Dysphagia Management in End of Life Care

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History of End of Life Care

- 1967 First modern hospice founded in London
- 1969 On Death and Dying published
- 1978 First U.S. hospice founded in New Haven
- 1982 Congress passes M/C Benefit Act
- 1990 Patient Self-Determination Act (AD)

Palliative Care

- PC seeks to prevent and relieve suffering
- Enhance comfort and quality of life
- It can be delivered with curative medical care
- PC can serve as intermediary between families and specialists- explaining complexities of illness; pros/cons of treatments; options

Hospice

- Hospice is an organized, legally defined concept for EOL care in any setting for widely varying lengths of time
- It doesn’t seek to cure disease, prolong life or hasten death

Defining hospice care

- Patient and family are single unit
- Address Living Will and DPO/HC
- Unresolved issues
- Family feuds

New model of end-of-life care

- Begins at diagnosis and covers quality-of-life issues as they occur through the illness
- If a cure isn’t possible, palliative care naturally progresses until hospice begins
- The 6-month prognosis then becomes just an administrative designation instead of a traumatic break with previous health care providers
Transforming the meaning of hope

- Hope for a comfortable death without pain or discomfort
- Hope for the patient to reaffirm or discover for the first time the value of their life
- Hope for the resolution of unresolved issues
- Hope for the patient’s affirmation or discovery of comforting spiritual beliefs
- Hope for quality of life
- Hope for the patient’s ability to accomplish their wishes during their final days

Transforming the meaning of hope— the SLP Role

Communication

- Counsel family to use pictures/stories or share their fondest memories with the patient
- Support patients’ spiritual beliefs with prayer; the rote aspect of praying can be calming and a language stimulant
- Identify favorite music—the soundtrack of life, another nonverbal activity that can be a language stimulant and mood elevator

Speech Pathology Role

- Communicate level of swallow function to nursing and pharmacy for comfortable administration of meds
- Quality of life
  - By providing high protein, high calorie foods that patients can enjoy
  - By maintaining oral integrity and skin integrity
- Understanding the process of the body shutting down
- Loss of desire for food
- Inability to process food (N/V/D)
- Often, complaints are “dry mouth”
- Not starving their loved one
- Allowing patient the dignity of decision-making

Artificial nutrition and hydration can be a life-saving measure for a body attempting to heal itself.

However, in end-of-life care, long-term use of tube feeding will neither reverse the course of the disease nor improve the quality of life.

For some, even nutrition and hydration are considered extraordinary means of prolonging life, and it becomes the decision of the patient along with input from the family and the physician to stop these measures.

Discussing withdrawal of treatment

- Make sure you know the applicable policies of your institution and the laws of your state.
- Choose a private setting to discuss plan.
- Find out what the patient and family already know about the patient’s disease, prognosis, and treatment options.
- Ask if the patient and family need any clarification.
- Ask the patient to talk about their values and goals of care; if they cannot speak, ask the person designated by the patient to make medical decisions for them.
- If anyone disagrees about the goals of care, allow more time for explanation and discussion.
Find out if the patient and family have a time frame in mind. Determine whether the physician has told them when the impending death is likely to occur. Talk about what can be done for the patient during the remaining time, focusing especially on comfort measures.

- Progress through the conversation in small increments, and watch the family’s reactions.
- Let the patient and family express their emotions freely as they struggle with the reality of the situation. Have colleagues such as the facility chaplain, social worker, or hospice nurse available to assist if needed.
- Reiterate the treatment strategy that the patient and family select.

**At a Loss for Words?**

- Scripting is key, especially if you are new to caring for the seriously ill patient, the dying patient and grieving family
- Case studies at end

**IMPACT:**

Palliative Care Consultation

<table>
<thead>
<tr>
<th>Service</th>
<th>Results</th>
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<tbody>
<tr>
<td>Hospice</td>
<td>23%</td>
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<tr>
<td>30 Day Hospital Readmissions</td>
<td>9% ± 4%</td>
</tr>
<tr>
<td>Patient/Family Satisfaction</td>
<td>99%</td>
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**Grief**

- One of the most pervasive emotions produced by loss, dying, and death
- Since Elisabeth Kubler-Ross introduced her five-stage model of loss (denial, anger, bargaining, depression, and acceptance) in 1969, others have developed models that describe grief
- These models share several traits:
  - Grief is a process
  - Grief includes a variety of intense emotions
  - Grief can result in a new level of emotional organization
  - A new identity is often gained at the end of the grief process

**Denial**

- I don’t have a swallowing problem.

**Anger**

- You people don’t know what you’re talking about. S/he doesn’t even cough when s/he eats and drinks. How could food be going into their lungs?
**Bargaining**

- Ice cream is thick; that’s all I want.
- I can avoid most of these foods but I want my cocktail. Little sips won’t hurt.

**Depression**

- Why should I put all this time into exercises? They won’t help.

**Acceptance**

- I think I’m coughing less; maybe this stuff helps a little
- “You know at first I thought puree food and thick liquids were awful, but watching him choke was worse and now he’s really comfortable eating, and eating better. Thank you for bearing with us.”

