

Palliative Nursing: Caring for the End-Of-Life Patient

This course has been awarded four (4) contact hours.

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Acknowledgments

RN.com acknowledges the valuable contributions of...

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Throughout the course you will find quotes from Ms. Schmal, who actively works with dying patients and their caregivers. We hope you will find these quotes enlightening and helpful as you review this material on end-of-life care. --- rn.com

Purpose

The purpose of this continuing nursing education course is to provide healthcare professionals with a palliative care perspective and knowledge to manage symptoms commonly experienced at the end of life.

The course includes:

- Physical, emotional, psychosocial, and spiritual dimensions.
- Quality of life at end of life and tasks of grieving.
- Realistic patient situations to challenge the learner's critical thinking skills.

This course includes discussion of medications used at the end of life. The guidelines presented may differ from your organization P&P. Always follow your organization standards.

You Matter Because You Are You

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

— Dame Cicely Saunders, nurse, physician and writer, and founder of hospice movement (1918 - 2005).

Learning Objectives

After successful completion of this course, you will be able to:

1. Explain the principles of symptom management at end of life.
2. Describe the assessment of symptoms commonly encountered at end of life.
3. Explain the pharmacologic and non-pharmacologic interventions commonly used at end of life.
4. Discuss physical, psychosocial, emotional, and spiritual issues at end of life.
5. Describe the patient's progression toward death and appropriate interventions during the last months, weeks, days, and hours of life.
6. Identify the components of a quality end-of-life experience.
7. Identify the tasks of grieving.

It Could Be You Some Day

When managing end-of-life symptoms, I remember that I may come to a time in my life when I lose control of normal body functions.

I certainly hope to be treated with the dignity and respect. That's one thought I keep in the forefront of my mind when I think about how" to manage these difficult symptoms.

Barb Schmal, MS, RN, CHPN

Principles of End-of-Life Symptom Management: Palliative Care

Heart disease, cancer, and chronic lung disease are the main causes of the death in the United States. Death from these cause is neither sudden nor unexpected yet the rate of hospice use remains low. Despite all the technological advances in health care, patients, families and providers are still dissatisfied with end-of-life-care (Dans & Sheldahl, 2015). The provision of palliative care is critical to meeting patient and family needs at the end of life.

“Palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice.” (NHPCO, n.d.)

Palliative care can be delivered in any setting including hospitals, skilled nursing facilities, and the patient’s home. It’s an organized approach to care delivered by an interprofessional team including physicians, nurses, social workers, chaplains, and pharmacists. The goal is to provide patient-centered, family-oriented, evidence-based care at the end-of-life (IOM, 2014).

Palliative care differs from the acute care model in that it:

- Focuses on comfort and managing symptoms.
- Views the unit of care as the patient and family.
- Operates in an interprofessional framework.
- Addresses psychosocial and spiritual aspects as well as physiological (whole-person oriented).
- Treats the underlying cause of symptoms when possible.

End-of-Life Symptom Management: Powerlessness

Palliative care patients may experience any number of symptoms at the end-of-life and they often feel powerless to control what is happening to them. This is evident in that many patients express feelings of having no influence over the situation or outcome. So it is important to keep some basic interventions in mind when trying to manage end-of-life symptoms to facilitate the patients' participation in their care.

1. Determine the patient's usual response to limited control situations. Determine the patient's usual locus of control (i.e., believes that influence over his or her life is exerted by luck, fate, powerful persons [external locus of control] or that influence is exerted through personal choices, self-effort, self-determination [internal locus of control]).
2. Support patient's physical control of the environment by involving him or her in care activities; knock before entering room if appropriate; ask permission before moving personal belongings.
3. Inform the patient that, although an activity may not be to his or her liking, it is necessary. This gives the patient permission to express dissatisfaction with the environment and the regimen.
4. Provide therapeutic rationale for the treatment plan, reinforce the explanations, and clarify misconceptions.
5. Include the patient in care planning by encouraging participation and allowing choices wherever possible (e.g., timing of personal care activities; deciding when pain medicines are needed).
6. Encourage family to permit patient to do as much independently as possible to foster perception of personal power.

Common End-of-Life Symptoms

1. Anorexia and Cachexia
2. Fatigue
3. Pruritus
4. Alterations in oral mucosa
5. Nausea and vomiting
6. Ascites
7. Dyspnea
8. Upper Airway Congestion
9. Pain
10. Constipation
11. Agitation and delirium

Fatigue, dyspnea, constipation, pain, and delirium are the most prevalent and distressing symptoms (Bookbinder & McHugh, 2010).

"Life is pleasant. Death is peaceful. It's the transition that's troublesome."

– Isaac Asimov, American science fiction novelist & scholar (1920 - 1992).

1 Anorexia and Cachexia

Anorexia

Anorexia is described as the generalized loss of appetite and inability to take in nutrients and is common in advanced illness and at end of life especially among the elderly (Bruera & Dev, 2015).

Family members and caregivers experience:

- Loss of the ability to nurture in the usual way of offering favorite foods.
- Feeling hopelessness and “giving up.”

Cachexia

Cachexia, or wasting syndrome, results in weight loss and wasting due to inadequate intake and/or absorption of nutrients (Bruera & Dev, 2015).

Cachexia often occurs as a part of the dying process, and represents psychosocial loss for patients and families. It is a symptom that cannot be ignored.

Cachexia also causes:

- A drastic alteration in body image.
- A loss of socialization associated with eating.
- An adjustment to dramatic decrease in body mass.
- A symptom that cannot be ignored.

When Appetite Decreases

Boy that is a difficult time for families and caregivers when they see their loved ones no longer able to nurture themselves.

The patient doesn't want that favorite chicken noodle soup anymore. Caregivers can't comfort with food or nutrition, and that's a pretty natural way to approach comfort.

Caregivers may feel as though they have become useless, as if they have failed and are not providing adequate care.

It's a difficult time when that appetite decreases.

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1 Causes of Anorexia and Cachexia

Causes of anorexia and cachexia in palliative care patients include:

- Pain
- Constipation
- Alterations in oral mucosa
- Dysgeusia (change in taste perception)
- Altered mental status
- Medications
- Natural disease progression
- Natural aging process
- Chronic fatigue
- Nausea
- Depression
- Gastroparesis

Sometimes it can be very difficult to pinpoint a cause, because there are so many and the patient may be experiencing several of them at once.

1 Management of Anorexia and Cachexia

There are a variety of interventions to assist the palliative care patient with anorexia and cachexia (Bruere & Dev, 2015). The patient should be encouraged to:

- Eat at the dining table (if possible) with family.
- Plan frequent small meals that are calorically dense.
- Prepare meals that require little preparation.
- Rest before meals.

In some cases medications may be helpful to stimulate the patient's appetite. These include:

- Progestin
- Megestrol acetate (Megace)
- Glucocorticoids (dexamethasone, methylprednisolone, betamethasone)
- Cannabinoids (marijuana)

There is no evidence to support the use of nutritional support, such as total parenteral nutrition (TPN) or enteral nutrition, in the palliative care patient. It rarely halts the progression of the disease and may actually add burden to the dying process as issues regarding discontinuation may become arise (Bruera & Dev, 2015).

Test Yourself!

The cause of anorexia at end of life can be easily identified.

True

False (Correct)

Because there are numerous causes of anorexia at end of life, it may be difficult to pinpoint a single cause.

2 Fatigue

Fatigue is a subjective symptom in which the patient feels tired, weak, and mentally exhausted (Bruera & Yennurajalingam, 2014)

A patient described it once as: "Feeling some sort of inertia that just doesn't go away."

Fatigue is the most common symptom seen in palliative care patients and it's also one of the most undertreated and underreported (Bruera & Yennurajalingam, 2014). It can be very distressing. Imagine how it must feel to be unable to do the things you want and desire to do.

The family might interpret this as giving up and push the patient beyond what he or she can respond to.

End of Life Patients Benefit from Activity

We used to think that the important thing was to conserve energy.

We may have previously said to rest and not do anything. But thinking has changed.

There's some evidence that even at end of life, the patient benefits from regularly scheduled activities or exercise regimens.

We can try to coordinate activities when the patient has the most energy.

Sometimes, it's helpful to continue to have regularly scheduled activities, like chair exercises.

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2 Causes of Fatigue

Fatigue in the palliative care patient is often multi-factorial. Causes include:

- Disease progression
- Common morbidities (renal, cardiac, diabetes)
- Lack of sleep
- Medications (side effects, cumulative effects, and drug interactions)
- Anemia
- Infection
- Hypoxemia
- Dehydration
- Pain
- Depression
- Nausea
- Anorexia
- Dyspnea

2 Management of Fatigue

Initial management of the patient with fatigue includes identifying and treating the underlying cause. Both pharmacologic and nonpharmacologic interventions are available to assist with the management of fatigue in the palliative care patient.

Medications may be of benefit to the patient. These include (Bruera & Yennurajalingam, 2014):

- Glucocorticoids (dexamethasone, methylprednisolone)
- Psychostimulants (dextroamphetamine, methylphenidate, modafinil)
- Testosterone replacement (in men with low testosterone)

There are a variety of nonpharmacologic interventions to assist the palliative care patient with fatigue. The patient should be encouraged to (Bruera & Yennurajalingam, 2014):

- Schedule activities at times of greatest energy.
- Maintain a regular activity schedule.
- Get assistance from volunteers, family, and friends.
- Engage in moderate exercise if able to tolerate it.
- Participate in yoga classes.
- Initiate routine sleep hygiene measures.
- Manage stress.

