

Oral Complications at the End of Life

Although dysphagia and stomatitis can have devastating effects on the quality of a patient's life, there are many ways to manage them.

By Constance Dahlin, MSN, APRN, BC, PCM

Ken Eldredge, a 76-year-old retired truck driver, has end-stage heart disease and dementia. In the last year, his health has worsened considerably. He is bedbound, extremely weak, and occasionally short of breath. He has a poor appetite and is losing weight. After an evaluation including a complete blood count and computed tomographic scans of the chest and abdomen revealed colon cancer, he received chemotherapy, which ended two months ago. Mr. Eldredge is being cared for at home by his 75-year-old wife, Jean, and two of their adult children. He complains of dry mouth and says that foods "don't taste right." During meals he often coughs and sputters and says his mouth hurts when he eats and that food gets caught in his throat. His wife reports that he often must be coaxed to eat more.

Swallowing difficulties (dysphagia) and oral mucosal inflammation (stomatitis) are common in patients who have progressive terminal illness. Perhaps because these conditions are common within the context of a patient's deconditioning near the end of life, many providers consider them relatively trivial and they're therefore underreported, underestimated, and frequently overlooked for more prominent symptoms such as pain or shortness of breath.¹⁻⁴

But swallowing difficulties and oral mucosal inflammation can have tremendous adverse consequences for patients and families and should not be dismissed. An impaired ability to eat threatens the patient's nutritional health. Furthermore, a patient's nutritional status and a lack of interest in

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Palliative Nursing



◀ *Sideways*, by Deidre Scherer, fabric and thread, 14.5" × 13", 1990; photo by Jeff Baird.

Part of the series "The Last Year," which documents the final months of an 89-year-old woman's life.

To view the entire series, or for more on the artist and her work, go to www.dscherer.com.

food can be deeply troubling to family members. The lament "If only he could eat more. . ." is often heard by palliative care staff. If speech is also impaired, it will be more difficult for the patient to communicate and to interact. By anticipating and recognizing symptoms, nurses can prevent or ease much of this suffering, either through direct intervention or by coaching caregivers.

DYSPHAGIA

Dysphagia is defined as difficulty in swallowing solid foods or liquids. Whether acute or chronic, the condition affects oral intake and is usually indicative of some other disease process.⁴

The act of swallowing involves approximately 50

muscles and requires intact oropharyngeal anatomy and unimpaired nerve conduction, permitting coordination between the respiratory and the digestive systems. From start to finish, a single swallow takes about 20 seconds and involves four distinct stages.

- During *oral preparation*, the teeth and tongue break food into small pieces, which are mixed with saliva and formed into one or more small boluses.
- During *oral transit*, the lips close to seal the food boluses inside the mouth, and the tongue propels them toward the pharynx.
- The *pharyngeal stage* begins with the involuntary, posterior movement of the tongue. The passage of the bolus stimulates sensory nerves that

TABLE 1.

Indicators of Dysphagia or Stomatitis

Changes in patient behavior at mealtimes

- Avoids eating, or refuses to eat in the presence of others
- Avoids particular foods or fluids
- Takes more time to finish meals, leaves more food on plate, requires more fluids to wash down solids
- Chews painstakingly, swallows numerous times for even small bites
- Alters posture while eating

Changes in oropharyngeal function

- Dysarthria or slurred, imprecise speech
- Dry mouth with thick oral secretions
- Wet-sounding, "gurgly" voice
- Inability to manage oral secretions; drooling
- Food residue remains in mouth after attempted swallow
- Frequent throat clearing
- Coughing or choking during meals
- Nasal regurgitation

Changes in swallowing process

- Reports sensation that food is caught in throat
- Coughing and choking while eating or drinking
- Oral or nasal regurgitation of solids or fluids or both
- Esophageal pain on swallowing after eating
- Food or fluid in tracheotomy tube
- Inability to manage oral secretions; drooling
- Shortness of breath during meals or shortly afterward or both
- Unexplained weight loss

Source: Dahlin C, Goldsmith T. Dysphagia, dry mouth, and hiccups. In: Ferrell B, Coyle N, editors. *Textbook of palliative nursing*. New York: Oxford University Press; 2001. Table adapted with permission of Oxford University Press.

carry the signal to the swallowing center in the medulla oblongata. A peristaltic wave pushes the bolus into the esophagus.