**Complicated Grief Reactions**

- Chronic- unusually long reaction which never reaches resolution
- Delayed- feelings may arise in response to another’s loss or feelings are unexpressed until a later loss
- Exaggerated- intense or out of proportion; disabled by clinical depression or other psych diagnosis
- Masked- feelings aren’t expressed overtly; feelings expressed as physical sx, even the same sx as deceased’s illness or as maladaptive behavior; survivor does not recognize that sx or behaviors are related to loss

**Risk factors for complicated grief reactions**

- Low-level risk factors
  - Trouble communicating with the SLP
  - Family conflict
  - Extreme dependency
  - Legal or financial issues
  - Signs of spiritual distress, such as expressing feelings of being abandoned by God

- High-level risk factors
  - Family members who express difficulty coping with previous deaths
  - Patient or family isolated from their support system by geography
  - Lack of close relationships
  - History of violence
  - Signs of inadequate coping skills
  - Signs of substance abuse or mental health issues
Depression

- Up to 1/3 of those who have a serious medical condition experience symptoms of depression
- Common symptoms include:
  - Loss of interest or pleasure in daily activities
  - Significant weight loss or gain
  - Sleep disturbances—sleeping too much or too little
  - Problems with concentration
  - Apathy—a lack of feeling or emotion
  - Feelings of worthlessness or guilt
  - Failure or loss of energy
  - Repeated thoughts of death or suicide

Understanding Concepts

- Advance Directives
- Preparing Advance Directives
- Living Wills

Advantages of advance directives

- Peace of mind for the patient that their wishes will be carried out even if they cannot communicate
- Clear directions for family and significant others about the patient's wishes
- Clear directions for health care providers about the patient's wishes
- Prevention of family arguments and increased stress at an emotionally difficult time

Preparing an advance directive

- Suggest the following steps to the patient:
  - Obtain information about the types of life-sustaining treatments available
  - If you are currently physically ill, obtain information regarding the expected progress of your disease
  - Discuss with your physician the expectations of your treatments and the risks of undergoing those treatments
  - Make sure your family and significant others are familiar with your value system and spiritual beliefs
  - Decide which treatments you would or would not want to receive
    - Document the types of treatments you would and would not like to receive if you can no longer communicate your wishes
    - Prepare several copies of the document and give one to your physician, attorney, and chosen surrogates. Keep a copy on hand for emergencies or future health care providers

NJ Practitioner Orders for Life-Sustaining Treatment

POLST

- GOC
- Medical Interventions: full vs limited treatment
- Artificially Administered Fluids and Nutrition
- CPR Airway Management
- Use of surrogate
- Signatures

Living Will

- Resuscitation: Does the patient want cardiopulmonary resuscitation? Would they want it performed even if they were in the final stage of a terminal illness?
- Mechanical ventilation: Does the patient want to be placed on a ventilator? If so, for how long? Would it matter to them what their prognosis was or their condition was deteriorating?
- Nutrition and hydration: Does the patient want to be fed artificially? If so, for how long? Would it matter to them what their prognosis was or if their condition was worsening?
- Dialysis: Does the patient want to be dialyzed in the event of kidney failure? Would it matter to them if the treatment evolved into a permanent one rather being temporary?
- Other end-of-life treatments: These include antibiotics and analgesics. Does the patient want to receive these as palliative care if death is imminent?
## Elements of cultural assessment

- Every patient and family hold a unique set of beliefs that both adhere to and depart from the norms of their culture. To help understand their preferences, investigate points such as:
  - Implications of silence and eye contact
  - Preferred form of address
  - Effect of age and gender
  - Permission to touch
  - Acceptable modes of expressing emotion
  - Beliefs about what causes sickness and supports healing
  - Importance of an individual vs. a group
  - Relationship between discussing illness and causing illness

## Variations in Cultures

- **African American**
  - **Health care belief and illness philosophy**
    - May believe that illness is related to supernatural causes
    - May seek advice and remedies from faith or folk healers
    - May exhibit a stoic response to pain until it’s unbearable and then seek emergency care
    - Family oriented—customary for many family members to remain with a dying patient in the hospital
    - May express grief by crying, screaming, collapsing, praying, singing, and reading scripture
  - **Dietary practices**
    - May have food restrictions based on religious beliefs (such as not eating pork, if Muslim)
    - Have a higher occurrence of high blood pressure and obesity, which may be diet-related
    - High occurrence of lactose intolerance with difficulty digesting milk and milk products
    - May view cooked greens as good for health
    - Traditional “soul” food diet is high in protein and fat
  - **Other considerations**
    - Values: family bonding, matriarchal, present orientation, spiritual orientation
    - Tend to be affectionate, as shown by touching and hugging friends and loved ones
    - Muslim women must keep their heads covered at all times
    - Primary religions: Baptist, other Protestant denominations, Muslim

- **Arab Americans**
  - **Health care belief and illness philosophy**
    - Aura of silence surround some health problems such as sexually transmitted diseases, substance abuse, mental illness
    - Devout Muslim may interpret illness as the will of Allah, a test of faith, representing a type of fatalistic view
    - May rely on ritual cures or alternative therapies before seeing a health care provider
    - Respect for the elderly—obligated to take care of their elderly relatives
    - May express pain freely
    - Death: family or community members may want to prepare the body by washing and wrapping the body in unsewn white cloth
    - Post-mortem examinations are discouraged unless required by law
  - **Dietary practices**
    - Other practices and requirements
Arab Americans

- Dietary practices
  - Choose foods based on the humoral theory of balancing hot and cold
  - Prefer dairy products, rice, and wheat bread
  - May avoid pork and alcohol if Muslim
  - Islam-observe month-long fast of Ramadan (begins about mid-October); those with chronic illness, pregnant, breast-feeding or menstruating women don’t fast
  - Don’t mix milk and fish, sweet and sour, or hot and cold
  - Don’t use ice chips in drinks; believe that hot soup can help recovery

- Other considerations
  - Values: Family patriarchal and hierarchical, respect for elders, modesty, respectability, and politeness.
  - Muslim women may avoid eye contact as a show of modesty.
  - Many Muslim women wear the traditional hijab (head cover).
  - Respect for higher education and advanced degrees.
  - Use same-sex family members as interpreters.
  - Preventive care among adults is not highly valued.
  - Primary religions: Muslim (Islam), Protestant, Greek Orthodox and Catholic.

