

Comfort

Promote comfort during end-of-life transition through pain and symptom relief.



Symptoms Other Than Pain

Diana J. Wilkie, PhD, RN, FAAN

Relieve distressing symptoms at end of life.

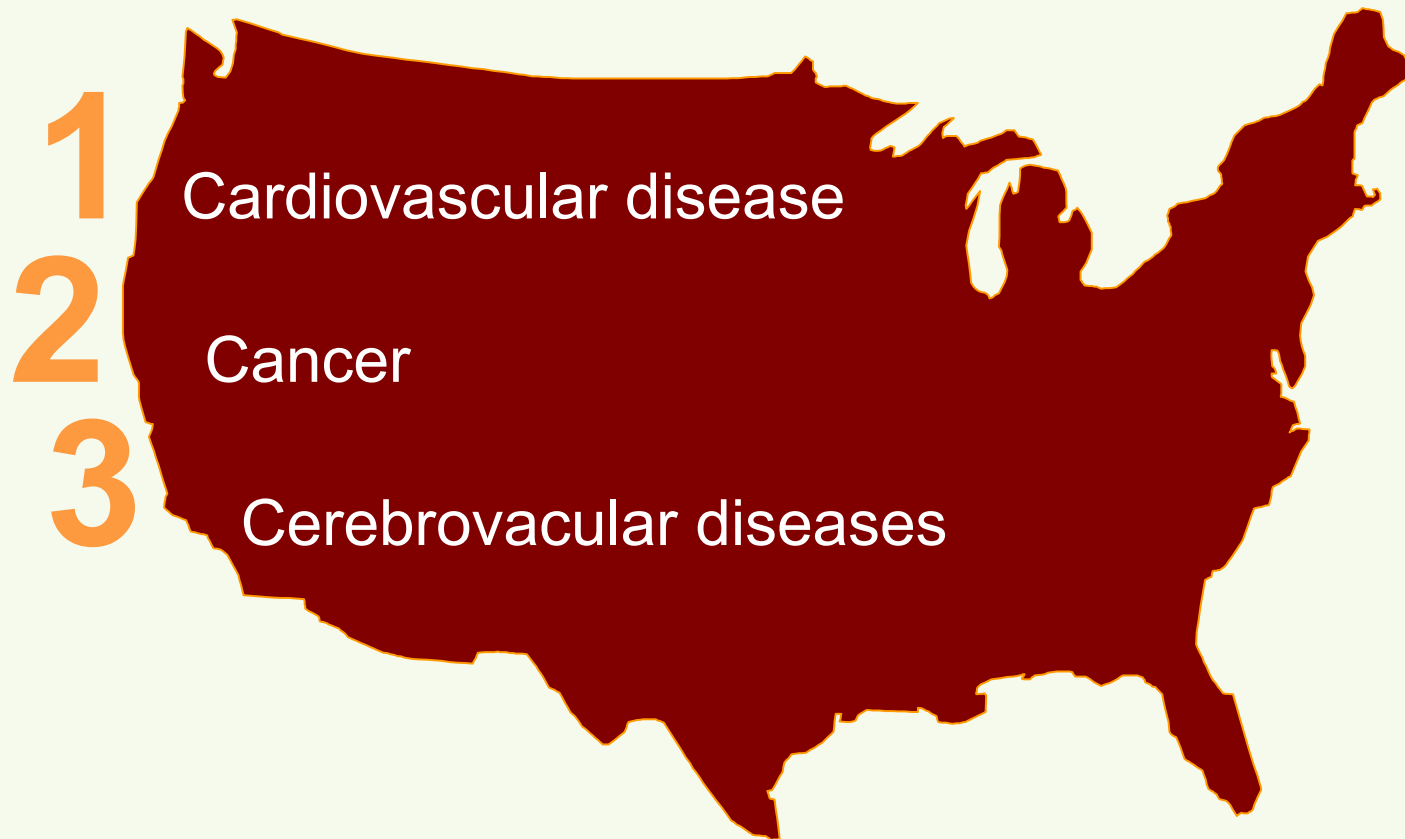
Signs & Symptoms of Approaching Death

- The dying process is variable depending on *individual* and *family* characteristics
 - There are predictable physical, physiologic, and emotional changes
 - During this important phase, the nurse serves as a **consultant, collaborator, coach, or guide** to assist the patient to achieve symptom relief
 - Knowing what to expect is vital