- The *esophageal stage* involves the peristaltic movement of food through the upper and lower esophageal areas and into the stomach.

Pathophysiology. During any stage, a disruption can interfere with swallowing. These can consist of internal obstruction by cancerous lesions or growths; external compression caused by tumors; diseases that affect the neurologic system (such as amyotrophic lateral sclerosis, Parkinson disease, and dementia); brain damage from strokes; adverse effects of treatments such as chemotherapy, surgery, radiotherapy, or medications; conditions causing reflux; and general deconditioning associated with the end stage of any chronic or terminal illness. Dysphagia has been found to occur in about 30% of patients with stroke, in 40% to 60% of patients with neurodegenerative disease, and in about 20% of patients with cancer.^{5,6} Moreover, dysphagia can cause or exacerbate other problems such as weight loss, debility, and aspiration pneumonia, and in some cases it can perhaps hasten death.

Assessment. The goals of care near the end of life must include identifying dysphagia and its underlying pathophysiology, as well as determining short-term interventions and helping the patient and family decide how to safely and effectively deliver nutrition and hydration.

Signs and symptoms of dysphagia include difficulty in chewing or in forming a food bolus, drooling, coughing during meals, choking on medications or foods, excessive throat clearing, the sensation that food gets stuck in the pharynx or esophagus, shortness of breath during or after eating, regurgitation, weight loss, and pain during any stage of swallowing. Other indicators of dysphagia may include altered cognition resulting from disorders such as dementia or stroke, behaviors marking a change in attitude toward eating (such as refusing to eat in the presence of others or avoiding certain foods), and vocal changes (such as slurred or gurgled speech).

The following questions may elicit vital information:

- When did the patient begin to have difficulty swallowing?
- Has the patient recently started a new medication regimen?
- Does the patient choke on all foods and fluids regardless of consistency? If not, which consistencies of foods and fluids cause the most difficulty?
- Does the patient feed himself?
- How has the patient's experience of eating changed since becoming ill?

Physical examination should include inspection of oral mucosa for dryness, lesions, signs of infection, and general hygiene, as well as observation of the patient's swallow. Note changes affecting the voice, such as gurgling or hoarseness, and evaluate mouth closure during speech and at rest. Observe tongue movement, checking for flaccidity, fasciculation, or spasticity. Inspect the mouth and pharynx, looking for white patches on the tongue or sides of mouth and reddened areas on the mouth or gums. Assess the moisture of lips, mouth, and tongue and the condition of the teeth. Evaluate cranial nerves V, VII, IX, X, XI, and XII; this involves assessing the strength and symmetry of facial expressions, lip movement, and cheek muscles and observing tongue, soft palate, and pharynx movement as the patient says "Ah."^{2,3,7} Having the patient first swallow a sip of water and then a teaspoon of yogurt can help determine the effectiveness of his swallow. Note whether he takes the sip or spoonful on his own or needs a cue, and whether he coughs, sputters, or drools while swallowing.⁸

Difficulty swallowing liquids may indicate poor muscular control, whereas difficulty swallowing solids may indicate a physiologic abnormality such as a tumor. Gradual onset of dysphagia may indicate a neoplastic or neuromuscular etiology. Sudden

TABLE 2. Swallowing Difficulties and Possible Etiologies

Patient's complaint	Possible causes
Choking on fluids	Impairment at any stage of swallow
Long, drawn-out meal times	Weak chew Fatigue and diminished endurance resulting from deconditioning Esophagitis
Nasal regurgitation	Impaired closure of posterior palate
Difficulty starting to swallow	Reduced oral and esophageal sensation
Solid foods catch in throat	Weak swallow resulting from deconditioning Esophagitis
Nasal or oral regurgitation (emesis) after swallow	Poor esophageal motility Esophageal obstruction
Postprandial taste changes	Gastroesophageal reflux
Metallic or cardboard taste in mouth	Dysgeusia
Little or no sensation of any or all of the four basic taste types (bitter, salty, sweet, sour)	Ageusia, dysgeusia
Pain with swallow	Stomatitis Esophageal obstruction
Presence of cottage cheese–like patches on oral mucosa	Candida
Presence of vesicles	Herpes simplex
Oral ulcerations	Stomatitis