Asian American

- Health care belief and illness philosophy
  - Have differing health views depending on their particular subculture
  - Chinese: may believe illness results when a person fails to act in harmony with nature, such as yin and yang
  - Filipino: may believe dying is God’s plan and that neither the patient nor the health care provider should interfere with God’s will
  - Korean: may adhere to traditional values that dictate that patient should die at home
  - Japanese: may believe that illness is karma, resulting from behavior in the current life or a past life
  - May value ability to endure pain and grief with silent stoicism
  - Typically very family oriented; extended family should be involved in care of dying patient

- Dietary practices
  - Hot/cold theory (yin and yang) often involved. Example: curing a “hot” disease such as arthritis may require cold foods or medicines
  - Hindu religious food practices: many refrain from eating cows, some are lacto-vegetarians eating only milk products and vegetables
  - Eat rice with most meals; may use chopsticks
  - Chinese: may use herbalist or acupuncturists before seeking medical help
  - Sodium intake is typically high (salting and drying foods and use of condiments)

- Other considerations
  - Values: group orientation, submission to authority, respect for elders, respect for past, modesty, conformity, tradition
  - May believe that prolonged eye contact is rude and invasion of privacy
  - Tend to be very modest; prefer same-sex clinicians
  - May nod without necessarily understanding (especially elderly Japanese patients)
  - May prefer to maintain a comfortable physical distance between the patient and the health care provider
  - Primary religions: Buddhist, Protestant, Catholic, Shinto (Japanese), Hindu and Islam (India), Taoism, Zen Buddhism, Confucianism

Latino American

- Health care belief and illness philosophy
  - May view illness as a sign of weakness, punishment for evil or retribution for shameful behavior
  - May use the terms “Hot” and “Cold” in reference to vital elements needed to restore equilibrium to the body
  - May consult with a curandero (healer) or voodoo priest (Caribbean)
  - May view pain as a necessary part of life and believe that enduring pain is a sign of strength (especially men)
  - May have open expression of grief, such as praying for the dead, saying the rosary
  - May use various amulets to protect individuals from evil
  - Family members are typically involved in all aspects of decision-making such as terminal illness
**Latino American**

- **Dietary practices**
  - May use herbal teas and soup to aid in recuperation
  - Traditional diet is basically vegetarian with an emphasis on corn, corn products, beans, rice, and breads
  - Select beans and tortillas are staples and may be eaten at every meal
  - Typically eat a lot of fresh fruits and vegetables, however, variety in diet may be limited
  - High occurrence of obesity, particularly central obesity, that raises the risk of diabetes and heart disease

- **Other considerations**
  - Values: group emphasis, extended family, fatalism, present orientation
  - May have fatalistic view of life
  - May see no reason to submit to mammograms or vaccinations
  - May need private room where grief can be expressed openly
  - May be modest (especially women)
  - Use same-sex family members as interpreters
  - Primary religion: Roman Catholic

**Native Americans**

- **Health care belief and illness philosophy**
  - May turn to a medicine man to determine the true cause of an illness, such as why a person is out of harmony with nature
  - May value the ability to endure pain or grief with silent stoicism
  - Views death as part of life cycle
  - Burial practices vary among tribal groups. Example: Navajos fear death and distance themselves from death
  - May avoid touching the dead or dying person
  - Many believe that the spirit of the dying person cannot leave the body until the family is there
  - Grief tends to be family oriented with all members assuming roles in the grieving process

- **Dietary practices**
  - Diet may be deficient in vitamin D because many suffer from lactose intolerance or don’t drink milk
  - Obesity and diabetes are major health concerns
  - Herbs are used in the treatment of many illnesses to cleanse the body of ill spirits or poisons

- **Other considerations**
  - Values: bonding to family or group, sharing with others, present orientation, extended family, cooperation with and acceptance of nature
  - May divert their eyes to the floor when they are praying or paying attention
  - Raised to be reserved and non-committal, may respond to assessment questions with silence or monosyllables
  - Belief system: characterized by intense relationship with nature

**Western Culture**

- **Health care belief and illness philosophy**
  - Value technology almost exclusively in the struggle to conquer disease
  - The strong shared belief in which the biomedical approach may result in serious barriers to communications with other cultures who choose to use alternative or complementary txs
  - Health is generally understood to be the absence, mini-immunization, or control of disease
  - Hospitalization may foster an atmosphere that requires the patient or family to be compliant, dependent, and vulnerable to get needs met.
  - Health care emphasis is shifting from treating diseases to disease prevention and health promotion
### Western Culture

#### Dietary practices
- Health care facilities often have standard dietary guidelines, which may or may not consider cultural variations.
- Eating utensils consist mainly of knife, fork, and spoon.
- Three meals eaten daily is typical.
- Values convenience and may substitute ready-to-eat (fast food) items typically low in nutrition.
- Eating out is a growing cultural trend. Meals eaten out tend to be higher in calories, fat, and sodium.
- Growing occurrence of obesity.

