communicating those findings to the team.

Those at risk include:
- Cancer patients at highest risk for suicide include those with diagnoses of oral, pharyngeal, or lung cancers.
- The strongest predictors for suicide are presence of a psychiatric disorder, depression, and alcohol abuse.
- Chronic deteriorating medical illness with perceived poor health, recent diagnosis of a life-threatening illness and a recent conflict and/or a loss of significant relationship are also predictors (Pasacreta et al., 2015).
- There is some research that indicates there is a correlation between PTSD and suicide. There is evidence that traumatic events such as sexual abuse, combat trauma, rape, and domestic violence generally increase a person's suicide risk. Considerable debate exists about the reason for this increase (Hudenko, 2009).

Other factors that may increase risks include:
- Current ideation, intent, plan, access to means
- Previous suicide attempt or attempts
- Alcohol/substance abuse
- Previous history of psychiatric diagnoses
- Impulsivity and poor self-control
- Hopelessness
- Recent losses—physical, financial, personal
- Recent discharge from an inpatient unit
- Family history of suicide
- Co-morbid health problems—especially a newly diagnosed problem or worsening symptoms
- Age, gender, race (elderly or young adult, unmarried, white, male, living alone)
- Same-sex sexual orientation

- Factors that may decrease risks or protective factors include:
  - Positive social support
  - Spirituality
  - Sense of responsibility to family
  - Children in the home, pregnancy
  - Life satisfaction
  - Reality testing
  - Positive coping skills
  - Positive problem-solving skills
  - Positive therapeutic relationship


Four steps to assessing suicide risk among Veterans:
1. Look for warning signs
2. Assess for risk and protective factors
3. Ask the questions
4. Respond in the appropriate way
Slide 52

**Suicide Assessment**

- **Warning Signs**
- **Assessment questions**
- **Emergency situation! Interdisciplinary care is critical!**

**Warning Signs:** Presence of any of the below warning signs requires immediate attention and referral:

- Threatening to hurt or kill self
- Looking for ways to kill self
- Seeking access to pills, weapons or other means
- Talking or writing about death, dying or suicide
- Hopelessness
- Rage, anger, seeking revenge
- Acting reckless or engaging in risky activities
- Feeling trapped-- like there is no way out
- Increasing alcohol or drug abuse
- Withdrawing from friends, family and society
- Anxiety, agitation, unable to sleep or sleeping all the time
- Dramatic changes in mood
- No reason for living, no sense of purpose in life

**Veterans with immediate, lethal, and precise suicide plans and resources to carry out the plan should be immediately evaluated by psychiatric professionals, hospitalized, or placed under appropriate close and continuous supervision. Those at highest risk for suicide are those with:**

- Severe rapidly progressing disease producing a rapid functional decline.
- Intractable pain.
- A history of depression, suicide attempts, or substance abuse
- Suicide lethality should be assessed by evaluating:
The presence of a suicidal plan, method to carry out the plan, availability of resources to carry out the plan.

Ability to communicate intent and intended outcome (gesture versus serious attempt to die).

Questions for suicide assessment:

♦ Are you feeling hopeless about your present/future?
  - If yes, ask: Have you had thoughts about taking your life? Are you thinking of taking your own life now?
  - If yes, ask: Have you ever had a suicide attempt?
    An example of a question you might ask, “I appreciate how difficult this problem must be for you at this time. Some of my patients with similar problems/symptoms have told me that they have thought about ending their life. I wonder if you have had similar thoughts?”

♦ Often, Veterans are looking for someone to open the door to communication. Interdisciplinary Care is CRITICAL!!

**Exercise - Stop and Consider:**

It is not unusual for a terminally ill Veteran to go back and forth between a desire to live and a wish to be relieved from the suffering and pain of the terminal illness. Suicidal thoughts in Veterans with advanced disease may have more to do with the lack of control or autonomy, uncontrollable disease-related symptoms, distressing emotions, past life experiences, etc.

- Have you seen a seriously ill Veteran in the last month who has experienced these feelings?
- How do you talk with the Veteran? What questions do you ask?
- How do you make sure that the interdisciplinary team obtains this information?
- Does your facility have a policy in place for Veterans who experience suicidal ideation? If so, how would you proceed if a Veteran said he was considering killing himself?
- If your facility does not have a policy in place for Veterans who experience suicidal ideation, how would you proceed?
- Hospice patients may say, “I want this to be over with.” But that statement does not mean that they would actively consider taking their own life.
- Listen and be present
• Of primary concern is to ensure the patient’s immediate safety from harm.

• Veterans who have been assessed as being a suicide risk need to be referred to a mental health professional immediately. Ensure that the appointment is made and carried out.