Causes of Death

- The three leading causes of death in adult Americans:

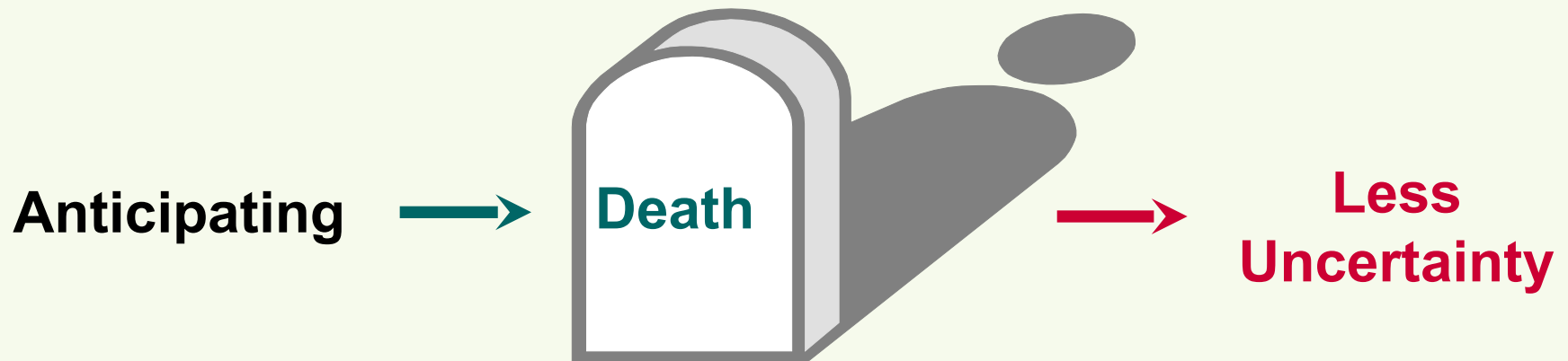


Signs & Symptoms of Imminent Death

System	Etiology of Failure	Signs	Symptoms
Circulatory	Myocardial infarction, arrhythmias, blood loss	Reduced tissue perfusion (decreasing blood pressure, tachycardia, irregular pulse, reduced mentation, cooling and cyanosis of the extremities, reduced urinary output, pulmonary and peripheral edema)	Chest pain, dyspnea
Pulmonary	Pneumonia, thromboembolism, pleural effusion, pulmonary edema, pulmonary or tracheal obstruction, depression of medullary respiratory centers	Hypoxia with hypercapnia (slowed mentation, confusion, restlessness, coma) Orthopnea, irregular or rapid breathing, tachycardia, use of accessory muscles to breathe, excessive secretions	Apprehension, dyspnea, cough, fear of choking or drowning

Physical, Physiological & Emotional

- Anticipating the changes and symptoms and preparing the patient and family to expect and deal with them decrease the uncertainty that often plagues this time of life



Signs of Approaching Death: The Last 48 Hours

1. Reduced level of consciousness

2. Taking no fluids or only sips

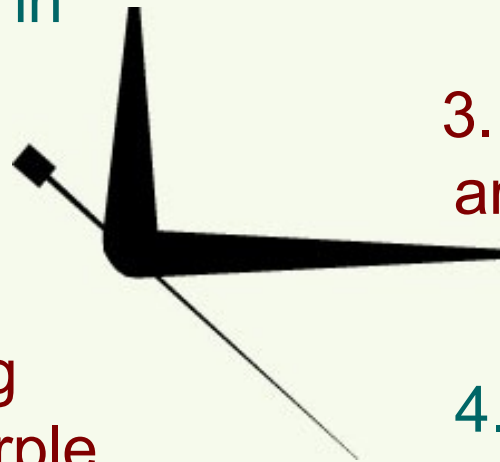
6. Bubbling sounds in
throat and chest
(death rattle)

3. No urine output or small
amount of very dark urine
(anuria or oliguria)

5. Progressing
coldness and purple
discoloration in legs
and arms

4. Progressing coldness
and purple discoloration in
legs and arms

(Blues & Zerwekh, 1984)