#### Other considerations
- Values: independence, self reliance and individualism, resistance to authority, nuclear or blended family, innovation, emphasis on youth, future orientation, competition.
- Health care is a culture of its own rituals and language often incomprehensible to patients and families of other cultures.

### Cultural considerations

- With the cooperation of its Commission on Legislation and Civic Action, a health care proxy form has been developed that reflects Jewish law. Part of the form acts as a directive that the surrogate decision maker refer all questions to the rabbinic authority who the patients themselves would consult were they able to do so. Along with designating a person to make health care decisions when the patient cannot, there’s a section for designating a specific rabbi to be consulted by the health care agent whenever questions involving Jewish law arise. According to Jewish tradition, preservation of life is considered to be paramount, surpassing all other commandments of the books of the Law.

### Maintaining oral care

- Maintain good oral throughout the patient’s life, even if they are unconscious.
- Frequent mouth cleaning with a wrung out swab or toothette dipped in a water/mouthwash mixture can remove debris and odor.
- Counsel Case Managers to request suction equipment for Home Hospice patients.

### Fatigue

#### A number of interventions are available to help ease the patient’s fatigue:
- Corticosteroids may decrease fatigue in cancer patients.
- Megestrol acetate can improve fatigue and general well-being within about 10 days in terminally ill patients.
- Thalidomide and mega-3 fatty acids can help manage cachexia and may decrease fatigue as well.
  - In patients with advanced HIV disease, thalidomide helps preserve the ability to function in daily activities.

#### Anemia
- Always assess for anemia if a patient complains of fatigue.
- Severe anemia, with a hemoglobin level less than 7 g/dl, usually warrants a blood transfusion.
- In patients undergoing chemotherapy, epotein alpha may help reduce fatigue.
  - A typical dosage is 10,000 units three times weekly increasing to 20,000 units three times weekly depending on the patient’s response.
Dyspnea

- Dyspnea becomes more likely-and more distressing-as the end of life approaches.
- Between 50-70% of dying patients experience it, sometimes with profound shortness of breath, copious secretions, fatigue, and coughing.

- Often, dyspnea in a dying patient has no clear cause.
- Many end-of-life complications can cause it, such as infections that cause fluid to accumulate around the lungs.
  - Fluid may also accumulate around the heart (pericardial effusion) or in the abdomen (ascites).
- Several medical treatments may contribute, such as fluids given to maintain hydration and nutrition that may interfere with breathing by causing unintentional fluid accumulation in the lungs and abdomen.
- If the underlying cause is intravenous fluids, you may need to stop them.
- Adding oxygen therapy may help, especially if you humidify the oxygen to help the patient breathe more restfully.

Respiratory secretions

- As death nears, patients may develop excess secretions in the upper and lower airways.
  - Conditions of the lungs or neck, pneumonia, heart failure, and renal failure all increase the risk of this symptom.
- Secretions can be reduced by giving an anticholinergic, such as hyoscyamine or transdermal scopolamine.
  - Make sure the patient receives frequent mouth care to offset the drying effects of anticholinergics.
- Coughing can be persistent and uncomfortable and lead to respiratory distress or increased secretions.
  - It may be caused by the patient’s drug regime, smoking, lung disease, or an irritable diaphragm.

- Drugs for constipation

  - Stool softener
    - Mixes fat and water in small and large intestines to soften stools
  - Bulk-producing laxative
    - Holds water in stool to maintain bulk, which stimulates peristalsis in the small and large intestines
  - Hyperosmotic laxative
    - Holds fluid in the colon, lowering pH and increasing peristalsis
  - Saline laxative
    - Attracts and holds water in the colon, increasing pressure in the small and large intestines and stimulating movement
  - Stimulant laxative
    - Acts directly on intestinal mucosa of the colon or nerve plexus; alters water and electrolyte secretion

Diarrhea

- May result from drugs, foods, fecal impaction, or the patient’s disease process
- Can predispose the patient to dehydration, electrolyte imbalance, and skin breakdown

- Facts about End-Stage Renal Disease (ESRD)

  - Almost half of people with ESRD are older than age 65.
  - More than 72,000 dialysis patients die each year.
  - About 1 in 4 patients who die of ESRD do so because they withdrew from treatment.
  - Most patients with ESRD also have other diseases that contribute to their deaths.
  - Almost two thirds of patients with ESRD die as hospital inpatients.
  - Few patients with ESRD die in hospice care.
### Course of chronic renal failure

- **Loss of nephron function leads to:**
  - Decreased excretion of metabolic wastes → increased end products of protein metabolism → increased blood urea nitrogen and serum creatinine levels, decreased urine creatinine clearance → itching, ecchymoses, purpura
  - Impaired erythropoietin production → decreased RBC production → decreased RBC life span → normochromic, normocytic anemia → drowsiness, lassitude, fatigue
  - Impaired phosphate excretion and vitamin D metabolism → hypocalcemia and hyperphosphatemia → secondary hyperparathyroidism → uremic osteodystrophy → demineralization of bone
  - Increased renin production → stimulation of adrenal cortex → increased aldosterone production → increased sodium and water reabsorption
    - Hypertension → hypertensive encephalopathy → retinopathy, headache
    - Fluid overload → heart failure → pulmonary edema