Source: Dahlin C, Goldsmith T. Dysphagia, dry mouth, and hiccups. In: Ferrell B, Coyle N, editors. *Textbook of palliative nursing*. New York: Oxford University Press; 2001. Table adapted with permission of Oxford University Press.

onset may be indicative of psychogenic etiology.^{1-3,8} In some situations, a referral to a speech–language pathologist may help in evaluation.

The case. Mr. Eldredge's initial evaluation reveals hoarseness and vocal slurring. He can't remember when his difficulties began; his wife says they began about two months before he was diagnosed with cancer. An oral examination shows a dry mouth and tongue, and there are red patches under his dentures and on the back of his throat. Given a sip of water, Mr. Eldredge takes a long time to swallow, and when he does, he coughs and sputters. When he's given a teaspoon of applesauce, his favorite soft food, some of it spills from his mouth and he again takes a long time to swallow.

A speech–language pathology evaluation reveals poor lip closure, poor tongue control, and reduced swallowing reflex. His difficulty in forming a food bolus and controlling it when swallowing indicates sensory losses. His inability to make the sounds *pa* and *ka* is a sign of facial muscle weakness. The speech–language pathologist's impression is that many factors cause Mr. Eldredge's dysphagia. Dementia may have affected the neural aspects of swallowing. Deconditioning (especially of cheek and tongue muscles) and concurrent lung disease

may cause swallowing to require greater effort. Finally, depression, which is associated with immobilizing fatigue, may be a factor.

Management. Because eating is often a social activity, it's important to consider not only the efficiency of oral intake and whether dysphagia threatens the patient's safety, but also how eating (or not eating) affects the patient's psychosocial health. Most people prefer to continue eating normally for as long as possible. Other routes of food administration such as intravenous nutrition or gastrostomic tube feedings may be pursued when they can no longer eat.

If the cause of the dysphagia is treatable, when caused by infection, reflux, or obstruction, a trial of appropriate pharmacologic therapy may be recommended, particularly if the patient is not imminently dying. Treatment for deconditioning may involve muscle strengthening. In some cases, assistance with eating may help to maximize intake and ensure the patient's safety.

There is a growing body of evidence showing that the use of gastrostomy tubes for feeding patients with dementia neither improves the quality of their lives nor prolongs them.⁹ Gastrostomy tubes aren't without complications. It's a common mis-

TABLE 3. Eating Positions for Specific Swallowing Dysfunctions

Dysfunction	Position during swallowing*
Reduced posterior propulsion by tongue	Head back
Unilateral vocal fold paralysis or absence	Head rotated to damaged side
Reduced pharyngeal contraction	Lying down on either side
Unilateral pharyngeal pareses	Head rotated to damaged side
Unilateral oral and pharyngeal weakness	Head tilted to stronger side
Cricopharyngeal dysfunction	Head rotated to either side

*Unless otherwise specified, the patient should be in an upright, sitting position.

Source: Galvan TJ. Dysphagia: going down and staying down. *Am J Nurs* 2001;101(1):37-42.

conception that tube feedings prevent aspiration of oral and regurgitated gastric secretions, prevent malnutrition, reduce infection, improve functional status, and prolong survival. Patients who receive tube feedings can and do develop aspiration pneumonia and upper respiratory infections, may continue to lose weight, and often fail to experience improved function. Often such patients can't tolerate feedings in amounts large enough to promote daily function. Instead they may develop cramping and diarrhea, build up gastric residue from the tube feeding fluid, and ultimately experience aspiration.