3 Types and Causes of Pruritus

Types

While pruritus may not be the most prevalent symptom in the palliative care patient, it can cause considerable discomfort and has a major impact on patients' quality of life. The pathogenesis of pruritus is not fully understood and can be very difficult to treat effectively (Seccareccia & Gebara, 2011).

There are four types of pruritus:

- Prurioreceptive – itch originates in the skin
- Neuropathic – itch originates in the afferent sensory pathways
- Neurogenic – itch originates in the central nervous system
- Psychogenic – itch is associated with a psychiatric disorder

Causes

Causes of pruritus are not completely understood. However pruritus is associated with the following conditions:

- Dermatitis
- Opioid medications,
- Uremia due to chronic renal failure
- Solid tumors
- Lymphoma
- Polycythemia
- Cholestasis

Dry skin is also often associated with many of these conditions (Seccareccia & Gebara, 2011).

3 Management of Pruritus

Both pharmacologic and nonpharmacologic interventions are available to assist with the management of pruritus in the palliative care patient.

Pharmacologic interventions include (Seccareccia & Gebara, 2011):

- Lidocaine 2.5% cream
- Paroxetine
- Mirtazapine
- Ondansetron
- Diphenhydramine
- Naloxone

There are a variety of nonpharmacologic interventions to assist the palliative care patient with pruritus.

The patient should be encouraged to Seccareccia & Gebara, 2011):

- Maintain a cool, humidified room.
- Soothe skin with moisturizers and emollients.
- Wear loose, nonirritating clothing. Minimize bathing. Bathe with tepid water and pH neutral soap. Avoid fragrant topical agents (perfumes, lotions).

4 Alterations in the Oral Mucosa

In the palliative care patient alterations in the oral mucosa can be very problematic as they interfere with the patient's ability to eat and thus contribute to worsening anorexia and fatigue. Patient who have undergone radiation are at high risk for developing problems with the oral mucosa. Other contributing factors include poor nutrition, poor dental hygiene, ill-fitting dentures and tobacco use (Radvansky, Pace, & Siddiqui, 2013). Common alteration in the oral mucosa of the palliative care patient include:

- Xerostomia (dry mouth)
- Oral Mucositis (stomatitis)

4 Management of Alterations in the Oral Mucosa

Management of both xerostomia and stomatitis is aimed at symptom relief. Both conditions can be extremely uncomfortable for the patient. The choice of intervention should be left up to the patient, as the each patient's response to the different interventions will vary.

Interventions for xerostomia include (Radvansky, Pace, & Siddiqui, 2013):

- Encourage proper oral hygiene.
- Drink plenty of water or suck on ice chips.
- Use artificial saliva to mimic the properties of real saliva (lubricating, hydrating, antimicrobial).
- Stimulate salivation with moistening agents or sialagogues (pilocarpine).
- Chew sugarless gum or suck on hard candies and mints.

Interventions for stomatitis include (Radvansky, Pace, & Siddiqui, 2013):

- Administration of pain medications
- Use of mouth rinses:
 - "Miracle mouthwash" or "magic mouthwash" (e.g., aluminum hydroxide, diphenhydramine, viscous lidocaine)
 - Saline rinses
 - 2% viscous lidocaine
- Providing around-the-clock mouth care,
- Avoiding spicy foods

TEST YOURSELF!

Which of the following interventions may be of benefit for the patient with xerostomia?

- a. Limit the patient's oral intake.
- b. Have the patient swish and spit with "magic mouthwash" once a day.
- c. Encourage the patient to chew sugarless gum (Correct)**
- d. Restrict the patient's diet to protein sources only.

Rationale: #3. Encouraging the patient to chew sugarless gum can help stimulate saliva production. Restricting the patient's oral intake will exacerbate the problem of dry mouth. "Magic mouthwash" is for stomatitis and not xerostomia. Restricting the patient's diet will only contribute to the problem of poor nutrition which can worsen the problem.

5 Nausea and Vomiting

Nausea is the unpleasant sensation of the need to vomit while vomiting is the forceful expulsion of gastric contents. Each can be experienced separately or they can be experienced together. Every patient experiences them differently (Nunn, 2014).

Severe, intractable nausea limits the time that you can spend around other people and is physically very draining. It affects one's ability to take in nutrients and contributes to worsening anorexia and fatigue.

People begin to struggle and question: "Why do I suffer in this way?" and "Why do people even care about me anymore?" For patients who have suffered with this symptom for a long time, it has severely impacted their ability to enjoy a good quality of life.

Two of the most debilitating symptoms seen in the palliative care patient is nausea and vomiting and it occurs in 17 – 49% of the patients (Kelly & Ward, 2013).

5 Causes of Nausea and Vomiting

There are a wide assortment of causes of nausea and vomiting. The vomiting center is located in the brainstem and it receives input from a variety of sources via the emetic pathways producing nausea (Kelly & Ward, 2013). Inputs to the vomiting center are as follows as well:

Sources of Stimulation via the Emetic Pathways	Biochemical Afferents Released in Nausea
Vagal Afferents <ul style="list-style-type: none"> ▪ Gastric stasis ▪ Distortion of GI tract (constipation, intestinal obstruction) ▪ Drugs (NSAIDS, iron supplements, antibiotics, cytotoxics, steroids, anticholinergics, opioids) ▪ Ascites ▪ Liver metastases ▪ Retroperitoneal cancer ▪ Peptic ulcers 	Vagal Afferents <ul style="list-style-type: none"> ▪ Acetylcholine ▪ Histamine ▪ Serotonin
Pharyngeal Afferents <ul style="list-style-type: none"> ▪ Irritation in pharynx: sputum, coughing, candida 	Pharyngeal Afferents <ul style="list-style-type: none"> ▪ Glossopharyngeal and vagal nerve stimulation
Vestibular System <ul style="list-style-type: none"> ▪ Motion sickness ▪ Medications ▪ Brain tumors 	Vestibular System <ul style="list-style-type: none"> ▪ Acetylcholine ▪ Histamine
Midbrain Afferents <ul style="list-style-type: none"> ▪ Anxiety, stress ▪ Sights, sounds, taste ▪ Increased intracranial pressure ▪ Brain tumors 	Midbrain Afferents <ul style="list-style-type: none"> ▪ Acetylcholine ▪ Histamine
Chemotherapy Trigger Zone (CTZ) <ul style="list-style-type: none"> ▪ Medications (opioids, cytotoxics, antibiotics) ▪ Chemicals ▪ Toxins ▪ Metabolic (organ failure, hypercalcemia, hyponatremia) 	Chemotherapy Trigger Zone (CTZ) <ul style="list-style-type: none"> ▪ Dopamine ▪ Serotonin (also released in the gut) ▪ 5-HT₃₊₄

5 Management of Nausea and Vomiting

There are a number of medications used in the treatment of nausea. It's important to identify and treat the underlying cause first if possible. Each anti-emetic medication is most useful in combating particular causes of nausea.

Medication	Blocks	Cause-specific Uses
Dexamethasone	Unclear as to action	Reduces swelling, useful in brain tumor
Diphenhydramine	Histamine	Idiopathic and opioid-induced nausea, vestibular causes, obstruction, malignant bowel obstruction, increased intracranial pressure
Haloperidol	Dopamine	Chemical/metabolic, opioid-induced nausea, malignant bowel obstruction, useful with patients with dementia who respond poorly to benzodiazepines, relieves agitation
Metoclopramide	Dopamine, 5-HT ₃₊₄	Gastric stasis, ileus, opioid-induced nausea
Ondansetron	5-HT ₃	Prevention of radiation- and chemotherapy-induced nausea and post-operative nausea NOT a first-line medication unless nausea is intractable
Prochlorperazine	Dopamine, Histamine, Acetylcholine Highly effective because it blocks multiple substances well.	
Anticholinergics (scopolamine) with caution, to avoid drowsiness, confusion, urinary retention and dry mouth, especially with elderly patients		Obstruction, increased gastric secretions, increased intracranial pressure

Caution with Metoclopramide

When you think of metoclopramide, think of a pastry tube, the kind you squeeze frosting or dough out of.

It's got a little tip at the end and if that tip is blocked and you're trying to squeeze that frosting out that could be a problem!

Think about metoclopramide being your hands squeezing that tube. If there's an obstruction in the bowel or the beginnings of an obstruction, it really can make a patient miserable, so use it with caution and never if a bowel obstruction is suspected or beginning.

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Test Yourself

Mr. D has end-stage cardiac disease. He suffers from intermittent chest pain and extreme discomfort in his lower extremities due to bilateral pedal edema. His physician initiates MSIR 5-10 mg PO Q4H PRN for pain. The following day, Mr. D reports that his pain is improved, but he cannot eat due to moderate nausea. Which drug will be MOST effective in treating Mr. D's nausea?

- a. Diphenhydramine (Benadryl®)
- b. Haloperidol (Haldol®)
- c. Metoclopramine (Reglan®)
- d. Ondansetron (Zofran®)

(Haloperidol works quite well for opioid-induced nausea. With a little help from an anti-emetic, it should resolve within a few days. Benadryl® is also a good choice. If Mr. D were 85-years-old, we might not choose Benadryl®. Reglan® can be used even for opioid-induced nausea. Zofran® is a preventive drug.)

5 Non-pharmacologic Interventions for Nausea and Vomiting

A number of non-pharmacologic interventions may be of benefit for the palliative patient with nausea and vomiting. These interventions include (Kelly & Ward, 2013):

- Maintain a cool, odor-free environment. A fan may help to facilitate this.
- Modify the patient's diet – bland, not spicy. Offer small, simple meals. Carbohydrates are often tolerated better.
- Cool, carbonated drinks are often tolerated better than hot or noncarbonated drinks.
- Treat constipation if present – common at end of life.
- Correct electrolyte imbalance if known – the patient may have decided against labs. Assess for symptoms of electrolyte imbalance.
- Consider switching opioids if transient nausea does not subside – switch from morphine to hydromorphone or oxycodone.
- Provide an open view, without clutter.
- Ensure the patient has access to a large bucket or bowl, tissues and water.
- Offer regular mouth care.