### Effects of end-stage renal disease

- **Renal system**
  - Oliguria results from a decreased glomerular filtration rate (GFR)
  - Hypercalcemia results from decreased GFR and metabolic acidosis
  - Metabolic acidosis results from the kidney’s inability to excrete hydrogen ions and reabsorb sodium and bicarbonate
  - Hyperphosphatemia and hypocalcemia develop because the kidney can’t excrete phosphorus
  - Hypotension and dehydration may occur during or after dialysis and may lead to further kidney ischemia

- **Cardiovascular system**
  - Hypertension results or worsens from fluid overload, stimulation of renin-angiotensin mechanism, or the absence of prostaglandins
  - Left ventricular hypertrophy, heart failure, or both may result from volume overload
  - Arrhythmias may result from hyperkalemia, hypermagnesemia, acidosis, and decreased coronary perfusion

- **Respiratory system**
  - Pulmonary edema results from heart failure and fluid overload
  - Pleuritis may result from toxic byproducts of metabolism

### Gastrointestinal system

- Anorexia, hiccups, nausea, and vomiting occur with uremia
- GI bleeding may result from coagulation abnormalities and uremic gastric irritation
- Peptic ulcer disease and symptomatic diverticular disease are common in chronic renal failure

### Neurologic system

- Peripheral neuropathy leads to burning feet or restless legs
- Seizures, forgetfulness, a shortened attention span, impaired reasoning and judgment, and central nervous system depression may result from circulation toxic substances

### Patients with cancer

- Cancer is the second leading cause of death in the US and the most common diagnosis in palliative and hospice care.
- The latter fact probably stems from several characteristics particular to cancer.
- It’s possible to predict the course of most forms of cancer relatively accurately, which gives physicians some confidence in making referrals to end-of-life care.
- End-stage cancer typically causes symptoms that can be relieved.
Lung, breast, prostate, and colon cancers cause most cancer deaths.
- Prostate cancer, the main hormone-related cancer in men, claims 30,000 lives yearly.
- Breast cancer kills 40,000 women yearly.
- Colon cancer kills 64,000 men and women yearly.
- Lung cancer, the leading cause of cancer deaths among Americans, kills 163,000 people yearly.

**Management**
- Treatments to reduce dyspnea in end-of-life settings are provided according to how the patient feels, not the amount of crackles you hear in his or her lung base.
- The most common and effective interventions are:
  - Oxygen therapy
  - Drug therapy
  - Environmental changes
  - Repositioning

**Hypercalcemia of malignancy**
- Normally, almost all of the body’s calcium stores are banked in bone. As metastases destroy bone, calcium is released into the bloodstream. Symptoms include:
  - Excessive thirst
  - Lethargy
  - Fatigue
  - Confusion
  - Muscle weakness
  - Nausea/vomiting
  - Loss of appetite

**Treatment of Mild-Moderate Hypercalcemia**
- Hydration dilutes the serum calcium level and increases urinary output of calcium. Mobility is also helpful in promoting resorption of serum calcium.
- For mild-to-moderate elevations of calcium, patients should try to increase their oral intake of fluids to 3-4 liters of water per day and maintain their mobility.

**Treatment of Severe Hypercalcemia**
- A patient severely compromised by his disease and nearing end of life may not want to be treated. In this case, symptomatic care with laxatives, antiemetics, and antipsychotics or anxiolytics for mental changes may be sufficient.
- A patient who is still active and can expect a significant number of weeks or months of good quality of life may choose active treatment. Immediately begin hydrating the patient with intravenous saline solution.
- Loop diuretics such as furosemide (Lasix) cause the kidneys to excrete more calcium.
- Increasing fluid intake and the use of loop diuretics can bring down corrected total serum calcium levels in the short run, however, the bisphosphonates are newer treatments.
- Pamidronate disodium (Aredia), and I.V. drug, is the first choice for long-term calcium reduction to lessen symptoms and improve quality of life.
Skin lesions in patients with cancer

- Wounds of terminally ill patients will not heal or improve. Care should focus on palliation and keeping the patient comfortable, clean, and odor free.
- This may involve treating pain, bleeding, oozing, necrosis, or infection at the wound or tumor site. Existing wounds may worsen or new wounds may develop, partly because the patient is eating less.
- As a result, the patient’s serum albumin levels fall and rapid skin breakdown occurs, especially on bony prominences and areas of unrelieved pressure.
- The problem is worsened because dying patients move less often and are unable to reposition themselves to lessen pressure during sleep.

Thrush

- Skin around the mouth or perineal area may develop candidiasis (thrush) particularly in patients with recued immunity as a result of chemotherapy, drug- or illness-induced dry mouth, or diabetes. Thrush of the oropharynx or esophagus may also occur in these patients.
- Treat external lesions of nystatin (Mycostatin) or clotrimazole (Lotrimin). Mild oropharyngeal and esophageal lesions can be treated with either a nystatin suspension using a “swish and swallow” technique, or clotrimazole troches. Patients with low fluid intake typically do not tolerate the troches.
- Systematic therapy can be used for more severe cases when the patient is in a lot of pain, drugs include fluconazole (Diflucan) and itraconazole (Sporanox).