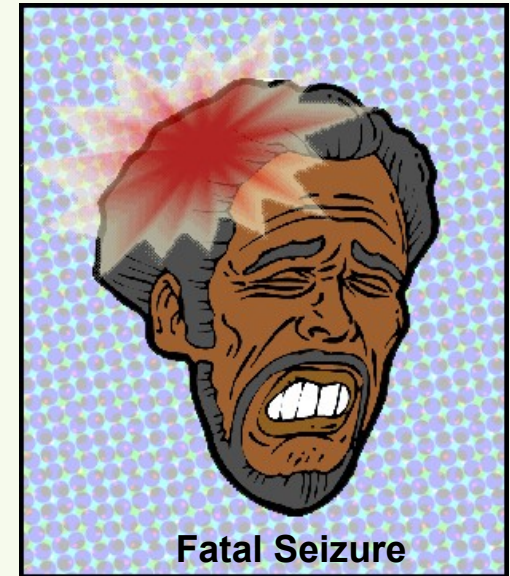
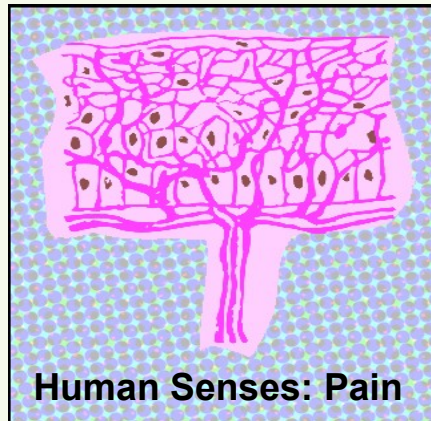


Uncommon Uncontrollable Events Prior to Death

→ Uncontrollable pain (when the pain was controlled prior to death)

→ Fatal Hemorrhage

→ Seizures



Dying Person's Bill of Rights

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness, however, changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however challenging this might be.
- I have the right to express my feelings and emotions about my approaching death, in my own way.
- I have the right to participate in decisions concerning my care.
- I have a right to expect continuing medical and nursing attention even though “cure” goals must be changed to “comfort” goals.

Dying Person's Bill of Rights II

- I have a right not to die alone.
- I have a right to be free from pain.
- I have a right to have help from and for my family accepting my death.
- I have the right to die in peace and dignity.
- I have the right to retain my individuality and not be judged for my decisions, which may be contrary to the beliefs of others.
- I have the right to discuss and enlarge my religious and/or spiritual experiences regardless of what they may mean to others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have a right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Signs of Death


- Cessation of heart beat and respiration
- Pupils fixed and dilated
- No response to stimuli
- Eyelids open without blinking
- Decreasing body temperature
- Jaw relaxed and slightly open
- Body color is a waxen pallor




After Death Care: Various Cultural & Religious Groups

- Cultural and religious beliefs and practices are important to nursing care at the end-of-life and immediately after death
- The following tables offer a common rituals and customs for the following cultural and religious groups:
 - **American Indians, African Americans, Mexican Americans, Catholics, Buddhists and Jews**


Death Rituals & Customs Observed: American Indians

Cultural Group	Ritual or Custom at Time of Death	Ritual or Custom Immediately After Death
<p>American Indians</p> 	<ul style="list-style-type: none"> • Family may hug, touch, sing, stay close to the dead person • Wailing, shrieking and other outward signs of grieving many occur, a startling contrast in demeanor compared to pre death display of positive attitudes 	<ul style="list-style-type: none"> • Turning or flexing the body, sweetgrass smoke or other purification • Family stays with the body • Some want the body to rest at place of death for 36 hours to allow the soul to depart. Women may want to prepare and dress the body • Some do not allow the mortuary to prepare the body. The family wraps the body for burial • Some avoid contact with the dead person and his/her possessions. Others want all possessions including collected hair and nail clippings • Autopsy not desired • Hair cutting may be done as a sign of mourning




Death Rituals & Customs Observed: African Americans

Cultural Group	Ritual or Custom at Time of Death	Ritual or Custom Immediately After Death
<p data-bbox="170 511 369 582">African Americans</p> 	<ul data-bbox="513 505 1103 739" style="list-style-type: none"> • Family may hug, touch, and be close to family and friends • May get agitated or emotional when anxious • Person may be brought to hospital when death is imminent 	<ul data-bbox="1199 505 1779 939" style="list-style-type: none"> • Report death to oldest family member, spouse or parent • Open and public emotions expected after death • May believe that death at home brings bad luck • Prefer to have body cleaned by professionals • Cremation avoided • Organ and blood donations not common