Caregivers may inadvertently be preparing foods or having odors in the home that exacerbate the patient's nausea.

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6 Ascites

Ascites can be a troublesome symptom at end of life. Pathologies such as liver disease, abdominal cancers, and sometimes congestive heart failure cause compression of lymph or portal systems. This mechanical interference with drainage causes fluid to accumulate.

Other potential causes include pancreatitis, nephrotic syndrome, and hepatic venous obstruction.

In addition to increased abdominal girth, patients experience:

- Nausea
- Bloating
- Pain
- Heartburn
- Dyspnea
- Orthopnea

6 Management of Ascites

Management of the palliative patient depends on the underlying cause. Patient with ascites related to portal hypertension may be responsive to diuretics. However, patients may become refractory to these medications at end of life. Up to 90% of the patient obtain relief with a paracentesis. If a patient requires continuous draining of the fluid, a drainage catheter can be placed to allow for continuous or intermittent drainage and promote patient comfort (LeBlanc & Arnold, 2010).

Test Yourself

Mrs. J, age 66 years, has ovarian cancer with liver metastasis. She is receiving hospice services. She can still ambulate occasionally, but has developed extensive ascites with increasing symptoms of dyspnea, nausea, and heartburn.

Which intervention do you expect to be most effective?

- a. Administer morphine liberally since patient is in hospice care
- b. Restrict fluids, provide good skin care, and encourage frequent repositioning
- c. Facilitate placement of an abdominal drainage catheter for intermittent drainage (Correct)
- d. Obtain an order for a diuretic

(Most effective is the placement of the drain for drainage, because it gets to the root of the problem, and that's the mechanical pressure and compression caused by that increased fluid. A. promotes a myth about hospice care. Morphine is titrated as needed to relieve pain and dyspnea. B. will not improve comfort at end of life. D. will probably prove ineffective at this time.)

Nobel Prize

"It's my personal opinion that the inventor of the abdominal drain should receive the Nobel Prize.

I've seen the dramatic difference it makes in the quality of life in patients who are trying to live out their last days at home.

Previously, these patients would have to go to the hospital for drainage of ascites or pleural effusion.

It doesn't forestall the malignant or incurable process but it really can add to the patient's comfort to relieve that mechanical obstruction even if it's just for a few days or even hours.

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7 Dyspnea

Dyspnea is the sustained unpleasant sensation of breathlessness (ATS 2013) and uncomfortable awareness of breathing (Bookbinder & McHugh, 2010). It is a progressively debilitating symptom that has a big impact on the patient's quality of life. If dyspnea is not well managed a patient can develop a dyspnea crisis. A dyspnea crisis as "sustained and severe resting breathing discomfort that occurs in patients with advanced, often life-limiting illness and overwhelms the patient and caregivers' ability to achieve symptom relief." (ATS 1999) The patient with dyspnea may or may not exhibit the signs of hypoxemia and as a result oxygen saturation is not a reliable measure of dyspnea.

7 Causes of Dyspnea

Dyspnea can be caused by a wide variety of conditions including:

- Chronic obstructive pulmonary disease (COPD)
- Pulmonary fibrosis
- Acute and chronic heart failure,
- Pulmonary embolism
- Cancer (primarily lung cancer)
- Pneumonia
- Anemia
- Pneumothorax
- Radiotherapy
- Anxiety

Uncomfortable Awareness of Breathing

Here's an interesting definition of dyspnea that I really like and agree with:

It's simply the uncomfortable awareness of breathing. You and I are sitting here, not really aware of our breathing. We don't really have to think about it.

Those patients who have shortness of breath, who have true dyspnea, are uncomfortably aware of the fact that it is difficult to breathe in and breathe out.

It's terribly frightening to be short of breath. This truly is a symptom management emergency. We never want to leave someone struggling for breath.

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7 Dyspnea: The Patient's Perception

Dyspnea, similar to pain, is a subjective symptom. That means that the patient is the only one who is an expert. Sometimes patients who exhibit signs associated with dyspnea are not actually experiencing difficulty breathing. Thus to effectively assess interventions to lessen dyspnea, the patient must be asked about his or her degree of breathlessness.

Sometimes our observations might fool us. We might think a person looks dyspneic. But the patient may not report dyspnea because he has compensated for so many years.

Chronic lung patients who have had the disease for 10-30 years may have learned to accommodate. When the patient has a dyspnea crisis, listen to the patient and ask: "Is your dyspnea mild, moderate, or severe?"

7 Management of Dyspnea: Pharmacologic Interventions

Many different medications may be useful, depending upon the underlying disorder and/or cause of dyspnea.

- Patients with COPD should be on inhaled beta-2 agonists and anticholinergic agents.
- Patients with asthma should be on inhaled steroids
- Patients with heart failure should be diuretics, beta-blockers, and antigotension-converting enzyme inhibitors.

Primarily opioids are also used to manage dyspnea as they blunt the central perception of breathlessness and lower the drive to breathe. Opioids may be administered via any appropriate route as needed. A typical dose range is 2.5 to 7.5 mg every 4 hours which can be titrated higher as needed,

Opioids may be combined with an anti-anxiety medication, such as lorazepam or alprazolam. Combined, these medications can make a huge difference in that they facilitate the patient's ability to relax, take in deep breaths, or just relieve fear (Bookbinder & McHugh, 2010).

7 Non-pharmacologic Interventions for Dyspnea

There are a number of nonpharmacologic interventions for dyspnea. These include (ATS2013):

- Position the patient in High Fowler's position or tripod position (leaning forward resting on elbows) or standing and leaning against a wall with arms overhead.
 - The tripod position assists the patient who has emphysema or chronic bronchitis in using accessory muscles to push air out. A patient who has pulmonary fibrosis and has difficulty getting air into the lungs and bronchioles may lean back in a kind of uncharacteristic way and even lay flat on the back to pull air in. Don't be surprised if the patient is trying to adjust himself in order to find the best way to reach some level of comfort.
- Administer oxygen therapy.
 - Some patients with chronic lung disease have received oxygen for years. Patients who have pulmonary fibrosis may require much higher doses of oxygen than a patient who has emphysema or chronic obstructive pulmonary disease.
- Provide the patient direct air flow from fan.
 - Cool air flow across the face has been shown to decrease the sensation of breathlessness.
- Reassure the patient and encourage the use of relaxation techniques.
- Encourage the patient to use different breathing techniques such as slow-breathing, pursed-lip breathing and/or diaphragmatic breathing.

Help Patients Train Their Breathing

At our hospice, we have some DVDs that the patients can use that are set to music with pictures of water and waves. The patients use them to help train their breathing and help teach their bodies to relax along with that DVD. It's been very effective and helpful.

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Test Yourself

Which of the following interventions has been shown to be of benefit to the palliative care patient with dyspnea?

1. Place the patient in supine with the head of the bed less than 30°.
2. Limit oxygen administration to less than 2 L/min.
3. Place a fan near the patient's face.
4. Monitor the patient's oxygen saturation level.

Rationale: #3

Cool air flow across the face has been shown to decrease the sensation of breathlessness and thus placing a fan near the patient's face should assist with management of dyspnea. The patient should be placed in High Fowlers position and oxygen should be administered at whatever level is needed. Monitoring the patient's oxygen saturation will not benefit the patient as dyspnea is a subjective sensation.

Test Yourself

Mr. D has advanced lung cancer and a history of congestive heart failure with recurring dyspnea. His current medication regimen includes digoxin and furosemide.

After assessing the patient, what is the first thing you will do?

1. Obtain an order for low-dose morphine.
2. Request an order for pulse oximetry.
3. Ask him if he has taken his medications.
4. Inform him that this is expected disease progression.

Ask the patient if he's taken his medication is the first thing to do, simply because we have to be sure that the patient is medically managing and maximizing the use of prescribed medication first. If not, we may have to administer those medications before proceeding with other interventions.

Test Yourself

Mrs. M, who has pulmonary fibrosis, uses supplemental O₂@4-5L/min per nasal cannula continuously. Upon standing to walk to the bathroom, Mrs. M exhibits circumoral cyanosis, increased respiratory rate and usage of accessory muscles. Mrs. M reports her dyspnea changes from moderate to severe upon ambulation.

What is the best initial action for the nurse to take?

1. Give morphine 5 mg and lorazepam 0.5 mg PO for dyspnea
2. Increase Mrs. M's oxygen flow rate to 6-7 L/min pre- and post-activity
3. Suggest that Mrs. M reduce her activity to complete bed rest
4. Maintain the oxygen flow rate @ 5L/min to prevent hypercapnia

Most pulmonary fibrosis patients, as the disease progresses, begin to tolerate higher levels of O₂ without causing hypercapnia, so "D" will not help Mrs. M at this point. We might give morphine 5 mg and lorazepam for dyspnea, but B is the most helpful initial action. It might be just the boost that she needs. You needn't be afraid of bumping up the O₂ flow rate that up in pulmonary fibrosis cases. Learn more about fibrosis since the disease is becoming more evident in the population.

8 Upper Airway Congestion

Commonly referred to as the “death rattle,” upper airway congestion can be an extremely distressful symptom. It is often seen during the last day or two of the patient’s life and is a strong predictor of death (Nunn, 2014).