Congestive Heart Failure

- About 5 million Americans have heart failure, and despite advances in treatment, deaths from heart failure continue to rise. About 1 in 4 people die within 1 year of being diagnosed, many from sudden cardiac death. The rest decline more slowly, with symptoms increasing as cardiac function decreases.

Understanding heart failure

- Heart failure is a complex condition that results from any structural or functional heart disease that reduces ejection fraction – the percentage of blood in heart that is expelled with each ventricular contraction.
- Usually, heart failure results from impaired function of the left ventricle. It may also result from diseases of the pericardium, myocardium, endocardium, or great vessels. Coronary artery disease, hypertension, valvar heart disease, and dilated cardiomyopathy are common causes of heart failure.

No matter what the cause of heart failure, if ejection fraction declines too far, the body’s need for oxygen goes unmet and the patient develops dyspnea, fatigue, and other symptoms.

Keep in mind, however, that symptoms may not always match the degree of ventricular impairment. Some patients have symptoms of heart failure with a normal-size left ventricle and normal ejection fraction (diastolic dysfunction); others have symptoms only with severe left ventricular dilation, markedly reduced ejection fraction, or both (systolic dysfunction).

New York Heart Association Classification of heart failure

<table>
<thead>
<tr>
<th>Class</th>
<th>Characteristics</th>
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<tr>
<td>I</td>
<td>No limitation of activities</td>
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<tr>
<td></td>
<td>No symptoms with ordinary activities</td>
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<tr>
<td>II</td>
<td>Slight, mild limitation of activity</td>
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<tr>
<td></td>
<td>Comfortable at rest or with mild exertion</td>
</tr>
<tr>
<td>III</td>
<td>Marked limitation of activity</td>
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<tr>
<td></td>
<td>Comfortable only at rest</td>
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<tr>
<td>IV</td>
<td>Discomfort and symptoms with any activity</td>
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<td>Should be at complete rest, confined to bed or chair</td>
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Depression in patients with heart failure

- We know that patients with heart failure have higher rates of depression than the general population. Between 11% and 25% of outpatients with heart failure develop depression; between 35% and 70% of inpatients develop it.
- Most depressed heart failure patients receive no treatment for their depression, and they are no more likely to see a mental health specialist than patients who are not depressed.
- Depression and anxiety tend to increase and peak between 1 month and 3 days before death.

Morphine: not just a pain reliever

- Morphine does much more than simply relieve pain. Because it acts as a vasodilator, it can increase cardiac output.
- It’s also a respiratory depressant, so it suppresses the horrible drowning sensation patients experience while decreasing the respiratory drive for that next, precious breath.
- When oral morphine is provided for patients, arterial blood gas values actually improve, proving the efficacy of morphine for dyspnea.
- Finally, morphine can produce a mild, but welcome, euphoria, relieving feelings of terror and panic.

Patients with neurologic disease

- Amyotrophic lateral sclerosis (ALS)
- Alzheimer’s disease
- Huntingdon’s disease

Amyotrophic lateral sclerosis (ALS)

- Progressive, degenerative disease
- AKA Lou Gehrig’s disease
- Most common motor neuron disease in the US, with about 5,000 new cases diagnosed each year
- More common in men and is usually diagnosed between ages 40 and 60
- About half of those who develop ALS die within 2-5 years after symptoms start, usually from respiratory failure

Progressive symptoms of ALS

- Upper motor neuron dysfunction
  - Spastic, weak muscles with fasciculations and increased deep tendon reflexes.
- Lower motor neuron dysfunction
  - Muscle flaccidity, paresis, paralysis, and atrophy
- Death of motor neurons results in axonal degeneration, demyelination, glial proliferation, and scarring along the corticospinal tract.

Special care issues in ALS

<table>
<thead>
<tr>
<th>Issue</th>
<th>Cause</th>
<th>Treatment</th>
</tr>
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<tbody>
<tr>
<td>Drooling</td>
<td>Bulbar dysfunction</td>
<td>- Antidepressive at bedtime &lt;br&gt; - Glycopyrrolate (Robinul) and hyoscamine (levisin drops) minimize cognitive failure &lt;br&gt; - Transdermal scopolamine helps with compliance (patch only needs to be changed every 3 days)</td>
</tr>
<tr>
<td>Dyspnea and hypoventilation</td>
<td>Weakened diaphragm and accessory respiratory muscles</td>
<td>- OS rarely used; may worsen hypoventilation &lt;br&gt; - BiPAP used intermittently or during sleep &lt;br&gt; - Invasive ventilation &lt;br&gt; - During terminal care, alivan and morpheme may be given for comfort to reduce anxiety</td>
</tr>
<tr>
<td>Dysarthria</td>
<td>Weakened muscles of articulation</td>
<td>- Alphabet charts and computer technology &lt;br&gt; - Code blinking used at end stages</td>
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<tr>
<td>Insomnia</td>
<td>Immobility, muscle cramping, respiratory insufficiency, anxiety, and depression</td>
<td>- BiPAP helps if desaturation is occurring &lt;br&gt; - Using sleep aids cautiously is BiPAP is not in place &lt;br&gt; - Antidepressants may be helpful</td>
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Alzheimer’s disease

- Form of dementia marked by progressive deterioration of:
  - Intellectual function
  - Emotional control
  - Social behavior
  - Motivation
- Progression rate varies, but eventually the patient will be unable to make judgments and care for themselves.
- Patients may live many years with the disorder, but the average time from diagnosis to death is 8 years.
- Most common degenerative neurologic illness and most common cause of cognitive impairment in adults; currently affects more than 4 million people in the US
- Early-onset Alzheimer’s disease, which is rare, can affect adults ages 30-60. Usually, however, it affects people older than age 60.