If the patient's prognosis is relatively poor (indicating only days or months to live), the benefits and burdens of oral intake should be considered carefully. In patients with multiple comorbidities, dysphagia may indicate that death is near. Life-prolonging interventions in such cases may be inappropriate. The focus should be on providing comfort through meticulous oral care, which can be performed by family members and other caregivers. This involves gentle cleansing of the mouth with a very soft toothbrush or oral swab, frequent misting or swabbing to relieve oral dryness, and frequent application of a water-based lip balm.

Strategies for maintaining safe, adequate oral nutrition may include pharmacologic treatments, dietary modifications, postural changes, and management of the environment.^{1-3, 10, 11}

Pharmacologic treatment. Steroids may temporarily reduce swelling of tissues adjacent to obstructive tumors, making swallowing easier. A trial of steroids, in pill or elixir form, might include dexamethasone (Decadron, Hexadrol, and others) 8 mg PO QID to 8 to 12 mg BID. To help reduce excess production of salivary and bronchial secretions, a 1.5-mg scopolamine transdermal patch (Transderm Scop) may be reapplied every three days.

Dietary modifications should be considered in terms of the five aspects of food consistency: texture, cohesiveness, viscosity, temperature, and density.¹¹ In 2003 the *National Dysphagia Diet: Standardization for Optimal Care* was published by the American Dietetic Association, based on standards developed by the National Dysphagia Diet Task Force. Recom-

mended dietary modifications vary according to the level and severity of dysphagia.¹² The "dysphagia pureed" diet consists of "homogenous, cohesive, puddinglike" foods such as applesauce, mashed potatoes, yogurt, and puddings. The "dysphagia mechanically altered" diet incorporates "moist, semisolid foods" such as pasta, scrambled eggs, and cottage cheese; the patient must have some chewing ability. The "dysphagia advanced" diet includes soft solid foods such as canned fruit, baked fish or chicken, and tofu, and requires greater chewing ability. For all levels of dysphagia, hard or crunchy foods, such as most raw fruits and vegetables, and dry foods, such as most bread products and crackers, should be excluded from the diet. Medication modifications, such as pill crushing and administration in pureed foods, may also help.

Postural changes can help patients swallow.^{1-3, 8} Sitting upright can help a patient focus on eating for two reasons: it's the usual position for eating, and it allows gravity to assist in swallowing. Tucking the chin immediately after taking a bit of food into the mouth usually enhances bolus formation since it increases pressure on the bolus and reduces the laryngeal opening. Similarly, raising the chin and tilting the head backward as the bolus begins to move down the esophagus usually improves transit time and facilitates passage into the stomach. If the patient's swallow is stronger (more intact) on one side—for example, in a patient with unilateral pharyngeal paralysis—turning the head toward the weaker side may help food move down the intact side of the esophagus, thus decreasing the risk of aspiration. In some cases it may help to have the patient turn his head toward the stronger side. For more on positioning the head, see Table 3, above.

Environmental modifications such as minimizing audio and visual stimuli, by turning off the television for example, can help the patient to relax and focus on eating. This is particularly effective with patients who have dementia or Parkinson disease.

For some patients, there may be no best solution to the problem of chronic aspiration. A patient and his family may weigh the heightened risk of pneumonia that comes with dysphagia against the pleas-

ure of eating and decide that he wants to continue eating anyway. These preferences will need to be communicated to the nurse and others on the treatment team. Such decisions are difficult for all involved; for more, see “Ethical Concerns in End-of-Life Care,” *AJN*, January 2003.

The case. Mr. Eldredge’s family tries to create a calm, quiet atmosphere during meals by turning off the television or radio and minimizing loud chatter. They take turns helping him sit upright and reminding him to chew by touching his cheek gently after he’s taken a bite of food. His diet is modified to include puréed, semisolid, and soft solid meats and vegetables that he can make into a bolus. Because thin liquids such as water are more likely to be aspirated, they’re excluded; liquids that can be thickened with an agent such as cornstarch are permitted. Family members are taught to mist his mouth frequently with water and to help him tuck his chin after he takes a bite, measures that will help in bolus formation and transit.