Death Rituals & Customs Observed: Mexican Americans

Cultural Group	Ritual or Custom at Time of Death	Ritual or Custom Immediately After Death
<p data-bbox="170 511 369 582">Mexican Americans</p> 	<ul data-bbox="513 505 1078 782" style="list-style-type: none"> • Extended family members obligated to visit dying person • Spirit may get “lost” in hospital and not return home • Prayers at bed of dying person • Wailing is acceptable as a sign of respect 	<ul data-bbox="1199 505 1763 901" style="list-style-type: none"> • Death important spiritual event • Extended family may help prepare body • Family says good-bye before dead person is taken to the morgue • Organ donation not accepted • Autopsy must be decided by entire family, usually not accepted

Death Rituals & Customs Observed: Religions

Spiritual or Religious Group	Ritual or Custom at Time of Death
Buddhist 	<ul style="list-style-type: none"> • Dying person's state of mind at moment of death influences rebirth • Many diverse rituals including last rite chanting at bedside, family members remaining with body • Cremation often preferred • Pregnant women should avoid funerals • Priest, monk or layperson may carry out traditions
Catholic 	<ul style="list-style-type: none"> • Permissible to refuse treatment that carries risk or would prolong a burdensome life • Euthanasia forbidden • Sacrament of the Sick [Extreme Unction] mandatory • Organ or body donation allowed
Jewish 	<ul style="list-style-type: none"> • All body parts must be buried together • Body may be ritually washed by members of Ritual Burial Society • Cosmetic restoration or embalming discouraged • Burial as soon as possible; cremation not appropriate • Euthanasia prohibited; autopsy permitted if legally required

Dyspnea

- **Dyspnea** is defined as:
 - Difficult or labored breathing
 - From the perspective of the patient:
 - An unpleasant awareness of breathing, a sense of breathlessness or sensation of shortness of breath
- Dyspnea is a subjective experience, like pain
 - Only the person experiencing it can know exactly what it feels like
- Health professionals show a great deal of ambiguity in the interpretation of dyspnea



Dyspnea: Mechanisms & Etiology

- Dyspnea is a symptom associated with a number of diseases and conditions
 - **Example:** Obesity is associated with dyspnea on exertion
 - Increased ventilatory demand, impaired mechanical responses, and combinations of the two lead to dyspnea
- Dyspnea at rest contributes to social isolation and decreased quality of life
- The neural mechanisms of dyspnea are unknown
- It is known that delta opioid receptors are present in lung tissues, which may partially explain the effectiveness of opioids in treatment of dyspnea

Prevalence of Dyspnea by Disease

Disease	Prevalence of Dyspnea
Chronic Obstructive Pulmonary Disease (COPD)	95%
Congestive Heart Disease	61%
Stroke	37%
Amyotrophic Lateral Sclerosis	47% to 50%
Dementia	70%
Outpatient Cancer	50%
Terminal Cancer	45% to 70%
Lung Cancer	90%

(Dudgeon, 2001)

Dyspnea: Assessment

- Visual analogue scales and 0 to 10 number scales successfully measure the intensity of the dyspnea sensation
 - It is important to seek intensity ratings with various levels of activity (pattern of dyspnea)
 - Walking outside, walking up stairs, eating, talking etc.
- Verbal descriptors such as chest tightness may prove useful in the future with additional research
- Dyspnea associated with life threatening illness evokes affective responses including:
 - Panic, frustration, worry, anxiety, anger, and depression

Dyspnea: Pharmacologic Management



- Primary control of dyspnea in people with life threatening illness includes:
 - Treatment for the underlying etiology of the dyspnea (when possible), and treatments focused on symptom relief
- Opioids, corticosteroids, and anxiolytics have been effective in reducing dyspnea sensation
- **Morphine** treatments for those without pain:
 - Typically **2.5 mg to 5 mg orally every four hours** and a double dose at bedtime will control dyspnea in most patients
 - Increase based on patient response