It is important to educate families and caregivers that the patient simply has lost the ability to swallow, leading to a collection of mucous or saliva at the back of the throat.

8 Causes of Upper Airway Congestion

Many etiologies can lead to airway congestion at end of life (Nunn, 2014).

- Excessive oropharyngeal secretions
- Excessive pulmonary secretions
- Fluid overload
- Decreasing level of consciousness
- Absent or suppressed gag and cough reflexes
- Supine recumbent position
- Inability to swallow

8 Management of Upper Airway Congestion

The best and easiest approach to manage these secretions is to turn the patient or reposition him slightly. Clean the mouth with a washcloth to remove some of the secretions.

The congestion will recur and may require repeated repositioning and cleansing. But a slight repositioning of the head or upper body may help relieve the congestion. It is not necessary to turn completely from one side to the other.

Suction rarely helps because the secretions continue to reoccur. Suction can be very intrusive and uncomfortable for the patient.

Antimuscarinic medications can be used to block the parasympathetic nervous system which ultimately leads to decreased production of secretions in the salivary, bronchial, and gastrointestinal tracts.

Medications that are commonly used are:

- Hyoscine hydrobromide
- Glycopyrronium
- Hyoscine butylbromide
- Atropine 1% eye drops (given sublingually)

Reposition the Patient Slightly

Once again, by giving a simple intervention, we're really helping those caregivers at the bedside to feel empowered to help. There's nothing worse than being at the bedside of a loved one and feeling powerless to help.

Barb Schmal, MS, RN, CHPN

Case Study

Laura is an alert 55-year-old with end-stage oat-cell carcinoma. She complains of severe dyspnea due to excessive bronchial secretions.

Which do you expect will relieve her discomfort?

- Atropine ophthalmic gtts 1% 1-2 SL Q4H PRN
- Gentle suction to clear her airway

Atropine is more useful to reduce oral secretions. Be sure to advise caregivers to administer SL and not as eye drops. Scopolamine or glycopyrrolate are the best choices. These medications, and atropine as well, are anti-cholinergics administered for their side effects of drying secretions, as adjuvant medications.

Suction will cause discomfort and actually increase secretions.

9 Types of Pain

Nociceptive pain - the pain pathways are normal. Put your finger on a hot stove, the stimulus goes up your arm to your spinal cord to your brain and your brain says, "Ouch, move your finger, that's hot and it hurts." That's a normal pain pathway.

Neuropathic pain - a nerve pathway has been disrupted, perhaps through resection, amputation, or pressure. Neuropathic pain is not the result of an external cause.

Somatic pain is musculoskeletal type of pain, bone pain - the framework pain, as opposed to visceral pain. Somatic pain requires NSAIDs or other medications.

Visceral pain is an organic type of pain, originating in the hollow tubes and organs, such as labor pain, kidney stone pain, and colicky pain. Visceral pain is normally treated quite well and adequately with opioids alone and may not require an adjuvant.

9 Pain Management in Palliative Care

At end of life, few patients actually need to use anything other than oral pain medication. It's often the most convenient and the safest. It's familiar and easy for caregivers to administer.

The optimal dose for the patient is established through titration. Through research and experience much as been learned about opioids in the last 20-30 years. Opioids are safe and effective ways to manage pain.

Prescribers had been concerned for years with overmedication. But through studying the dying population, clinicians learned that can be safely medicated with whatever they need to make them comfortable. Medications are administered until the person experiences relief.

For chronic and severe pain, around-the-clock dosing, rather than the short-term, immediate-acting preparations are generally used. When extended-release (ER) preparations, also known as sustained-relief (SR) preparations, are given a plan to address breakthrough pain should be in place for the times when the ER dose is just not enough (Pasero & McCaffery, 2011).

9 Pain Assessment

Managing pain begins with careful assessment. Assessment parameters should include:

Site

Intensity

Current, best, worst, acceptable

Quality or type of pain

Onset, duration, patterns

Most pain will be worse at night simply because of less competing sensory stimuli. Most people report higher levels of pain at night.

Alleviating factors

Impact on quality of life

Accompanying symptoms

Pain and nausea together tend to escalate and accentuate one another in the patient's experience.

9 A Bill of Rights for People with Pain

By The American Pain Society



(Pasero & McCaffery, 2011)

9 Summary of American Pain Society Guidelines

(APS, 2008)

- **Individualize** the route, dosage, and schedule.
 - *Oral is most convenient and safest.*
- Establish optimal dose through **Titration**.
 - *Usually begin with immediate-release (IR) to establish lowest effective sustained-release (SR) dose.*
- **Around-the-Clock** dosing for chronic, severe pain.
- Appropriate IR dosing for **breakthrough pain**.
- Know patients **History of Opioid Use**.
 - *Both prescription and street drugs.*
- **Assess** and **Reassess** patient closely when beginning or changing analgesics.
- Use **Equianalgesic Dosing Charts** when changing to a new opioid or a new route.
- Recognize and **Treat Side Effects**.
- Ceiling doses of opioids limited only by unwanted side effects.
- Avoid meperidine.
- Avoid **poly-opioid pharmacy** whenever possible.

9 Opioids in Palliative Care

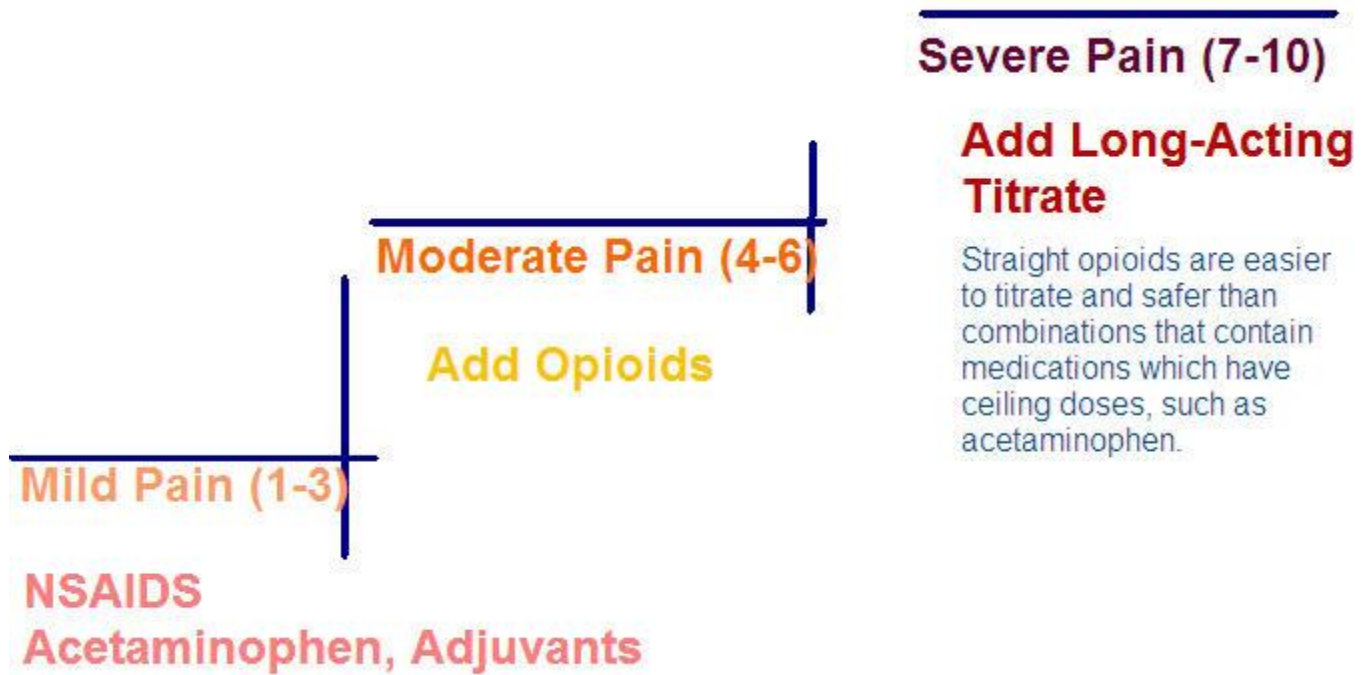
The patient's history of opioid use or lack thereof affects management simply because prescription or street drugs may impact the ability to process pain medication. Even though the patient is no longer actively using, pain receptors in the spinal cord may be adversely affected by substance abuse. Even years down the road, it may cause the patient to need more and more opioids to control pain.

The reason that opioids are so powerful, is that they, especially morphine and oxycodone, are not limited by a ceiling dose like other medications. Meperidine is rarely used in end-of-life care simply because the metabolites produced affect renal and hepatic clearance. It's not a very effective medication at the end of life.

Try to avoid poly-opioid pharmacy. It's best to simplify the opioid to one particular type rather than having for example, a fentanyl patch, an oxycodone extended-release and a morphine preparation for breakthrough. If possible, stay in the same pharmacological family for the ease of titration and conversion.

9 World Health Organization Pain Management Ladder

The WHO developed these recommendations for managing pain with medications.



Case Study: Management of Pain

Mr. G, age 76, is newly admitted to home hospice. His primary caregiver is his 78-year-old wife.

He has completed treatment for malignant melanoma with metastasis to his liver, lungs, and lumbar vertebra.

Initial pain assessment reveals a moderate, dull, aching pain in his lumbar area and a sharp, shooting pain radiating down his left leg that keeps him awake at night. His last BM was two days ago.

He is oriented x3 but reports increasing difficulty articulating his thoughts and communicating clearly. He reports "feelings of sadness," a fear of the future, and increasing anxiety.