Staging Alzheimer’s disease

- Mild
  - Trouble with word- or name-finding
  - Trouble retaining names of new acquaintances
  - Trouble training written material
  - Misplaces or loses valuable objects
  - Decreased ability to plan and carry out activities
  - Some trouble maintaining social conversation
  - Generally intact judgment
  - Declining work skills

- Moderate
  - Inability to remember recent events and larger current events
  - Trouble counting backward from 100 by 7s
  - Decreased ability to handle finances
  - Declining memory of personal history
  - Trouble completing complex tasks
  - Withdrawal in social situations
  - Clouded judgment for complex issues
  - Deficits in work skills

- Moderately severe
  - Inability to remember address or phone number however, able to remember and name family members
  - Trouble with simple math and reading
  - Decreased ability to identify date and season
  - Decreased memory of recent personal history
  - Needs assistance with simple tasks
  - May respond inappropriately to social questions
  - Impaired judgment about personal safety
  - Inability to work
  - Declining ability to dress appropriately to season or follow social conventions for eating in groups
  - Personality changes

- Severe
  - Disoriented to place and time (can remember own name)
  - Possibly impaired sleep-wake cycle
  - Declining interests in reading or other former activities due increased confusion
  - Inability to recall date, significant seasons, or holidays
  - Inability to recount personal history
  - Inability to carry out simple tasks
  - May forget family or caregiver names but recalls familiar faces
  - Inappropriate judgment in familiar situations or may wander
  - Trouble with dressing, grooming, eating with utensils
  - Personality changes (i.e., suspicion/paranoia, anxiety, delusions, anger)
  - Possible start of urinary or fecal incontinence
End stage
- Disoriented to person, place, and time
- No interest in former past times or ability to reason
- Decreased evidence of awareness of surroundings
- Forgets family and familiar faces
- Inability to participate in daily activities
- Inability to speak or very rarely speaks intelligibly
- No judgment skills
- Needs help with all ADLs, forgets how to swallow or chew food or loses airway protection
- Persistent personality changes
- Complete incontinence
- Inability to walk and gradual inability to sit upright

Huntington’s disease
Progression of disease
- Progresses slowly over 10-25 years
- Cells in caudate nucleus and putamen are destroyed
- Other areas of the brain such as the frontal lobe may atrophy as well
- Motor symptoms parallel personality and mood changes
- Often patients describe feeling restless and fidgety
- Choreiform movements progressively worsen eventually involving the entire body
- Environmental stimuli and stress may aggravate symptoms
- Breathing becomes impaired due to decreased movement of the diaphragm

End-stage neurologic disease
Starting palliative care
- Dementia patients are at risk for receiving poor end-of-life care
  - Difficult to establish when life expectancy has reached 6 months, which is the requirement for entering hospice care
- Advancing disease places great burdens on caregivers
- Palliative care team interventions are more helpful than late referral for hospice care
- Major supportive and rehabilitative resources
  - Home health nurses, social work, physical, occupational, speech, and respiratory therapies
  - Can teach alternative ways for ADLs based on individual patients’ needs

Managing symptoms
- Dysphagia
  - Changing patients’ diets to soft foods and thickened liquids
  - Patient and family works with SLPs to improve safety and swallowing while eating
  - For ALS patients, PEG tubes can maintain nutrition and weight for a period of time however, they can become harmful to the patient by causing overfeeding and discomfort
- Asthenia
  - Profound tiredness after usual or minimal effort
  - Described as generalized weakness
  - Important to determine if there are any specific causes such as depression, infection, and anemia
  - OT and PT are consulted regarding energy conversation techniques and modification of ADLs

Chronic Obstructive Pulmonary Disease
- COPD is a slow progressive disorder
- Affects more than 14 million Americans
- 4th leading cause of death in the US
- Disorders that obstruct air movement
  - Emphysema
  - Chronic bronchitis
  - Aspergillus
  - Pseudomonas
- Categorized based on severity

Emphysema
- Destruction of alveolar walls causes irreversible enlargement of air spaces distal to terminal bronchioles and decreased elastic recoil of lungs
- Prognosis: most common cause of death from respiratory disease in the US
- Causes and pathophysiology
  - Cigarette smoking and congenital deficiency of alpha1-antitrypsin
  - Recurrent inflammation and release of proteolytic enzymes from lung cells damage and ultimately destroy bronchiolar and alveolar walls. Loss of supporting lung structure results in decreased elastic recoil and airway collapse on expiration. Destruction of alveolar walls decreases surface area for gas exchange.
- Clinical features
  - Insidious onset, main symptom: dyspnea
  - Other signs and symptoms of long-term disease: anorexia, weight loss, malaise, barrel chest, use of accessory muscles of respiration, prolonged expiratory period with grunting, pursed-lip breathing, and tachypnea
  - Complications: recurrent respiratory tract infections, cor pulmonale, and respiratory failure
**Chronic bronchitis**
- Excessive mucus production and productive cough for at least 3 months yearly for 2 consecutive years
- Prognosis: significant airway obstruction possible but uncommon
- Causes and pathophysiology
  - Severity depends on amount and duration of smoking; respiratory infection worsens symptoms
  - Hypertrophy and hyperplasia of bronchial mucous glands, increased goblet cells, damage to cilia, squamous metaplasia of columnar epithelium, and chronic leukocytic and lymphocytic infiltration of bronchial walls, widespread inflammation, distortion, narrowing of airways, and mucus in the airways produce resistance in small airways and cause severe ventilation-perfusion imbalance
- Clinical features
  - Insidious onset, main symptoms: productive cough and exertional dyspnea
  - Other signs:
    - Upper respiratory infections with increased spumon production and worsening dyspnea, which take progressively longer to resolve; copious sputum (gray, white, or yellow), weight gain from edema; cyanosis; tachypnea; wheezing; prolonged expiratory time; and use of accessory muscles of respiration
  - Complications: recurrent respiratory tract infections, cor pulmonale, and polycythemia

