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# Mouth Pain and Discomfort

## All You Need to Know About Oral Mucositis

Presented by

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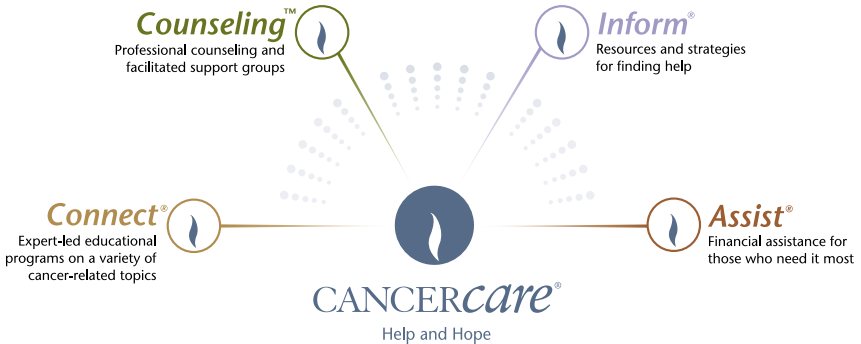
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- How to cope with mouth sores
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# It's vital to work closely with your health care team to manage mouth sores.

## What Is Oral Mucositis?

Irritation on the inside of the mouth—what doctors call **oral mucositis**—is a side effect of some cancer treatments. This irritation of the **mucosa**—soft tissues that cover the tongue and inside of the mouth—causes mouth sores.

Every year in the United States, some 400,000 cancer patients—including up to 90 percent of children under treatment—experience mouth sores. These types of sores aren't always confined to the mouth. They can also affect the upper part of the throat and parts of the digestive system.

Mouth sores are a serious problem because they can cause pain and infections and can make it difficult to swallow, eat, and drink. These symptoms can lead to weight loss and, in some cases, the need for a hospital stay. Further, patients who cannot eat or drink for a prolonged period must receive fluids and nutrition **intravenously (IV)** through a needle placed into a vein or through a feeding tube directly into the stomach.

## WHO IS AT RISK FOR MOUTH SORES?

Not every cancer patient develops mouth sores, but generally those who do have:

- Undergone bone marrow transplants

- Received high-dose chemotherapy
- Been treated with radiation to the head and neck

Talk to your doctor to find out whether your particular treatment could lead to mouth sores.

Once treatment ends, mouth sores do disappear. But before they fade, mouth sores (sometimes referred to as ulcers) can cause a great deal of pain for some patients. Understandably, some people wish to stop treatment, even for a little while, to let the tissues rest. However, interrupting treatment can reduce a person's chances for a cure. That's why it's so vital to work closely with your health care team during your cancer therapy for help in managing mouth sores and other side effects.

## How Mouth Sores Develop

For the first few days after chemotherapy or radiation, the mouth feels fine. But after three to five days, the soft tissues of the mouth may feel a little warm. There might be some tingling and mild soreness. Within about a week and a half after the start of cancer treatment, sores may begin to appear. Typically, they linger until after treatment stops. A week or two after treatment ends, the sores begin to heal, and usually by the third week after treatment stops, the ulcers and pain will have disappeared. With very aggressive treatments, mouth sores can be more severe and long-lasting.

### Signs and Symptoms

- Shiny, swollen tissues in the mouth and on or under the tongue
- Red, inflamed patches; may include white spots
- White or yellow film in the mouth
- Sticky **secretions**
- Blood in the mouth
- Pain in the mouth
- Raw feeling in the throat

## Course of a Mouth Sore

Not everyone undergoing treatment for cancer develops mouth sores, and among those who do, each person experiences this side effect differently. This chart explains the typical course of oral mucositis.

**1<sup>st</sup> Day of Treatment**

No noticeable change in the mouth. However, injury is beginning to accumulate.



**3–5 Days  
After Treatment**

Damage to genetic material in mouth cells continues to accumulate. Soft tissues of the mouth begin to feel warm.



**7–10 Days  
After Treatment**

Tissues show more signs of injury. **Inflammation** and sores appear.



**During  
Treatment Period**

Sores can become painful and infected. Eating and swallowing can become difficult.



**2–9 Weeks  
After Treatment**

Sores heal and disappear.

Doctors have long known that, aside from killing cancer cells, radiation and chemotherapy harm healthy tissues, including those inside the mouth. But this damage is not the only reason mouth sores develop. It turns out to be more complex than that. Because there are more causes for the problem, there are also more ways to tackle it. Researchers are now trying to better understand and deal with those causes.