A family meeting is held. Mr. Eldredge and his family talk about nutrition and hydration issues that can be expected to arise as his illness progresses. He says that he loves food and wants to continue eating “no matter what.” He doesn’t want to be moved to a nursing home and he doesn’t want a feeding tube to be inserted or other life-prolonging measures to be taken. The family agrees to respect his wishes. Everyone understands that if he does develop aspiration pneumonia, it won’t be treated with antibiotics; rather, the focus of treatment will be on comfort, with acetaminophen (Tylenol) suppositories given to reduce fever and opioids to relieve respiratory distress. It’s also agreed that when oral nutrition becomes unsafe or ineffective for Mr. Eldredge, further interventions, specifically tube feeding, will not be initiated.

STOMATITIS

The terms stomatitis and mucositis are often used as synonyms, although they’re not exactly the same. Stomatitis refers to inflammation of the oropharyngeal mucosa and can stem from a variety of causes. Mucositis refers to mucosal inflammation at any point in the gastrointestinal (GI) tract that’s caused by chemotherapy or by radiotherapy to the GI tract. The term stomatitis is used here for the purpose of addressing a wider population than patients with cancer and because this article concerns only oral complications.

Stomatitis, which can be an underlying factor in dysphagia, frequently occurs in immunocompromised patients, such as those undergoing chemotherapy or radiotherapy for head and neck cancers or those with HIV. Oral ulcerations can accompany any type of cancer, as well as a variety of other conditions. Contact stomatitis can occur as an allergic



Contact stomatitis.

Photograph: Stedman's Medical Dictionary

reaction to medications, food flavorings, or preservatives, or as a response to irritants such as heat or frictional trauma.¹³ A burdened immune system may cause such reactions even in a patient who hasn't previously shown sensitivity. Those at greatest risk for stomatitis include the seriously ill, as well as frail, older adults with poor oral hygiene.¹⁴ Although it may seem to be a mere inconvenience, stomatitis can be painful and may lead to malnutrition, volume depletion, electrolyte imbalance, infection, and bleeding.¹⁵

Pathophysiology. Squamous epithelial cells line the entire GI tract, serving as the first line of defense against infections. Stomatitis is a process whereby persistent damage to these cells occurs; possible causes are chemotherapy, radiotherapy, and immunosuppression (a low white blood cell count can lead to bacterial or fungal oral infection). Viruses, dehydration, poor oral hygiene, tobacco, alcohol, and certain medications may predispose the mucosa to infection and cell damage.^{16, 17} Symptoms include initial burning, followed by pain and difficulty swallowing.¹⁶ Risk factors for the development of stomatitis include ages younger than 18 or older than 65, high-dose and intensive chemotherapy and radiation (especially to the head and neck), impaired renal function, concomitant conditions such as diabetes or HIV infection, poor oral hygiene, concurrent oral trauma such as that caused by ill-fitting dentures, and mucosal irritants such as alcohol and smoking or chewing tobacco.^{16, 18} However, a correlation between risk factors and incidence has not been clearly demonstrated.^{18, 19}

Sonis has described five stages of mucositis development,¹⁶ and this analysis can be applied to stomatitis as well. In stage 1, damage occurs to mucosal epithelial cells, resulting in the production of reactive oxygen species (also known as oxygen free radicals). During stages 2 and 3, further injury to the epithelium and mucosa occur. Ulceration occurs in stage 4. In stage 5, healing begins. Red ulcerations can appear seven to 10 days after an insult. In cancer, without infection, stomatitis can heal in two to four

weeks by itself.²⁰ In patients with HIV, there may be a recurrence of aphthous ulcers.²¹

Assessment for stomatitis includes history taking and an inspection of the voice, swallow, lips, tongue, saliva, mucous membranes, gingiva, and teeth. Patients may complain of voice changes or painful swallowing. Listening for voice strength or hoarseness may give clues. Examining for cracked lips, erythema of the mouth, pain, bleeding, dry mouth, thick or absent saliva, and abnormal tongue surfaces is essential.¹⁷