His hospital discharge orders are as follows:

1. 5 mg oxycodone/325 mg acetaminophen (Percocet® 5 mg) two tabs Q4H PRN. Currently taking 12 tablets/24 hours.
2. Acetaminophen (Tylenol®) 500 mg Q6-8H PRN. Currently taking 1000 mg/24 hours.
3. Lorazepam 0.5-1.0 mg Q1H PRN. Currently not taking this.

Test Yourself

What type of pain is Mr. G experiencing?

1. **Neuropathic and somatic**
2. Nociceptive and visceral
3. Neuropathic and visceral
4. Nociceptive and somatic

He describes his pain as dull, aching. That is somatic pain, a musculoskeletal kind of dull pain. And he said sharp pain radiating down his leg. That's a red flag for neuropathic pain. Words like radiating, tingling, and sharp describe neuropathic pain.

Test Yourself

What is the MOST important medication change to make immediately on the initial admission visit with Mr. G?

1. Increase the oxycodone/acetaminophen (Percocet®)
2. Add an NSAID
3. **Stop the extra-strength acetaminophen (Tylenol®)**
4. Schedule the lorazepam (Ativan®) around the clock

If he is taking Percocet®, he's already at the maximum ceiling dose for acetaminophen (4 grams/day, for the elderly, 3200 - 2600 mg). It's very important to be sure that patients aren't taking Tylenol® on the side, or that they're double-prescribed with acetaminophen. If the patient's pain is increasing, we might eventually increase the percocet. However, we are limited because of the acetaminophen dose. An NSAID or lorazepam might be added later.

Test Yourself

Mr. G reports that his pain is at an intensity level of 6/10 and is unacceptable. You call the physician and he changes the oxycodone/acetaminophen (Percocet®) to an extended-release opioid.

Which opioid will most likely be ordered?

1. Morphine or oxycodone without acetaminophen (Correct)
(Hydromorphone (Dilaudid®) is often the opioid of choice, but not in this situation because no ER form is yet available. Morphine is available in many forms, is easy to titrate, and has been well-researched. Some prescribers might choose to stay with oxycodone instead. Though fentanyl is effective for chronic pain, it is less effective at end of life because the transdermal absorption is slow and is difficult to titrate.)
2. Hydromorphone or fentanyl

Converting One Opioid to Another

Mr. G is currently taking 12 tablets daily of oxycodone/acetaminophen (Percocet®) 5 mg. Which morphine order would be recommended to the physician when rotating from the Percocet® to morphine?

1. Calculate total 24-hr dose used currently:

$$12 \text{ tablets per day} \times 5 \text{ mg oxycodone} = 60 \text{ mg}$$

2. Convert 24-hr total to equivalent dose of morphine using the equianalgesic chart.

Analgesic Opioid Agonist	Equianalgesic Dose	Equianalgesic Dose	Dosing Interval	Dosing Interval
	Oral	IM/SQ/IV	Immediate-Release	Controlled-Release
Morphine	30 mg	10 mg	1-4 hours	8-12 hours
Oxycodone	20 mg	N/A	1-4 hours	8-12 hours

$$\frac{30 \text{ mg morphine}}{x} = \frac{20 \text{ mg oxycodone}}{60 \text{ mg oxycodone}}$$

$$20x = 1800$$

$$x = 90 \text{ mg}$$

3. Because of cross-tolerance, initiate the new opioid at ½ - ⅔ recommended equianalgesic conversion.
 $90 \text{ mg} \times \frac{1}{2} = 45 \text{ mg}$; $90 \text{ mg} \times \frac{2}{3} = 60 \text{ mg}$ *

* As always these are guidelines. Follow your organizational P&P.

Calculating a Breakthrough Dose

Mr. G's prescriber conservatively ordered morphine sulfate extended-release (MS ER) 30 mg Q12H. What is the appropriate morphine sulfate immediate-release (MSIR) breakthrough dose for the new extended-release morphine order?

The breakthrough dose is 10% – 20% of the new 24-hour dose Q1H PRN.

24-hour dose = 60 mg

10% of 60 mg = 6 mg; 20% of 60 = 12 mg

10% - 20% of the 24-hour dose of ME ER = 6 mg – 12 mg

The breakthrough dose can be adjusted slightly to accommodate the route of administration and available dosages. In this case, the order might be written as 5 – 10 mg for ease in administration with tablets or liquid forms.

These are general guidelines. Follow your organizational P&P.

Cancer Pain Guidelines

When a patient's pain is escalating, you must determine how much more pain medication to give.

Total the long- and short-acting medication dose to find out the amount taken safely in the last 24 hours. The rule of thumb for mild to moderate pain is to increase the 24-hour amount by 25%. The 24-hour total plus an additional 25% is the new extended-release dosage.

These patients are not opioid naïve, but have been accustomed to the effects of morphine including respiratory depression and other side effects, so you don't have to worry about adverse effects. If pain is severe an additional 25%-50% of the 24-hour dose may be added.

The total of the 24-hour dose and additional percentage is the new 24-hour dose. The extended-release dose, administered Q12H, is $\frac{1}{2}$ the new 24-hour dose.

The Titrating Procedure

Titration requires continuous assessment of pain and of the effectiveness of medication.

1. Calculate the total amount of controlled-release (long-acting, sustained-release, and extended-release) opioid taken in 24 hours.
2. Calculate the total amount of breakthrough.
3. Add #1 + #2 together to determine total opioid dose in 24 hours.
4. New dose = total amount in #3 + (based on patient response):
 - Additional 25% increase for mild to moderate pain
 - Additional 50% increase for moderate to severe pain
5. Divide the new 24-hour dose by 2 for the Q12H dose
6. Recalculate breakthrough:
 - Use 10 – 20% of the new 24-hour dose Q1H PRN

As always these are guidelines. Follow your organizational P&P.

Titration: Breakthrough Dosage

After titrating, recalculate the breakthrough dose, using 10-20% of the new 24-dose, every hour PRN.

The PRN dosage every hour of an immediate release oral liquid preparation enters the bloodstream and begins to become effective at 15-30 minutes. Within one hour, it has reached its peak plasma level. At that time, the body begins to excrete it. The patient will receive no more maximum effect after that hour. If an hour-and-a-half later, the patient is still in extreme pain, the breakthrough dose can still be administered safely because the body has already begun to eliminate the previous dose.

Test Yourself

Mr. G is converted to morphine sulfate extended-release (MS ER) 30 mg Q12H PO/SL with morphine sulfate immediate-release (MSIR) 5-10 mg Q1H PRN. Appropriate dosages of Senna and Docusate Sodium were initiated.

What additional medication change would be MOST appropriate on this initial visit?

1. Resume the Acetaminophen (Tylenol®) to address the bone pain.
2. Continue the Lorazepam (Ativan®) due to his increased anxiety.
3. Obtain an order for generic Temazepam (Restoril®) to help the patient sleep at night.
4. Obtain an order for ibuprofen (Advil®) 800 mg Q8H due to the presence of somatic pain.

Obtaining an order for ibuprofen or some other NSAID to address the somatic pain and bone pain to related bone metastasis is MOST important and may produce a dramatic response. A patient may have been on an opioid for months or years and not been given the additional boost of an NSAID. Sometimes within 24-36 hours after a few doses of TID Advil®, there's a dramatic difference in pain.)

Mr. G's Other Medications

What about the other choices among his medications?

Acetaminophen is not useful in the treatment of bone pain.

Continuing the lorazepam due to his increased anxiety is a good option. At least revisit the issue because he's talked about some of his feelings and anxiety. Temazepam may also help.

Patients like Mr. G often say something like "Boy, I'm fine until I try to walk." For a prostate cancer patient who suddenly begins to complain about leg pain, it could be that there is some metastasis. Ibuprofen or an NSAID could make a tremendous difference in the quality of that pain.

Test Yourself

Which instruction is most important to give Mr. G's 78-year-old wife initially?

- a. Count Mr. G's respirations for a full minute at regular intervals.
- b. Expect that Mr. G may sleep for an extended period of time.
- c. Keep a detailed record of pain intensity and breakthrough doses.
- d. Observe for signs of myoclonus that could indicate neurotoxicity.

Let Mrs. G know that when the morphine is initiated that Mr. G might sleep for a while. It could be the first time that his pain is well-controlled and may cause transient sedation. As long as she can arouse him, give her some tools to use to make sure that she knows that she hasn't caused him to become unconscious and make sure that she knows how to assess his level of consciousness easily, and just let her know that he may sleep for a good 8-10 hours after relief of his pain.

Family Education

One of the challenges in end-of-life care in the home is considering the limitations and abilities of caregivers. Mr. G was not opioid naïve so there is no need to add to the wife's anxiety by asking her to count his respirations. He will not exhibit respiratory depression if he's been opioid tolerant for some time.

We might ask Mrs. G to keep a record of the dosages she gives him, but that would not be the first thing we would emphasize. We do the best we can to help caregivers at home to keep an accurate record of dosages and a pain diary, but we don't want it to become too burdensome. We adjust it to that caregiver's ability.

We would also educate the family about the possibility of Mr. G developing myoclonus. Myoclonus is a sudden, mild, involuntary jerking action in the limbs that can progress to quite severe spasmodic jerking. Myoclonic twitches or jerks are usually caused by sudden muscle contractions, called positive myoclonus, or by muscle relaxation, called negative myoclonus. Myoclonic jerks may occur alone or in sequence, in a pattern or without pattern. They may occur infrequently or many times each minute. Myoclonus sometimes occurs in response to an external event or when a person attempts to make a movement. (NINDS, 2015).