## What You and Your Doctor Can Do

Although there is not yet a drug approved to prevent mouth sores or reduce their severity, you and your doctor *can* do a number of things to help ease your discomfort and address the consequences of mouth sores—pain, **dehydration**, weight loss, infection, and fatigue. **It's important to report any symptoms as soon as possible** (see box on page 3). They can be managed. Here's how:

**Take care of your mouth and keep it clean.** That means *careful* brushing and flossing based on discussion with your health care team.

- Use the softest bristle brush available or an oral sponge. (Rinsing the bristles in hot water can make them even softer.)
- If toothpaste irritates your mouth, use a mixture of ½ teaspoon of salt with 4 cups of water.
- Floss gently, no more than once a day. It's OK to skip the areas that feel too tender.
- Gargle regularly with a solution made up of:
  - 1 quart of plain water
  - ½ teaspoon table salt
  - ½ teaspoon baking soda



**Drink plenty of fluids—at least two or three quarts a day.** Talk with your doctor or dietician about the types of fluids you should drink.

**To soothe the pain of mouth sores, you can use:**

- Ice chips or popsicles. It's a simple technique, but sucking on ice brings relief to many patients.

## When a Nurse Becomes the Patient

**M**y name is Pat Kramer. I am an oncology nurse. Two years ago I was diagnosed with breast cancer. During my treatment I developed severe mucositis. I want to share my experience with you and talk about how important it is for patients and families to communicate with their health care team and stay actively involved in their own care.

I received standard-dose chemotherapy for my stage II breast cancer. The three drugs put me at risk for developing mucositis. After my first course of therapy, I developed some soreness in the mouth. I was very careful to brush, floss, and stay aware of mouth care. After my second cycle of chemotherapy, I quickly developed a severe case of mucositis.

Soreness in my mouth progressed to more severe pain. I was having trouble eating, drinking, and staying hydrated. This really affected my quality of life.

I tried eating soft and pureed foods. It was difficult to swallow because the mucositis was not only in my mouth but down my throat and esophagus, so swallowing became very difficult—even swallowing water. It got to the point where I could not swallow water. It became very hard for me even to talk because my mouth was so sore.

I was admitted to the hospital for six days. I required intravenous hydration and nutrition and strong painkillers. I also was given

- Ibuprofen (such as Motrin) or acetaminophen (such as Tylenol) for mild pain.
- Over-the-counter anesthetics, such as Xylocaine, Anbesol, or Orajel. Let your doctor know if you are using them, especially if he or she prescribes a lidocaine-based mouthwash.
- Gelclair—an oral gel designed to coat and soothe mouth sores by forming a protective barrier in the mouth. Gelclair

antibiotics and antiviral and antifungal drugs. When the lining of your mouth breaks down and your blood counts are low, you are at risk for developing an infection, as I did. I also developed a fever that needed to be treated.

In the course of that week, I lost 15 pounds; my treatment was delayed to give my body time to heal. I know how significant the impact of mucositis on patients can be, not to mention the tens of thousands of dollars in health care costs. For me, personally, it was the lowest point of my cancer treatment and the most difficult thing to go through.

How did I cope with it? It was important for me to work with my multidisciplinary team—my physicians, medical oncologist, dentist, nutritionist, social worker, oncology nurses, chemotherapy and radiation nurses, and nurse practitioner. All of these people followed my case, helped manage it, and helped me get through it.

It is so important to talk with your nurses, doctors, and other members of the health care team and ask questions: “Am I at risk for mucositis? What’s the best way to care for my mouth? What should I be doing on a daily basis? What should I report to you?” It’s important for patients and family members to know what to look for and know what to report to the doctor or nurse.

There are some exciting things coming in the future. But there are things we can do now to make patients more comfortable and to reduce some of the side effects of cancer treatment. Stay well informed, stay proactive, stay involved with your health care team.

## On the Horizon

Clinical trials conducted around the country are now testing a number of different drugs for mouth sores. You may wish to ask your doctor about joining a clinical trial. You can learn more about clinical trials by visiting [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials).

Among the drugs tested recently:

- **Amifostine (Ethyol)** Protects salivary tissues against radiation damage. Approved for reducing **dry mouth**. May also reduce mouth sores; research is ongoing.
- **N-acetylcysteine (RK-0202)** Prevents inflammation due to radiation therapy.

contains three key ingredients: one substance to coat the raw tissues in the mouth and form a protective film over them; a second substance to moisten and lubricate the tissues; and licorice root extract, for flavoring. Available by prescription only, Gelclair may help reduce mucositis mouth pain.

### **Don't resist taking stronger drugs for severe pain.**

Pain causes stress, depression, and fatigue. It can affect quality of life and slow progress toward better health—or at least toward feeling more comfortable. Many patients fear “addiction” to powerful pain-relieving drugs, but the chances of that happening are *very* small. **Opiates**—a class of drugs that includes morphine for effective pain relief—are important tools for controlling pain and not something to be shunned or feared.