• Increase your contact with the patient and make a commitment to help him/her through this crisis.

• Other specific ways to be helpful in these situations include:
  ➢ Seek help from those who are close to the patient
  ➢ Take action—limit access to means of suicide
  ➢ Be aware—learn the risk factors and warning signs for suicide and where to get help
  ➢ Be direct—talk openly about suicide, what you have observed, and what your concerns are regarding his/her well-being
  ➢ Be willing to listen
  ➢ Be non-judgmental
  ➢ Be available—show interest, understanding, and support
  ➢ Do not act shocked
  ➢ Do not dare him/her to engage in suicidal behaviors
  ➢ Do not ask “why”
  ➢ Do not be sworn to secrecy
  ➢ Do offer hope that alternatives are available
**Note:** Suicide risk often needs to be managed in a hospital medical unit because end-of-life patients are often inappropriate for psychiatric hospitalizations. Suicide CAN BE PREVENTED AND ACUTE SUICIDALITY CAN BE TREATED.
There are a wide-variety of medications used to treat depression. These drugs may be used alone or in combination with other psychotropic agents.

- **Antidepressants:**
  - Serotonin selective reuptake inhibitors (SSRI’s) (e.g., fluoxetine, paroxetine, sertraline, citalopram)
  - Tricyclic antidepressants (TCAs) (e.g., amitriptyline, nortriptyline)
  - Note: reassess for effectiveness at approximately 4 weeks. If insufficient relief seek new orders for increased titration or an alternative.

- **Others**
  - venlafaxine (Effexor®)
  - bupropion (also helpful for smoking cessation) (e.g., Wellbutrin®, Buproban®, Aplenzin®, Budeprion®, and Zyban®)
  - Psychostimulants: methylphenidate
There are many non-pharmacologic interventions used for depression. Suggested non-pharmacologic cognitive behavioral techniques, include (Kravits, 2015):

- Promote and facilitate as much autonomy and control as possible.
- Encourage patient and family participation in care, thus promoting a sense of control and reducing feelings of helplessness.
- Reminiscence and life review can assist terminally ill Veterans to focus on life accomplishments and to promote closure and resolution of life events.

- Grief counseling can assist patients and families to deal with past, present, and future losses. **Maximize symptom management to decrease physical stressors that can exacerbate depression and anxiety symptoms.** Counseling may be needed for those experiencing significant inability to cope with the experience of their medical illness. Exploring the concepts of hope and meaning are important. This can be challenging for the terminally ill patient who is depressed. Nurses must work closely with the interdisciplinary team, especially the psychologist, to foster hope so that the quality of life can contribute to a “good death” (Cotter & Foxwell, 2015).

- Assist the patient to draw on previous sources of strength, such as faith and other belief systems.

- Using the cognitive behavioral techniques, assist the patient to re-frame negative thoughts into positive thoughts. Examples. “I am stupid,” “Why try, nothing ever works out for me?” Counter these by breaking down the monumental problems the depressed person is having into small steps, so it is not so overwhelming. Behavioral
approaches, such as identifying and engaging the Veteran in pleasant activities is also encouraged.

- Interdisciplinary communication and care is vital. The verbal reporting and documenting of patient behaviors are important as all members of the team review and collaborate together. Mental Health professionals must be included in these team meetings. It is vital that patients have a connection with a mental health professional so depression can be addressed.

**Note:** A psychologist is required to be part of the Hospice and Palliative Care team in VHA.
Anxiety is a subjective feeling of apprehension, tension, insecurity, and uneasiness, usually without a known specific cause (Dahlin, 2015; Pasacreta et al., 2015).

Signs and symptoms that accompany anxiety occur along a continuum that can be assessed as mild, moderate, or severe. The greater the threat perceived by the patient, the greater the anxiety response.

Patients may be more worried about family, finances, than about dying itself.

Anxiety is sometimes a sign of PTSD, which can become exacerbated at end of life as cognition wanes and unwanted memories surface unbidden (Grassman, 2009).
Many medications/substances can be associated with feelings of or similar to anxiety.

- Medications and other substances: Stimulants, thyroid replacement hormones, neuroleptics, corticosteroids, digitalis, antihypertensives, antihistamines, antiparkisonian medications, anticholinergics, analgesics, and various drug withdrawal states and paradoxical reactions.