**Asthma**
- Bronchial reactivity to many stimuli is increased, which produces episodic bronchospasm, airway obstruction, and airway inflammation
- Childhood onset usually related to certain allergens. Adult onset usually without distinct allergies
- Status asthmaticus: acute attack with severe bronchospasm that doesn’t respond to broncho-dilator therapy
- Prognosis: childhood onset usually has no adult symptoms; adult onset is usually persistent with occasional severe attacks
- Causes and pathophysiology
  - Reversible airway inflammation usually occurs in response to an allergen. Swelling of membranes, bronchospasm, and production of mucus obstruct airways. Activated mast cells release chemical mediators. Upper airway infection, exercise, and anxiety can cause an asthma attack; nocturnal flare-ups are common. Airway obstruction may result from spasm of bronchial smooth muscle that narrows airways, inflammatory edema of the bronchial wall, and thickening of tenacious mucoid secretions, particularly in status asthmaticus.
- Clinical features
  - History of intermittent attacks of dyspnea and wheezing. Mild wheezing progresses to severe dyspnea, audible wheezing, chest tightness, and cough that produces thick mucus.

**Aspergillus**
- A common mold that lives indoors and outdoors, most people breathe in Aspergillus spores every day without getting sick
- Some types are mild, but some are very serious
- Causes and pathophysiology
  - Most often occurs in people who have cystic fibrosis, asthma, tuberculosis, COPD, sarcoidosis, and weakened immune systems, such as people who have had a stem cell transplant or organ transplant, are getting chemotherapy for cancer, or are taking doses of corticosteroids
- Symptoms
  - Vary depending on the type
  - Wheezing, shortness of breath, cough, fever, stuffiness, runny nose, headache, reduced ability to smell, weight loss, fatigue, chest pain
  - Other symptoms: can develop if the infection spreads from the lungs to other parts of the body
  - http://www.cdc.gov/mycotoxins/aspergillus.html

**Pseudomonas**
- Opportunistic pathogen, meaning that it exploits some break in the host defenses to initiate an infection
- Causes and pathophysiology
  - Caused by strains of bacteria found widely in the environment; the most common type is Pseudomonas aeruginosa
  - Usually occur in people in the hospital and/or with weakened immune systems; infections of the blood, pneumonia, and infections following surgery can lead to severe illness and death in these people
  - However, can develop mildly and present as ear infections, especially in children or eye infections in persons using extended-wear contact lenses
  - http://www.textbookofbacteriology.net/pseudomonas.html
  - https://www.cdc.gov/hai/organisms/pseudomonas.html

**Dyspnea**
- As COPD progresses, functioning lung tissue decreases and lung compliance worsens-usually leading to dyspnea
- Physical signs:
  - Labored breathing
  - Shortness of breath at rest or with exertion
  - Increased respiratory rate (more than 24 breaths per minute)
  - Increased respiratory effort
  - Altered lung sounds
- Later stages of COPD, patient may be using accessory muscles of respiration or may complain of pain with breathing

**Causes of restrictive lung disease**

**Intrapulmonary causes**
- Atelectasis
- Neoplasm
- Pneumonia
- Pulmonary fibrosis
- Sarcoidosis
- Surgical lung resection

**Extrapulmonary causes**
- Amyotrophic lateral sclerosis
- Congenital wall deformities
- Excessive obesity
- Head or spinal cord injury
- Muscular dystrophy
- Myasthenia gravis
- Pleural effusion
- Sleep disorders
Management
- Treatment depends on the specific cause of the disease
- Oxygen may be needed to correct altered gas exchange.
  Priority nursing goals are:
  - Maintaining a patent airway
  - Providing adequate oxygenation based on patient need
  - Helping the patient maintain activities of daily living and physical function
- End stages develop when hypoxemia becomes severe and less responsive to therapy
  - Cor pulmonale, pulmonary hypertension, and respiratory failure occur late in the disease
- End-of-life care
  - Palliative care involves treatments to reduce the effects of the underlying condition as well as supportive measures for cardiovascular effects

Caring for Individuals
- “The sensitivity (or lack of it) of professionals in telling family members bad news will be remembered long after the event and may be relived repeatedly as the survivor grieves the loss.”

The age-continuum
- SPICT- Supportive and Palliative Care Indicators Tool
- ID and recognize key points in clinical trajectory
- Recognize individuals with chronic and terminal diseases

Case Studies