- For people who cannot swallow pills because of mouth sores, opiates are also available in liquids and skin patches; the pain-relieving drug seeps into the skin from the patch and enters the bloodstream, where it travels to the mouth and soothes the pain.
- Severe pain can be treated with IV infusions of opiates. Ask your doctor about using a **patient-controlled analgesia (PCA) pump**. A portable device, the pump operates continuously, dispensing pain-relieving medication under the

skin or into a vein. If more medication is needed, a simple push of a button increases the dose temporarily.

- A fast-acting drug called fentanyl citrate (Actiq) is available in a berry-flavored lozenge on a stick. Actiq dissolves in the mouth. It's delivered quickly into the bloodstream, taking effect within 10 to 15 minutes. Actiq is intended only for adults who are already taking other opiate pain relievers.
- There are prescription medications that reduce the severity of oral mucositis. A calcium phosphate rinse called Caphosol is a recently approved treatment that works similarly to human saliva to moisten, lubricate, and cleanse the mouth, tongue, and throat. It loosens tough mucus and prevents mouth tissues from sticking together, which makes chewing and speaking easier for patients. The drug palifermin (Kepivance) is used to treat oral mucositis in people with blood cancers who have received high-dose chemotherapy followed by bone marrow transplant.

**Fight infections.** Because chemotherapy and radiation can weaken the immune system, bacteria that live at the base of mouth sores can spread. Your doctor will prescribe antibiotics should mouth sores become infected.

**Keep up your strength with a healthy diet.** It is critical to take in adequate calories and nutrients while undergoing cancer treatment. This may require a change in your diet. For some patients, a feeding tube or IV nutrition may be required.

- Talk to your doctor and nutritionist about the foods that will help you stay strong.
- You may need liquid supplements to maintain your calorie intake.
- Mouth sores can make eating difficult, so try grinding up or pureeing your food in a blender.
- Avoid spicy foods; choose more mild seasonings such as basil or oregano instead of pepper, curry, or cumin.

## Foods to Choose, Foods to Avoid

If you have mouth sores, eating becomes a challenge. It's important to maintain your weight and stay hydrated. This list will help you make better food choices.

### **Say YES to soft and soothing foods such as:**

- Ice cream
- Milkshakes
- Baby food
- Fruits such as bananas and applesauce
- Fruit nectars (apricot, pear)
- Mashed potatoes
- Cooked cereals
- Soft-boiled or scrambled eggs
- Cottage cheese
- Macaroni and cheese
- Custards, puddings, and gelatin
- Foods cooked and pureed in a blender
- Herbal tea
- Liquid (or powdered) nutritional supplements
- Cooked meats, pureed in a blender, with gravy, a mild sauce, or broth added



### **Say NO to acidic or irritating foods such as:**

- Tomatoes
- Citrus fruits and juices (orange, grapefruit, lemon)
- Salty or spicy foods, such as chili, tacos
- Raw vegetables
- Raw fruits (unless ripe and soft)
- Drinks containing caffeine or alcohol
- Pickles
- Vinegar
- Chocolate
- Rough and dry foods (pretzels, popcorn, crusty breads, chips, crackers, nuts)



- Avoid citrus drinks; choose soothing fruit nectars, such as apricot or pear.
- Eat foods at room temperature rather than foods served hot.

**Managing fatigue.** It's not unusual for cancer patients to feel tired, even after sleeping. Often, this "bone weary" fatigue cannot be relieved by rest. But there are things you can do to feel better.

- Find out the underlying cause. It's important to talk to your doctor if you are feeling unusually tired or fatigued. He or she will want to make sure you're not suffering from fever, anemia, or infection. These problems can be treated with appropriate medications.
- Keep a diary of your ups and downs. You'll see a pattern emerge. Then you can schedule the most demanding part of your day for the time you have the most energy.
- Stay as active as possible. Even moderate amounts of exercise can help prevent and treat fatigue. Try walking for 15 minutes; gradually increase the amount of time each day. With your doctor's help, work out your own exercise "prescription."
- Take short "power naps." A 30-minute nap can help boost your energy. But be sure to set your alarm. It's best not to sleep away the day, which could disrupt your regular bedtime schedule.
- Pace yourself. Don't rush to finish a task. Do it in stages, if need be.
- Delegate. When friends and relatives ask, "What can I do?" give them a specific task, whether it's picking up a prescription at the drugstore, taking in the dry cleaning, or dropping off the kids at school. They'll be glad to know they can be of use.