Veterans with life-limiting diseases often face uncertain futures. Examples include:

- Dealing with difficult and exhausting treatment regimens and their side-effects
- Lifestyle changes (Note: Veterans may experience withdrawal, as keeping up with family and friends may be too exhausting. Doing “life closure work” may cause extra time to focus on lifetime of experiences and may cause anxiety regarding regrets, “what-should-have-been,” “what-could-have-been”).
- Financial concerns
- Dependency on others
- Confront family conflicts
- Facing mortality

Others

- Disease-related (i.e. dyspnea, endocrine and neurological disorders, sepsis, etc.)
- Prior history of anxiety disorder

**Stop and Consider:** Have you had a recent conversation with a terminally ill veteran who expressed anxiety? If so, what was causing the anxiety? What did you do with that information? How were you able to assist this Veteran?
Fear and anxiety are expected reactions to a terminal diagnosis and require frequent assessment (NCI, 2015b). The patient may report the following circumstances: chronic apprehension, worry, inability to relax, difficulty concentrating, and difficulty falling and staying asleep. These may all be a part of the normal dying process. These symptoms may reflect normative fears or existential suffering and are likely to co-occur with depression and/or delirium. Also, consider exploring the nature of the patient’s and involved family members’ fears.

Physical symptoms can include: Sweating, tachycardia, restlessness, agitation, trembling, chest pain, hyperventilation, tension.

Cognitive symptoms include: Recurrent and persistent thoughts, ideas, or impulses, the fear of "going crazy", and the fear of dying. If symptoms do not subside or worsen, intervention should take place. Treatment depends on the etiology and severity of symptoms.

Questions for anxiety assessment:
- Have you experienced any discomforts since your diagnosis or treatment? When do they occur and how long do they last?
- Do you ever feel nervous, shaky, or jittery?
- Have you had a sudden feeling you might be going crazy, losing control, or dying?
- Do you worry about when your pain will return and how bad it will get? Do you worry if you'll be able to get your next dose of medication on schedule?
Pharmacologic interventions for anxiety can be multi-faceted, including:
- Benzodiazepines
- Anticonvulsants
- Neuroleptics
- Azapirones (buspirone)
  - As with all medications, use with extra caution in older adults

Chai et al., 2014; Derby et al., 2015; Pasacreta et al., 2015

Note:
There are many non-pharmacologic interventions available for the treatment of anxiety. Non-pharmacologic techniques include:

- Good listening skills are the cornerstone of anxiety management. Acknowledging patient fears, using open-ended questions, reflecting, clarifying, and use of empathic listening and remarks, helps the patient to identify effective coping strategies they have used in the past and to learn new coping skills.
- Relaxation & distraction interventions (music, massage, guided imagery, etc.)
- Responding to verbalizing and venting anger with appropriate reassurance and support.
- Providing concrete information to eliminate fear of the unknown, and in appropriate situations, provide stressful event warning.
  - Encouraging use of a stress diary, which helps the patient to understand relationships between situation, thoughts and feelings.
  - Exploring patients' experiences with "near-miss" events. These events can be traumatic stressors that the patient or a family member has experienced in the past, or during illness or treatment, which impacts on potential coping ability. These experiences may include the death of a loved one, or their own near-death experiences (Pasacreta et al., 2015). Ask how they coped in the past.
  - **Maximizing symptom management to decrease physical stressors that can exacerbate depression and anxiety symptoms.**
• Promoting the use of cognitive behavior therapy techniques through the use of audiotapes, breathing exercises, progressive muscle relaxation, behavioral relaxation exercises, mindfulness, etc.

• Counseling may be needed for those experiencing significant inability to cope with the experience of their medical illness.

• Always consider prevention strategies. Provide concrete, objective information. Be mindful of the possibility or reality of stressful events. Structure uncertainty as best as possible and encourage hope related to how the plan of care honors the patient’s goals of care.
Nurses are in a unique position to manage a wide range of symptoms experienced by those with terminal illness. Key nursing roles in symptom management include:

- Advocacy for the relief of suffering
- Comprehensive assessment and interdisciplinary plan of care
- Administering pharmacologic and non-pharmacologic interventions
- Patient and family teaching
- Invaluable team member!

• Advocacy for the relief of suffering
• Comprehensive assessment and interdisciplinary plan of care
• Administering pharmacologic and non-pharmacologic interventions
• Patient and family teaching about how interventions work to provide relief
• Invaluable team member!
• Multiple symptoms are common for Veterans with serious illness and at the end of life. In this module we have identified common symptoms associated with palliative care and end-of-life processes for Veterans across the life span.

• While not an exhaustive review of symptoms, we have identified potential etiologies and holistic assessment considerations.

• Nurses must work closely with physicians and other disciplines to coordinate optimum pharmacologic and non-pharmacologic interventions to promote quality of life for Veterans and their families.

• Veterans and their families may benefit from extensive teaching and support to understand how disease process and treatments contribute to symptom burden, and how palliative interventions may prevent or relieve suffering.