Dyspnea: Pharmacologic Management II



- **Corticosteroids** such as **dexamethasone 8 mg daily** also relieve dyspnea associated with an inflammatory response
 - Superior vena cava syndrome and pulmonary metastatic lymphadenopathy
- **Chlorpromazine** reduces dyspnea without affecting ventilation or causing sedation
 - Effective alone or combined with morphine for treatment of dyspnea in COPD or advanced cancer
- **Scopolamine** effectively reduces secretions and also sedates the patient. The effective dose of scopolamine is **0.4 mg to 0.6 mg I.M. every four hours**, or **2 mg to 4 mg every 24 hours** by continuous subcutaneous infusion
 - **Transdermal patches** deliver 0.5 mg every 24 hours for a period of 72 hours

(Schiro, 1992)

Dyspnea: Nonpharmacologic Management

- Oxygen
- Increasing air movement
 - A portable fan directed towards patient's face
- Positions that increase the ventilatory capacity
 - Improve the function of the diaphragm and accessory muscles
- Avoid all activity, including talking



Fatigue and Weakness (Asthenia)

- **Fatigue** is a common symptom experienced by people with life limiting illness
- As illnesses progress, fatigue causes people to curtail first the pleasurable and leisure activities and then other activities of daily living
- The dying person may not have sufficient strength or energy to flush a toilet
- The impact of these activity restrictions compromises the person's quality of life



(Dean & Anderson, 2001)

Prevalence of Fatigue by Disease

Disease	Prevalence of Fatigue
Coronary Artery Disease	41% to 77%
Cancer	60% to 99%
Renal Hemodialysis	72%
General Palliative Care	51%
AIDS	50%
Children with Cancer	50%

(Dean, 2001)

Fatigue: Mechanisms & Etiology

- Fatigue is conceptualized as a multifaceted symptom with physiological, sensory, affective, cognitive, and behavioral components
- Several theories have been proposed to explain the fatigue associated with various illnesses
- **Unknown:** Whether the mechanisms are similar or different by disease
- Some evidence that is inconclusive, includes:
 - Accumulation of lactate or cytokines, anemia with depletion of red blood cells or hemoglobin, or neural mechanisms

Fatigue: Assessment

- Many assessment tools to measure fatigue
 - Some are multidimensional, comprehensive measures of fatigue
 - Screening tools such as the Schwartz Cancer Fatigue Scale
- As with pain, fatigue assessments that focus *only on the intensity* of the fatigue provide *limited* perspective
- Assessing the following are critical:
 - **Location** (parts of body sensed as fatigued), **intensity** (0 to 10 scale or other intensity scale), **quality** (how the fatigue feels), and **pattern** (onset, duration, aggravating factors, alleviating factors)
 - Additional data about the patient's history, physical exam, or laboratory findings

Schwartz Cancer Fatigue Scale: A 6-Item Screening Tool for Fatigue

SCFS-6

The words and phrases below describe different feelings people associate with fatigue. Please read each item and circle the number that indicates how much fatigue has made you feel in the past 2 to 3 days.

1 = not at all
 2 = a little
 3 = moderately
 4 = quite a bit
 5 = extremely

Tired	1	2	3	4	5
Difficulty thinking	1	2	3	4	5
Overcome.....	1	2	3	4	5
Listless	1	2	3	4	5
Worn out	1	2	3	4	5
Helpless 1	2	3	4	5	

(©1997 A. L. Schwartz)

Fatigue: Pharmacologic Management



- Virtually no information is available regarding pharmacologic management of fatigue
- **Exception:** People with chronic renal failure or cancer
 - In these two populations, fatigue has been reduced by the epoetin, which stimulated red blood cell production
- Pharmacologic management of fatigue is an understudied area and virtually nonexistent related to end-of-life care

(Littlewood, 2001)

Fatigue: Nonpharmacologic Management

- Many interventions are suggested to alleviate fatigue, but with the exception of exercise, none have been tested
- Exercise, in most cases, is a neglected area of the treatment plan for people facing the end-of-life transition
 - Health care providers often fail to advise patients about exercise and the benefits that can be gained from it
- Inactivity may in fact be the trigger for marked fatigue and weakness experienced by patients



Fatigue:

Nonpharmacologic Management II

- **Aerobic exercise** may prevent reduced functional capacity, nausea, fatigue, decreased self-esteem, and other quality of life issues that confront cancer patients
- Balancing energy reserves with energy expenditures is the goal for the management of fatigue
 - **Walking** and other types of low-impact exercise
- **Weight training** early in the illness trajectory to improve muscle tone and function, particularly in the elderly
- **Distraction techniques** may reduce fatigue
 - Taking car rides, listening to music, praying, meditating, engaging in hobbies, spending time with family and friends