# Frequently Asked Questions

**Q My mouth sores developed after radiation to my jaw. I've had mucus build up in my mouth. How can I deal with this?**

**A** This is a very bothersome side effect of mouth sores. Secretions can form after two or three weeks of radiation and they can lead to nausea or gagging. But there are things you and your doctor can do about it:

- Rinse and gargle frequently with a salt and baking soda solution (mix half a teaspoon of table salt and half a teaspoon of baking soda in a quart of plain water), as recommended by your health care team.
- Ask your doctor about cough syrups that contain chlorpheniramine, such as Tussionex. They can reduce secretions.
- To thin out thick secretions, your doctor can recommend or prescribe cough medicines that contain guaifenesin, such as Robitussin DM or Humibid.
- If the secretions become very heavy, your doctor may need to order a portable suction machine for your use.
- Use a humidifier at night to thin secretions.

**Q How does an oral gel work to reduce pain from mouth sores?**

**A** A prescription oral gel such as Gelclair sticks to and coats the inside of the mouth. The manufacturer compares it to a liquid bandage that can relieve mouth sore pain. It does this by coating exposed nerve endings so patients can eat and drink with more comfort. It may take several doses of the gel to soothe mouth sores. You pour the contents of a Gelclair packet into a glass and add a tablespoon of water. Stir it up and immediately rinse it around your mouth for at least one minute or as long as possible. The instructions are to gargle and spit out the gel, but if you swallow it, no side effects are expected. You can use the product several times a day, as needed.

**Q How do I find out about joining a clinical trial?**

**A** Aside from talking to your doctor, you can research this question on the Internet. There are a number of websites that list current clinical trials, such as [www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials). For more information, see the list of Resources on page 16.

**Q I'm feeling so down; the pain of my mouth sores has gotten me really depressed and sometimes I feel like quitting my treatment. What should I do?**

**A** It's perfectly natural to feel stressed, anxious, or even depressed, especially when a side effect like mouth sores affects your quality of life. And it's certainly understandable that you would want to stop taking a treatment that leads to mouth sores. But your doctor can help manage your symptoms and control your pain so that you can continue treatment

and have the best possible chance of beating your cancer. Antidepressants and medications for anxiety can help you manage this difficult period. Just talking with a therapist can help as well. You can also share your feelings with other cancer patients so you'll know you're not alone in this. Your doctor and organizations such as CancerCare® can help you cope.

CancerCare's staff of professional oncology social workers can help you cope with oral mucositis and other side effects of treatment. We provide free individual counseling and support groups over the phone, online, and in person. CancerCare also offers education, practical help, and referrals to other resources that can help you manage your concerns related to cancer. Call us at 1-800-813-HOPE (4673) or visit [www.cancercare.org](http://www.cancercare.org).

# Glossary

**dehydration** A potentially dangerous lack of water in the body. In the case of people with mucositis, dehydration results from inadequate intake of fluids. Can also occur as a result of excessive sweating, vomiting, or diarrhea.

**dry mouth** Also known as xerostomia. Caused by radiation damage to the salivary glands.

**inflammation** Refers in this case to the swelling, redness, heat, and pain produced in the mouth as a result of cancer treatments.

**intravenously (IV)** Fluid delivered through a needle into a vein.

**mucosa** Soft tissue that covers the tongue and inside of the mouth. Also found in other parts of the body.

**opiates** A class of drugs that includes morphine for effective pain relief.

**oral mucositis** Commonly called mouth sores. These sores form as a result of some cancer treatments.

**patient-controlled analgesia (PCA) pump** A portable device that operates continuously, dispensing pain-relieving medication under the skin and directly into the bloodstream. If more medication is needed, the patient simply pushes a button to increase the dose.

**secretions** Refers in this case to phlegm or mucus in the mouth. Cancer treatments can cause mucus to thicken, making swallowing and eating difficult. It can also lead to nausea or gagging.

# Resources

## **CancerCare**

1-800-813-HOPE (4673)  
[www.cancer.org](http://www.cancer.org)

## **National Institute of Dental and Craniofacial Research**

1-301-496-4261  
[www.nidcr.nih.gov](http://www.nidcr.nih.gov)

## **American Cancer Society**

1-800-227-2345  
[www.cancer.org](http://www.cancer.org)

## **National Cancer Institute**

Cancer Information Service  
1-800-422-6237  
[www.cancer.gov](http://www.cancer.gov)

## **People Living With Cancer**

(Patient Website of the American Society of Clinical Oncology)  
[www.plwc.org](http://www.plwc.org)

## **To find out about clinical trials:**

National Institutes of Health  
[www.cancer.gov/clinicaltrials](http://www.cancer.gov/clinicaltrials)

Coalition of National Cancer Cooperative Groups  
[www.CancerTrialsHelp.org](http://www.CancerTrialsHelp.org)



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