

MANAGING  
Oral Mucositis

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# Managing Oral Mucositis

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*It is very important to work closely with your health care team to manage mouth sores, also known as “oral mucositis.”*

Oral mucositis refers to mouth sores caused by some cancer treatments such as high dose chemotherapy, or head and neck radiation for treatment of mouth cancer. The mouth sores typically occur on the lining tissues of the mouth such as the inside the cheeks as well as sides of and under the tongue. Depending upon the type of cancer treatment, oral mucositis can be a serious side effect. These types of sores aren't always found just in the mouth. Depending upon the type of cancer treatment, the condition can also affect the upper part of the throat and other parts of the digestive system.

Mouth sores can cause pain and infection that make it difficult to swallow, eat, and drink. For this reason, they can also lead to weight loss in some people. Patients who are unable to eat or drink for a long period of time may need to receive fluids and nutrition through an intravenous line or a feeding tube, which could require a hospital stay.

It is important that you talk with members of your health care team about how best to manage this side effect, even before cancer treatment begins. If you experience mouth sores, there are medications they can prescribe to reduce pain, infection, and discomfort from mouth sores until you finish your cancer treatment. There are also things you can do on your own to help manage this symptom. Once the cancer treatment ends, mouth sores gradually fade over the next few weeks.

## How Mouth Sores Develop

Mouth sores do not develop right away after the cancer treatment begins. For the first few days of chemotherapy or radiation, you probably won't notice any changes in your mouth. However, after about three to five days, the soft tissues of the mouth may feel a little warm. There might also be some tingling and mild soreness that you notice at this time.

Sores may begin to appear within about a week and a half after the start of cancer treatment. Usually, the sores remain until after treatment stops. A week or two after treatment ends, the sores generally begin to heal. Usually, by the third week after treatment stops, the mouth sores and pain disappear. If your treatment has been very aggressive, you may experience more severe mouth sores that last longer.



## Mouth Sores: What to Expect

### **First day of treatment.**

No noticeable change in the mouth, but damage is starting to build up.

### **3–5 days after treatment starts.**

Damage to mouth cells keeps building. Inside of mouth may begin to feel warm.

### **6–10 days after treatment starts.**

Red, inflamed spots and sores may start to appear.

### **During remainder of treatment.**

Sores may become painful and infected. Eating and swallowing may be difficult.

### **2–9 weeks after treatment ends.**

Sores begin to heal and disappear

## Indications of Mouth Sores

- Throat and mouth feel sore or tender
- Small ulcers
- Discomfort in the throat or mouth, especially when eating hot or cold foods
- Shiny, swollen tissues in the mouth and on or under the tongue
- Red, inflamed patches, sometimes with white spots
- Sticky mucous or blood in the mouth
- A white or yellow film in the mouth

## Controlling Mouth Pain

There are a number of approaches available to control pain caused by oral mucositis, including medications. You can buy some of them over the counter. Others require a prescription.

**Rinsing with salt and baking soda rinses several times day may help alleviate pain.** Try a mix of ½ teaspoon salt, ½ teaspoon baking soda and 8 oz. water as a rinse, 4–6 times/days. Swish in your mouth gently for about a minute, and then spit out.

**Ice chips or popsicles.** These can provide a soothing effect in the mouth.

**Over-the-counter pain relievers** for mild pain include ibuprofen (such as Motrin) and acetaminophen (such as Tylenol).

**Over-the-counter local anesthetics** may also be effective for mild pain. Let your doctor know if you are using them, especially if he or she prescribes a lidocaine-based mouthwash.



**Magic Mouthwash.** Another prescription product specifically for use in the mouth is “magic mouthwash.” It contains Maalox to coat the mouth, an anti-histamine, and lidocaine to relieve the pain. Some pharmacies that specialize in cancer care offer their own versions of magic mouthwash.

**Prescription pain medication.** Pain may cause fatigue, sadness, stress, or worry, and can affect your quality of life. Talk with your doctor about using opiates, a class of drugs that includes morphine, for effective pain relief. For people who cannot swallow pills because of mouth sores, some medications 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.

In addition to the approaches described above, some patients such as individuals undergoing bone marrow transplantation may benefit from use of Palifermin (Kepivance). This drug, which needs to be prescribed, has been approved by the U.S. Food and Drug Administration (FDA) and can be effective in reducing oral mucositis severity during the bone marrow transplant experience.



## Mouth Care

### Using the Team Approach

Today, many different kinds of health care providers come together as a team to care for people with cancer. If you experience mouth sores, your oncologist and nurse are excellent resources to help prevent and manage this side effect as well as other concerns you may have. There are also other important members of the team with whom you can consult as well, including your dentist, registered dietitian, and an oncology social worker.