The twitching cannot be controlled by the person experiencing it. Myoclonus sometimes occurs when opioids are administered in very high doses (1,000 milligrams or more per day). When liver and renal clearance starts to fail, the metabolite is not processed. This seems to be the cause of myoclonus at end of life. Lorazepam is a recommended intervention to reduce myoclonus which may occur when the patient is receiving high doses of morphine.

However, Mr. G is not on high dosages at this time, and probably will not experience myoclonus. If his dosages were to increase and we were to observe the mild twitching, we might explain the cause and treat accordingly.

Addressing Neuropathic Pain

What about the other medication choices?

If his pain is increasing, why not bump up the morphine and make sure we get the pain under control? The shooting radiating pain suggests nerve involvement and gabapentin addresses neuropathic pain specifically.

Often overlooked when addressing bone pain, is titration of ibuprofen doses. However, his bone pain has improved, so probably ibuprofen is at a correct and helpful dosage.

A tricyclic anti-depressant (TCA) can also be used to help treat neuropathic pain. Amitriptyline (Elavil®) 10 mg at night was very commonly used in the past. One of the downsides of TCAs is anti-cholinergic side effects. Nortriptyline (Pamelor®) can be used for neuropathic pain as well. It offers additional benefits at the end of life, such as mood elevation and possibly improved appetite, so keep that in your tool kit for neuropathic pain.

Amitriptyline produces significant anti-cholinergic side effects. However, nortriptyline has much less likelihood of causing anti-cholinergic effects such as urinary retention, confusion, and others.

9 Pain Relief after Swallowing Ceases

Ways to actively manage pain when a patient is unable or unwilling to take oral morphine include converting to a subcutaneous dose and giving that as an infusion.

Another possibility is to return to immediate-release morphine, which can be given in liquid form depending on the desires and needs of the patient.

Extended-release morphine tablets can be given rectally and have the same efficacy of absorption. Those tablets are produced by taking a small amount of medication with a wax-type coating, and then more medication and more wax. As they melt away they release the medication. Those tablets must not be crushed, because then the whole dose is delivered at once.

The absorption and melting action takes place equally well in the rectum. If the patient is actively dying, it might be very effective within the last day or two of life. If the caregiver is able and doesn't object, the rectal route allows continued pain management without the need for new dosing.

9 Pain Management Myths and Facts

1. If you need morphine, it means death is near.

Morphine is the drug of choice for many kinds of pain management. Its use does not signal impending death.

2. Pain medicine will make me sleep all the time.

Our bodies adjust to the effect of sedation from pain medications within just a few days.

3. If I take too much pain medicine, it will not work later when I really need it.

Tolerance is a common occurrence in individuals when certain medications are taken continuously. If tolerance to a certain dosage does occur, it can safely be increased, or a different drug can be used.

4. Pain medications are dangerous and interfere with breathing.

Pain medications are used routinely and rarely cause respiratory depression when given as prescribed at end of life.

9 Morphine

Pain management clinicians intentionally do not use the word “narcotics.” In hospice and palliative care, nurses learn to have the “end talk” with patients and families. They reassure individuals that we know a lot about morphine: it’s safe, how to use it responsibly, and that it’s not intended to simply induce a coma. We can use it effectively to manage symptoms.

It shouldn’t make people sleep all the time. Sedation may occur in the first few days, especially if the patient is opioid naïve, but usually we adjust and if the patient has been on opioids for weeks or months, they rarely experience sedation even if their dosage is increased.

Morphine does not have a ceiling. Tolerance may occur, requiring a little more morphine to accomplish the same effect. That’s not the same as addiction. It will continue to work most of the time. If tolerance occurs to such a degree that dosages become high and produce symptoms like myoclonus, we rotate the opioid to perhaps hydromorphone or oxycodone.

Every healthcare provider associates respiratory depression with morphine. In the acute care setting and in an opioid naïve patient, it may occur. However, opioid-tolerant patients become tolerant to that side effect. Respiratory depression rarely occurs when we routinely use pain medications, as we do with the cancer patient.

10 Constipation

Constipation is infrequent bowel movements or difficult passage of stools. Constipation interferes with quality of life. It occurs in nearly all patients receiving opioids (Nunn, 2010)

A host of unpleasant symptoms can accompany constipation:

- Increased pain
- Nausea and vomiting
- Anorexia
- Weight loss
- Bowel obstruction
- Urinary retention
- Fever
- Sepsis
- Erratic absorption of medications
- Ileus

Treat Constipation Seriously

It breaks my heart when I hear healthcare professionals say, "These elderly, they just obsess about their bowels."

Well, when our bowels aren't working or we're constipated, life is miserable.

And I have to say, for the patient at end-of-life, it's a huge obstacle to a good quality of life.

Sometimes, constipation can be more distressing than the disease process itself so we need to treat it seriously and with dignity.

Barb Schmal, MS, RN, CHPN

10 Causes of Constipation

There are numerous causes of constipation and they can be classified as lifestyle-related, disease-related, or opioid-induced (Nunn, 2010).

Constipation can be caused by:

- Certain diseases,
- Advancing age,
- Decreased physical activity,
- Low fiber diet, depression,
- Cognitive impairment,
- Medications such as opioids, calcium channel blockers, diuretics, anticholinergic drugs, iron, serotonin antagonists, and chemotherapy, and,
- Metabolic abnormalities, such as hypercalcemia and hypothyroidism.

10 Management of Constipation

Management of constipation usually starts with identifying and treating the underlying cause. If a reversible cause cannot be addressed then symptomatic treatment should be initiated. Common medications that may be used to treat constipation include (Nunn, 2010):

- Bulk laxatives – methylcellulose, polycarbophil, psyllium
- Stool softeners – docusate calcium, docusate sodium
- Osmotic laxatives – lactulose, magnesium citrate, magnesium hydroxide, polyethylene glycol, sodium bisphosphate, sorbitol
- Stimulant laxatives – bisacodyl, cascara sagrada, castor oil, senna
- Prokinetic agents - tegaserod

Enemas and/or suppositories may be indicated for distal fecal impaction or if a patient has not had bowel movement for three days or more.

Manual disimpaction may become necessary.

There are numerous bowel regimens available. Each used a progressive approach to achieve results. The next slide shows an example of a progressive bowel regimen for constipation.

10 Example of a Progressive Plan

1. Evaluate for medications contributing to constipation and eliminate when possible.
2. Senna 1 – 8 tabs daily and docusate sodium 100 – 800 mg/day (1 tab/30 mg morphine) PO maximum of 8 tabs daily.
3. Bisacodyl 2 – 8 tabs PO daily PRN.
4. Bisacodyl suppository 1 daily per rectum; if no bowel movement, repeat in one hour.
5. Magnesium hydroxide 15 – 60 mL PO 2 – 4 times daily PRN.
6. Sorbitol 70% solution, 30 – 60 mL PO every other day twice daily PRN.
7. Enema daily PRN for a maximum of two consecutive days.
8. Manual disimpaction PRN.

10 Assess the Medication Regimen

Not only do many medications contribute to constipation, but a patient may be continuing habits of many years related to bowel function.

For example, your patient may have taken Fibercom® all her life and may be continuing to without telling you. Or perhaps her family is still giving her the medications. So when you ask, "How many tablets do you take and do you drink a full glass of water?" The answer may be "Well, no, I just take a couple and take a few sips."

That practice is contributing to a big block of cement in her bowel.

Fiber Laxatives Least Helpful Choice

For the elderly patient at end of life, fiber laxatives are the least helpful choice to relieve constipation and may actually add to the problem if fluid intake is limited.

Barb Schmal, MS, RN, CHPN

10 Assessing Bowel Status

The significant parameters to assess include:

- Degree of distention
- Bowel sounds
- Color, volume, odor of vomitus
- Level of consciousness
- History and onset of concomitant symptoms

We often have to rely upon caregiver report. We may have to train caregivers to respond to specific questions: Is the abdomen becoming more distended? We may or may not be actually measuring abdominal girth.

Color, volume, and odor of vomitus can tell us whether it is bile or stomach contents or has become foul smelling and dark which might indicate bowel obstruction. Nausea and vomiting may slow bowel function.

Decrease in level of consciousness may indicate progression of illness, which also decreases bowel function.

Additional Interventions for Bowel Obstruction

Identifying her priorities and wishes is paramount. The nurse also checks for fecal impaction, listens to and assesses bowel sounds, and very possibly inserts a nasogastric tube for the patient's comfort.

It's common at end of life for patients to simply have gastric decompression to gain relief from an obstruction.

Case Study

Mrs. T has stage 4 ovarian cancer with extensive abdominal metastasis. She is receiving hospice services.

She is on MS-ER 300 mg Q12H with MSIR 50-100 mg PO Q1H PRN for breakthrough pain. She also takes 8 Senna tabs daily with 8 tabs docusate sodium.

She has frequently required sorbitol and Fleets® enemas for relief of constipation.

She now reports nausea and vomiting of dark, foul-smelling emesis, and increased abdominal distention.

Test Yourself

What is the most important INITIAL action of the hospice nurse who visits?

- a. Insert a nasogastric tube.
- b. Auscultate bowel sounds.
- c. Check for fecal impaction.
- d. Discuss the patient's goals.

A hospice patient, first talk to her about what may be happening. Many patients are aware of the changes that occur with a bowel obstruction. They may understand that they are vomiting stool and that this has implications. The most important thing is to explore with the patient her awareness of the meaning of some of these symptoms and what direction she wants to take.