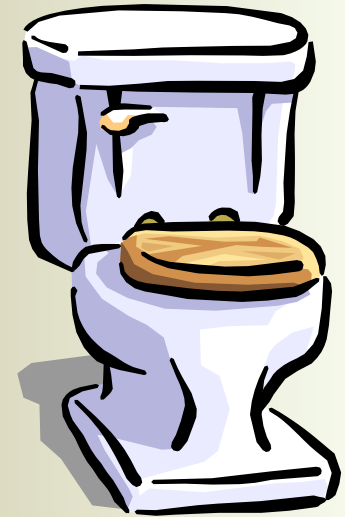
Prevalence of Constipation

Population Group	Prevalence of Constipation
Adults with Cancer	78%
Diabetes	10% to 17%
Children with Cancer	6 to 50%
Older Adults	72%
Children	11%
General Population	10 to 28%

(Collins, 2000)

Constipation: Mechanisms & Etiology

- **Constipation** is a problem for many people with life-limiting illness
- There are many causes of constipation:
 - Mechanical, metabolic and neural processes associated with the life threatening disease
 - Dietary alterations
 - Immobility
 - Drug therapy side effects and combinations of these factors are the typical etiologies of constipation at end of life
- Its prevention is easier and more desirable to all involved than treatment after it occurs



Constipation: Assessment

- McMillan and colleagues developed and tested a simple 8-item tool to measure self-reported constipation
- Establishing the person's normal pattern prior to the illness is also important to judge the degree to which current bowel patterns are altered
- Bowel functions are variable from person to person
 - Establishing the baseline pattern for the person with life-limiting illness is a critical assessment not documented by the Constipation Assessment Scale
- Documentation of other history and physical exam data is essential

(McMillan & Williams, 1989)

Constipation Assessment Scale

Directions: Circle the appropriate number to indicate whether *during the past three days* you have had NO PROBLEM, SOME PROBLEM or a SEVERE PROBLEM with each of the items listed

Item	no problem	some problem	severe problem
1. Abdominal distention or bloating	0	1	2
2. Change in amount of gas passed rectally	0	1	2
3. Less frequent bowel movements	0	1	2
4. Oozing liquid stool	0	1	2
5. Rectal fullness or pressure	0	1	2
6. Rectal pain with bowel movement	0	1	2
7. Smaller stool size	0	1	2
8. Urge but inability to pass stool	0	1	2

(McMillan & Williams, 1989)

Constipation: Pharmacologic Management



- Vigilance is required to prevent constipation
- **The cornerstone of treatment:** Anticipating that constipation will occur in people if dietary and fluid intake is altered
- Prevention of constipation requires the expectation that constipation will be a side effect of all opioids and many of the adjuvant analgesics
- Patients should expect a bowel movement no less than every three days regardless of intake and activity level

Constipation: Two Rules for Management

- 1. Anticipate and prevent constipation**
- 2. Reverse specific cause of constipation with specific therapy**

Constipation: Commonly Effective Pharmacologic Agents

Generic Drug (Trade Drug) [Alternate Form]	Typical Dose	Onset of Effect	Comments
Senna (Senokot) [Senokot-S with docusate (Colace)]	1-8 (max 10) tabs po based on opioid dose and response	6-12 hr	1 tab reverses constipating effect of Morphine 15 mg po or 120 mg Codeine po. Activated in large intestine by bacterial degradation, stimulates submucosal nerve plexus and reduces sodium and water absorption
Casanthranol with docusate (Peri-Colace)	1-4 tabs po 10-15 mg po	6-12 hr	
Bisacodyl (Dulcolax)	10-15 mg pr	6 hr	Strong stimulation effects with cramping, urgency, incontinence
Lactulose (Chronulac)	15-30 ml po	15-60 min	
Phenolphthalein with docusate (Doxidan)	1-4 tabs po	1-3 hr	Liver and colon metabolism; effect difficult to predict and control.