Management. There are no preventive or curative therapies for stomatitis; treatment focuses on palliation of ulcers to promote healing.¹⁶ Most research on stomatitis and mucositis has focused on populations with cancer, with the following results. The use of antimicrobial agents has been studied and has been found to reduce infection. Chlorhexidine (Peridex and others) is used to control plaque-dependent oral disease and is effective against Gram-positive and Gram-negative bacteria. Coating agents such as sucralfate (Carafate) and viscous lidocaine (Xylocaine and others) are thought to facilitate healing and cell regeneration, although studies haven't consistently demonstrated changes in the severity of stomatitis. Antiinflammatory rinses have not been shown to reduce stomatitis. Most effective is oral rinsing with bland mouthwash, although further study is needed.¹⁹

Good oral care for patients at risk for stomatitis should include the following:

- daily oral assessment
- meticulous oral hygiene and the use of cleansing rinses, especially before chemotherapy or radiotherapy begins
- oral care after each meal and at bedtime, including the use of fluoride toothpaste and the softest toothbrush available

If stomatitis develops, treatment can include

- antibiotics. Fungal infections may appear as cottage cheese-like lesions and respond to nystatin (Mycostatin and others) or clotrimazole (Mycelex and others). Viral infections such as herpes respond to acyclovir (Zovirax and others); recurrent aphthous ulcers can be treated with topical steroids such as fluocinonide (Lidex) 0.05% six times daily or clobetasol (Temovate and others) 0.05% TID.²¹ Dexamethasone (Hexadrol and others) 0.5 mg can be used as a swish-and-spit rinse TID.²¹
- oral rinses of normal saline or sodium bicarbonate solutions; the latter is the safest and gentlest rinse. Studies have found both to be equally effective in removing oral debris and cleansing the mouth.²² Other rinses include those containing chlorhexidine or sucralfate, available by prescription, and glutamine, an over-the-counter amino acid typically sold in powder form. These

rinses can be costly, and studies have not demonstrated healing with their use.^{19,22}

- diet modifications. Sharp, hard, coarse, spicy, salty, and acidic foods that can irritate or damage fragile mucosa and existing ulcers should be avoided. A bland, low-acid, high-protein diet is recommended, including milk shakes, bananas, applesauce, mashed potatoes, cooked cereals, soft-boiled or scrambled eggs, cottage cheese, macaroni and cheese, pudding, custard, and gelatin. Popsicles and frozen yogurt or ice cream may be especially soothing.
- preprandial protectants. Single-agent anesthetics such as lidocaine or sucralfate are safest and may be comforting. "Triple" mouthwash mixes, such as those containing viscous lidocaine, diphenhydramine (Benadryl), and loperamide (Imodium), are not recommended because they may cause further ulceration.^{19,22}
- analgesics. Cryotherapy (sucking on ice chips) may help, as can nonsteroidal antiinflammatory drugs. Oral or parental opioids may be prescribed if pain is severe.
- minimizing oral trauma by, for example, serving food in "bite-size" pieces or puréed; pills can be crushed into powder, if it's appropriate.
- oral hydration and lubrication by using a water spray or a saliva substitute and by applying a nonpetroleum lip balm.²³

The case. When examined, Mr. Eldredge's mouth appears reddened, with ulcers on his tongue and particularly under his dentures. His lips are dry and cracked, and saliva is absent. It's clear that he has not been able to maintain adequate dental hygiene. His treatment for stomatitis overlaps with the management of his dysphagia. He has already been placed on a soft diet, which will protect his fragile mucosa. He and his family have been instructed in mouth care, and he'll be assisted with oral hygiene after meals and at bedtime. In this case, the use of rinses is contraindicated because thin fluids are difficult for patients with dysphagia to manage and Mr. Eldredge's dementia may cause him to forget to spit a rinse. Instead, oral swabbing with sucralfate slurry several times a day as a protectant and viscous lidocaine before meals to reduce pain and discomfort is recommended. Monitoring for new oral vesicles or lesions will be ongoing. ▼



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Continuing Education

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LEARNING OBJECTIVES: After reading this article and taking the test on the next page, you will be able to

- describe the swallowing process as well as several factors that impede it.
- outline an assessment approach for patients who have dysphagia, stomatitis, or both.
- plan the management of these conditions.

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