11 Agitation and Delirium

Difference between agitation and delirium

- Agitation – excessive restlessness, increased mental and physical activity, inability to be consoled.
- Delirium – an acute alteration in mental status which includes:
 - Clouding of state of consciousness.
 - Development of symptoms over hours to days.
 - Fluctuation of signs and symptoms.
 - Normalization or improvement after treatment of underlying condition, or spontaneous recovery.

While commonly associated with the elderly patient, even younger patients, can experience an acute episode of delirium after spending time in the hospital.

11 Causes of Delirium

Many circumstances common at end of life can cause delirium, including (Nunn, 2010):

- Dehydration, metabolic changes
- Hypoxia
- Acute cerebrovascular accident, myocardial infarction, renal failure
- Infection
- Pain
- Environmental changes, such as removing, adding, or rearranging items
- Urinary retention
- Fecal impaction
- Medications /polypharmacy; particularly anticholinergics, benzodiazepines, opioids, steroids, digoxin
- Unfinished business, unresolved psychosocial issues

11 Management of Delirium: Pharmacologic Interventions

Haloperidol (Haldol®) is the medication of choice for managing delirium. It does not produce the paradoxical effects that benzodiazepines might cause. The dose depends upon the patient's weight and is usually ordered:

Haloperidol 1-5mg PO/IM/IV Q1H until calm. Maximum x 6 doses/24H then Q4H.

For agitation, lorazepam may be given, only if the patient has no dementia and is not of advanced age. Benzodiazepines must be used with caution because of the potential for a paradoxical effect.

11 Non-pharmacologic Interventions for Delirium

Because so many factors can contribute, it is important to assess and eliminate underlying and pharmacologic causes, including anticholinergics, steroids, opioids, or benzodiazepines.

The presence of others, consistent familiar faces, and sensory input help. Overstimulation, such as continuous television or a constant barrage of visitors, may increase agitation.

A subdued, but well-lighted environment has a calming effect.

Adequate pain management improves relaxation, such as acetaminophen for undiagnosed arthritis.

Team support from a social worker, chaplain, or family members may address psychosocial issues.

Complementary and alternative therapies such as pet therapy, music therapy, or aromatherapy may provide relief.

Non-pharmacologic Approaches Can be More Effective

Many times for that poor guy climbing out of bed, we would say, 'Let's try something to calm him down.' We'd give him a little lorazepam. All of a sudden he's not only climbing out of bed but pulling off his clothes and trying to jump out the window!

We've discovered that many medications like benzodiazepines, especially in the elderly, can cause a paradoxical reaction. Instead of calming the patient, the patient becomes more agitated. Many effective methods to treat delirium have to do with the environment, with non-pharmacologic approaches.

Barb Schmal, MS, RN, CHPN

Caring for the Dying Patient

As the patient approaches death the goals of symptom management become even more profound. The goal is to achieve a peaceful death experience for the patient. Symptom management in this setting becomes more simplistic and should be viewed in the context of the whole person who is the patient.

Many of these symptoms are tied to the whole being through the mind-body connection. So it is important to remember to assess the patient as whole and look at all factors are when dealing with the dying patient.

Family concerns come to the forefront during this time and may impact the quality of the person's environment and preparation for death – for both the patient preparing to die and the caregivers and loved ones at the bedside. All parties should be making the attempt to get ready for this event.

Guiding principles for the last weeks:

- Patient choice and control
- Balance between activity & rest
- Titration to relief of symptoms
- Focus on patient goals

Caring for the Dying Patient: Relief of Stress

Symptoms take on different meanings at end of life. Anxiety, fatigue, and emotional, psychological, and spiritual distress can exacerbate symptoms. Symptom management can be improved by alleviating stress by whatever means possible.

Relief from stress also improves the patient's decision-making capacity. When the patient experiences extreme pain or uncontrollable nausea, it's difficult to deal with anything else. Symptom management is so important because it allows quality of life at the end of life and the frame of mind to approach the work of dying.

Caring for the Dying Patient: End of Life Needs

Maslow's theory on the hierarchy of needs can be used to view and frame the dying experience and focus interventions to provide the patient and family a peaceful death experience. Zalenski and Raspa (2006) modified Maslow's original hierarchy and adapted it to palliative care.

The five levels, from the bottom to the top, are:

5. Self-actualization needs – growth in illness, peace, and transcendence.
4. Esteem needs - value, respect, and appreciation for the person;
3. Love and Belonging needs - affection, love and acceptance in the face of devastating illness;
2. Safety needs - fears for physical safety, of dying or abandonment;
1. Physiological needs - distressing symptoms, such as pain or dyspnea;

When the bottom level is not met, those basic needs of comfort, the patient can't do the important work of dying.

The Work of Dying

Only approximately 6% of deaths are sudden deaths. The majority of people know in advance what disease process will take their lives.

The work of dying begins with the diagnosis of life-threatening illness. Psychosocial, emotional, and spiritual issues come to the forefront. Abraham, Kutner and Beaty (2006) reported that 34% of respondents in a multinational survey stated that their ***greatest suffering*** was from nonphysical sources.

Resolving Life Issues

A person wonders, "Have I done everything I was supposed to do?" "How do I fix those things that need fixing or finishing?"

Practical and Emotional Planning for the Well-Being of Loved Ones Left Behind.

A person may consider, "What should I do with the house?" "Should I clean up the garage so that my wife doesn't have to deal with it when I'm gone?"

Family members and caregivers may not be ready for this planning as early as the patient is. Palliative care professionals can help by listening to the planning process and act to bridge those conversations.

Finding Meaning

Finding meaning in life, suffering, and dying.

Coping With Fears of Loneliness and/or Abandonment.

Family members also experience feelings of loneliness and abandonment as they contemplate the death of their loved one. Patient and family become the unit of care as they walk through the process together.

Acknowledging One's Individualized Meaning of Departure From This Life.

In her model of death and dying, Elizabeth Kubler-Ross identified "acceptance" as the final stage in the process. However, at the end of her own life, she expressed a different belief.

She saw not a nice, neat process, but rather the reality that not everybody goes through some of the stages she had identified - it can be a very erratic process.

Acceptance implies that everything's just fine, which is rarely the case. However, many people can really get to a place of acknowledgement and say, "I'm dying and that's okay."

The Work of Dying: Spiritual Issues

Never think that those who lack a formal religious background or faith practice have no spiritual issues that they're working through. All of us, regardless of our belief systems, will begin to examine what we really believe. This is a time of introspection and reconciliation.

- Examining beliefs relating to death, eternal life, and afterlife.

People of faith may struggle with, "I've believed this all my life, is it true? Am I being strong enough?" Many people of faith struggle with a fear of dying because they feel that they should be stronger than that and they are hard on themselves.

- Reconciling with God or others.

Atheists too, who may not believe in an afterlife or Supreme Being, still struggle with existential issues, "Why was I here? What did I live for? Do I need to be reconciled with other people?"

- Determining the meaning of pain, suffering, dying process.
- Exploring one's potential legacy.

Physical Causes Are Rarely Single Cause Of Suffering at the End Of Life

When you work with dying patients, one thing you learn may be to change the way that you live yourself.

What is it that I'm leaving? We have time to think about that. This is certainly something that patients who know they're running out of time begin to think about.

It's important to think about pain and symptoms in terms of suffering. Physical causes are rarely the simple, single cause of suffering at the end of life.

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The Work of Dying: Tailoring Symptom Management to Patient Goals

As death approaches, patients begin to sense their own decline. They know their bodies and their body clocks very well, even if they don't know their disease processes.

This can be a difficult time for family as the patient begins to lose interest in socialization. The patient is conserving energy at the very same time that the family may want to hold onto that person just a little bit longer.

During this time, empower the patients and families by giving the patients choice and control over what they eat and do, finding the right balance between activity and rest, making sure we're titrating medication to the relief of their symptoms, and trying to determine their goals.

The most important thing may be, "I want to go ride my horse one more time." Manage symptoms so the patient can reach that goal.

The Weeks Before Death

Several weeks preceding death, the body begins to shut down (Dans & Sheldahl, 2015).

Most patients, at this time, are becoming close to bed-bound, if not already bed-bound. The patient typically exhibits:

- Obvious physical deterioration.
- Potential for increase in symptoms. Some cancer patients might exhibit a spike in pain about 6-8 weeks before death as the metastasis or disease makes that final push into the system. Usually, once pain is controlled, it stabilizes.
- Difficulty swallowing, disinterest in food. "It feels like something's stuck in my throat." They become disinterested in food. The body is saying, "I don't need many calories anymore." The gut slows and the body naturally knows not to eat.
- Decreasing mobility, loss of independence.
- Increased likelihood of incontinence.
- Changes in sleep/rest patterns. The patient may sleep 18-22 hours a day.
- Emotional withdrawal. Patients try to conserve their energy for simply breathing or having a conversation or two in a day. The withdrawal is difficult for the families who begin to sense, "I'm losing my loved one."

The Weeks Before Death: Comfort Measures

Manage dysphagia with backward diet progression, similar to a reverse of post-operative diet progression. A small dropper or oral syringe may be useful to administer liquids, just to moisten the oral cavity.

A patient may reject an indwelling catheter to manage incontinence. Adult briefs, avoiding the demeaning term "diapers," may be an alternative. Be cognizant of dignity issues. Protect patient from skin breakdown if possible. Skin failure at end of life may lead to unavoidable breakdown.

To adjust to changes in sleep/rest pattern, maintain a calm environment.

Use caution with medications and avoid polypharmacy. Medications may be limited to those required to relieve symptoms.

Families Often Need Help To Cope with the patient's emotional withdrawal. Support them in conserving the patient's energy, perhaps with fewer interactions than they would like. Recognize that family members may feel guilty and need support.