Constipation: Treatment Plan to Restore Bowel Function

- Start with **senna** (Senokot, fruit paste), **Peri-Colace** or **Doxidan**
- If bowel movement does not occur within **24 hours**, increase doses to BID or TID administration until maximum dose is reached
- If no bowel movement within **48 hours**, add **bisacodyl 2-3 tabs po HS** to TID or **Milk of Magnesia with cascara 30 cc po HS**
- If no bowel movement within **72 hours** and no rectal impaction, use **water or oil retention enema** or a **bisacodyl suppository**
- If **disimpaction** is needed, premedicate with an oil retention enema, an analgesic and a sedative
- Follow with a cleansing enema and an appropriate constipation-prevention plan

(Levy, 1991)

Constipation: Nonpharmacologic Management

- If the patient is able to increase fluid intake or activity levels, there are effective nonpharmacologic treatments for constipation
- Increasing fluids to 1 to 1.5 liters per day and dietary fiber intake are recommended, but often not achievable goals as disease progression limits the person's intake and activity
- If a patient is not able to maintain adequate fluid intake, bulk laxatives may cause severe constipation or obstruction and are contraindicated
- Hospice nurses speak highly of this treatment plan: Using natural senna a part of the dietary intake (not supported by research)

Constipation: Anti-constipation Recipe

Yakima Valley Anti-Constipation Fruit Paste

Dionetta Hudzinski, Hospice of Yakima

2 ½ cups boiling water	1 lb pitted figs
3-4 oz senna tea leaves	1 cup brown sugar
1 lb pitted prunes	1 cup lemon juice
1 lb raisins	

Prepare tea: Add tea leaves to the boiling water and let steep for 5 minutes. Strain and remove tea leaves.

Add fruit: Place 2 cups of tea in a large pot. Add all the fruit to the tea. Boil fruit and tea for 5-10 minutes. Remove from heat.

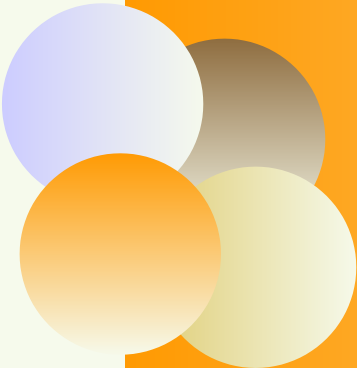
Add sugar and lemon juice and allow to cool.

Use a hand mixer or food processor to turn fruit and tea mixture into a paste. Place in freezer containers and store in freezer. Paste will not freeze.

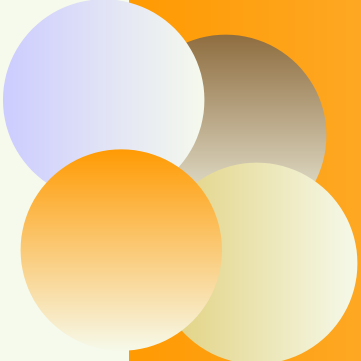
Serving Ideas: spread on toast, eat straight from the spoon, mix with hot water, use as fruit topping on cereal.

Adapted from *WSCPI News*, Spring, 1993, p. 10. Used with permission of Dionetta Hudzinski, MN, RN.

Multiple Symptoms

- 
- Successful treatment of symptoms requires *collaboration* of the **patient, family, nurses, physicians, social workers, spiritual guide** and other care providers
 - In review of 1,000 patients, 50% experienced 11 or more symptoms with the number of symptoms experienced ranging from 1 to 27
 - Pain, fatigue, weakness, anorexia, lack of energy, dry mouth, constipation, early satiety, dyspnea, and greater than 10% weight loss were the **10 most prevalent symptoms** (Walsh, 2000)

Multiple Symptoms

- 
- Other investigators note similar that not all symptoms are relieved to the satisfaction of the adult or child patient and the family
 - Appropriate symptom management depends on the patient and the family working in partnership with the health care provider team
 - The collaboration includes the patient and family and requires **intradisciplinary** and **interdisciplinary** efforts to understand the patient's symptoms and to find successful treatments

(Collins, 2000; Ng, 1998; Oliver, 1996; Wolfe, 2000)

Multiple Symptoms: Necessary Skills

- Assessment of single and multiple symptoms using standardized scales, interview history-taking, and physical exam techniques
- Management of pharmacologic and nonpharmacologic therapies
- Recognition and management of treatment-induced side effects
- Advocacy for patient-family-centered and collaborative care at end of life
- Patient and family education for them to fulfill their partnership roles