Guiding Principles for the Days and Hours before Death

In the last days of life, it becomes very evident to the family that time is running short. The goal is to keep the patient comfortable.

Pain and other symptom management are very important. Symptoms should be managed with a minimum amount of invasiveness. Preservation of the patient's dignity and mental clarity are also important considerations.

This is a time to uphold caregivers and offer support. Educate them during this difficult time as to the meaning of what they're seeing as they ask. Some caregivers will ask many questions. Others don't want to know. Meet them where they are.

Administering medications to keep the patient comfortable gives the family something to do and combats the family's awful sense of helplessness at the bedside.

Comfort Measures in the Last Hours

In the hours before death, the comfort measures for the care of the patient become relatively simple. Sometimes the care of the family becomes a little more intense in the last day or hours of death as they understand the significance of what they are seeing.

By explaining to the family the most likely scenario of death, you give a gift to the caregivers. You might describe what is likely to happen. It's not guaranteed, but you've removed the fear of the unknown.

Explain that probably breathing will simply stop and then the heart will stop, or the heart will stop and then breathing will cease. Most people fear witnessing death. They don't know what it is going to look like and it's important to give a mental picture of an anti-climactic, peaceful death. That is how the majority of deaths in home care, hospice, or palliative care occur.

Give Care as You Would Hope to Get Care

'Personally, it helps me to remember as I give care, that this will be me someday. This will be my parents someday, my brother and sister, their children, my own children and grandchildren.

I will give care as I would hope my loved ones or myself will receive care at end of life.

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Comfort Measures in the Last Hours: Respiratory Symptoms

Labored respirations are not uncommon. They are not necessarily respiratory distress. Respirations become noisier and more noticeable to the family because of upper airway congestion. Elevating the head of the bed and using a fan should give relief. Pooling of oral and bronchial secretions may be relieved by repositioning to allow drainage.

Room air may be equally effective as oxygen. Oxygen may or may not help a patient's respirations at the end of life and may not be necessary. If the patient experiences true dyspnea, we administer medications such as morphine.

A family member might say, "I was sitting next to Mom and she stopped breathing for a few seconds, what's that all about?"

That's a golden opportunity to explain the meaning of what is happening. Most people have not had that experience and don't know what to expect. Any appropriate response would be, "It's interesting that you notice that Mom has those periods of time when she has a little break in her breathing. This is probably going to continue to occur. Those periods will get a little longer. She is going to take breaths a little more deeply and slowly, and in one of those periods after not breathing, she may take her last breath."

Comfort Measures in the Last Hours: Other Changes

A patient may go for days with little or no oral intake of any kind without exhibiting symptoms of discomfort. Frequent mouth care is very important.

Patients may begin to lose the corneal reflex and we might use artificial tears because their eyelids may not close entirely. Even though they may have only days to live, the eyes might be drying out a little bit and causing discomfort.

Body temperature may fluctuate. The patient may spike a temperature causing the family concern that the patient has pneumonia or a new disease process. The temperature usually is evidence of hypoxia, or brain stem involvement. Treat symptomatically with sponge baths, cool cloths, possibly acetaminophen suppositories, or whatever comforts the patient.

End of Life Goals

Patients have described the goals and outcomes they seek at end of life.

In a classic study conducted by Singer, Martin, and Kelner (1999), they asked dying patients to identify and describe elements of quality end-of-life care from their perspective. Five outcomes were identified:

1. Receiving adequate pain and symptom management
2. Avoiding inappropriate prolongation of dying
3. Achieving a sense of control
4. Relieving burden
5. Strengthening relationships with loved ones

While no one can truly define what a good death is, except for the patient himself or herself, these goals can serve as the basis for providing quality palliative care. Achieving these goals is what palliative care is really about!

Tasks of Grieving

Some bereaved persons have described a reaction to the death of a loved one as freezing, being numb in response to the loss, and that as a thawing of this freeze occurs, they begin to experience the pain of the event.

John Worden (2008) described a process that applies also to anticipatory grief as a patient enters this process, for patients themselves and the family who will be left behind.

Accepting the reality of the loss. Wakes and funerals play a role, but acceptance may take weeks or months.

Experiencing the pain caused by the event. Sometimes people seek relief by drinking or substance abuse. This is a time when help and support are needed. That's why hospice programs offer bereavement support up to a year. You're thawing out. Some describe it as feeling frozen at the time of death. Then as you thaw out, you feel the pain.

Adjusting to a new environment without the presence of the loved one.

Reinvesting emotional energy in relationships and rebuilding a new life.

A Final Word

In dealing with patients at end of life, it is the highest calling of the medical community to prepare a family for the death of their loved one by de-mystifying the dying process and equipping them to walk through it.

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Summary

In this course, you learned:

- The principles of symptom management at end of life.
- How to assess and manage a variety of symptoms common at end of life
- The pharmacologic and non-pharmacologic interventions commonly encountered at end of life.
- Physical, psychosocial, emotional, and spiritual issues at end of life.
- How patients progress toward death and appropriate interventions during the last months, weeks, days, and hours of life.
- Components of a quality end-of-life experience.
- Tasks of grieving.

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Note: All dosages given are for adults unless otherwise stated. The information on medications contained in this course is not meant to be prescriptive or all-encompassing. You are encouraged to consult with physicians and pharmacists about all medication issues for your patients.

Recommended Resources

Martinez, H., & Berry, P. (Eds.). (2015). *Core Curriculum for the hospice and palliative registered nurse (4th ed.)*. Hospice and Palliative Nurses Association (HPNA). Pittsburgh, PA: Kendall Hall.

Ferrell, B. R., Coyle, N., & Paice, J. A. (2015) *Oxford textbook of palliative care nursing*, NY: Oxford Press.

American Academy of Hospice & Palliative Medicine <http://www.aahpm.org>

Center to Advance Palliative Care <http://www.capc.org>

Hospice & Palliative Nurses Association <http://www.hpna.org>

Arizona Hospice & Palliative Care Organization <http://www.ahpco.org>

National Hospice & Palliative Care Organization <http://www.nhpco.org>

National Council for Palliative Care <http://www.ncpc.org.uk/>

Worldwide Hospice Palliative Care Alliance <http://www.thewhpc.org/>

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Glossary of Terms

Agitation: An unpleasant state of extreme arousal (stirred up or excited), increased tension, and irritability.

Anorexia: Loss of appetite; Inability to take in nutrients.

Biochemical afferents: Chemicals produced when nerves are affected. These biochemicals are involved in transmitting to the vomiting center.

Breakthrough dose: An amount of medication for sporadic pain administered on an as needed basis. Given in conjunction with extended-release medication when the patient experiences pain despite receiving extended-release pain medication.

Cachexia: Weight loss and wasting due to inadequate intake and/or absorption of nutrients.

Chemotherapy trigger zone (CTZ): A center in the brain which is susceptible to emetic stimuli delivered through the blood system or cerebrospinal fluid (CSF). The CTZ acts by stimulating the phrenic, spinal, and visceral nerves.

Death rattle: A lay term for the sound produced by upper airway congestion and loss of the ability to swallow at end of life. Passage of air in breathing through the accumulated secretions produces the sound.

Delirium: A serious disturbance in a person's mental abilities that results in a decreased awareness of one's environment and confused thinking.

Dysgeusia: Altered in taste perception.

Emetogenic pathways: Centers of the brain that are responsible for the development of nausea and vomiting.

Equianalgesic: Doses of different pain medications that are equivalent in effect, for example oral morphine 30 mg = oral oxycodone 20 mg.

Idiopathic nausea: Bothersome nausea occurring several times a week usually not associated with vomiting.

Ileus: Non-mechanical bowel obstruction produced by hypomotility in the small or large intestine.

Maslow's hierarchy: A model of human motivation described by Abraham Maslow: Basic needs must be satisfied before higher level needs such as safety, belongingness esteem, and self-actualization emerge in sequence.

Midbrain afferents: Innervation that allows impulses to travel to the midbrain.

Myoclonus: Quick, involuntary twitching and jerking of muscle groups. May occur with high doses of morphine.

Neuropathic pain: Discomfort experienced as a result of a disruption of normal nerve pathways because

of resection, amputation, or pressure. Not the result of an external cause.

Nociceptive pain: Discomfort experienced as a result of impulses traveling over normal nerve pathways, such as discomfort from touching a hot stove.

Palliative Care: An approach that emphasizes care, comfort, and quality of life rather than cure.

Paradoxical effect: The opposite response to the expected response from a medical treatment or medication. For example, when benzodiazepines increase agitation and confusion, rather than producing the desired calming response.

Pharyngeal afferents: Innervation of the pharynx which transmits impulses that produce nausea and vomiting.

Poly-opioid pharmacy: The use of more opioid medications concurrently than are needed to manage pain. May make titration difficult and increase the incidence of adverse effects.

Skin failure: An event in which the skin and underlying tissue die due to hypoperfusion that occurs concurrent with severe dysfunction or failure of other organ systems.

Somatic pain: Discomfort from musculoskeletal sources.

Stomatitis: Inflammation of the mucous lining of any structures in the mouth. May involve the tongue, cheeks, lips, roof or floor of the mouth.

Titration: A method of increasing doses of medication to safely manage symptoms, usually pain.

Vagal afferents: Nerve fibers that innervate the gastrointestinal system, liver, and pancreas. They transmit signals that lead to the sensation of nausea and vomiting.

Vestibular system: The center in the brain that supports the sense of balance and spatial orientation.

Visceral pain: Discomfort originating in the hollow tubes and organs.

Vomiting center: Region of the brain which receives impulses via afferents and controls nausea and vomiting.

Xerostomia: Dry mouth due to lack of saliva.

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