### Caring for Your Teeth and Gums

The best time to start managing mouth sores and caring for your mouth is before cancer treatment begins. Your dentist should perform a careful examination to make sure there are no broken teeth, cavities, or gum irritation. If you wear dentures, the dentist should check to make sure they fit well.

Here are some ways you can care for your mouth before, during, and after treatment:

**Visit your dentist before treatment.** As noted above, the dentist can make sure that your mouth is as healthy as possible before you begin treatment, and can provide important information to the rest of your health care team.

**Keep your mouth clean with careful brushing.** 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 half a teaspoon of salt with four cups of water.



**Floss gently.** There is no need to floss more than once a day during your cancer treatment. It's OK to skip the areas that feel too tender. It is, though, important that you floss correctly so that you do not injure the gums. Talk with your dentist about the correct flossing approach as well as other ways to keep your teeth and gums clean.

**Gargle regularly.** Use a solution made up of one quart of plain water, half a teaspoon of table salt, and half a teaspoon of baking soda.

**Drink plenty of fluids.** Talk with your doctor or dietitian about the types of fluids you should drink, as well as how much fluid each day you should drink.

**Fight dry mouth with water or sugarless drinks.** If you have dry mouth, it can make mouth sores more painful. Avoid caffeine, tobacco and alcohol, as well as spicy, peppery, or salty foods, which can make dry mouth more severe, especially if you have mouth sores.

**Gargling may also help.** Use a solution made up of one quart of plain water, a half teaspoon of table salt and a half teaspoon of baking soda.

## Making It Easier to Eat

Serotonin antagonists are often used to counter nausea and With mouth sores, you may need to change your diet to make sure you get enough calories and nutrients. A registered dietitian can recommend liquid supplements to help you maintain your weight and make sure you're getting enough liquids. Here are some of the things you can consider in your discussion with your cancer team:

**Choose foods that are soft, moist, and creamy, or blend foods to make them easier to swallow.** The blender also makes great milkshakes and smoothies. Sipping blended food with a straw helps avoid areas in the mouth that are tender and sore. You can also eat foods such as cottage cheese, yogurt, mashed potatoes, and avocados. Avoid pretzels, crackers, or chips, which could irritate a mouth sore.

**Avoid acidic foods and beverages.** For example, oranges, grapefruits, lemons, limes, tomatoes and pineapple can further irritate mouth sores.

**Make sure that each bite is packed with high calories and protein.** Try adding protein in the form of powdered milk or whey protein. Use milk with dry cereal or when cooking oatmeal, scrambled eggs, pudding, or cream soups. Peanut butter, butter, and cream can also add needed calories to foods.

**Use supplements.** Ensure, Boost, Carnation Instant Breakfast, and similar products can help you meet your nutritional needs. If it's too painful to swallow solid foods, it's OK to substitute four to six eight-ounce shakes per day.

**Drink liquids with calories.** Because fluids and calories are both so important, be sure to drink liquids that give you both, such as milk and non-acidic juice. Non-acidic popsicles are another option.



# Communicating with Your Health Care Team

It is important to remember that you are a consumer of health care. The best way to make decisions about health care is to educate yourself about your diagnosis and get to know the members of your health care team, including doctors, nurses, dietitians, social workers and patient navigators.

Here are some tips for improving communication with your health care team:

**Start a health care journal.** Having a health care journal or notebook will allow you to keep all of your health information in one place. You may want to write down the names and contact information of the members of your health care team, as well as any questions for your doctor. Also, keep a section of your journal with symptoms related to your illness or treatment. Note the date and time the symptoms occur and rate them on a scale of 1 to 10 to measure how strongly they affect you. These notes will make it easier to share details of your symptoms with your health care team.



**Prepare a list of questions.** Before your next medical appointment, write down your questions and concerns. Because your doctor may have limited time, you should ask your most important questions first, and be as specific and brief as possible. Questions you may want to ask your health care team:

- What is causing my oral mucositis?
- What can I do to manage the pain?
- Is the recommended treatment for my oral mucositis covered by my insurance?
- Should I avoid certain activities while experiencing symptoms?
- How long can I expect symptoms to last?

**Bring someone with you to your appointments.** Even if you have a journal and a prepared list of questions or concerns, it's always helpful to have support when you go to your appointments. The person who accompanies you can serve as a second set of ears. He or she may also think of questions to ask your doctor or remember details about your symptoms or treatment that you may have forgotten.

**Write down your doctor's answers.** Taking notes will help you remember your doctor's responses, advice, and instructions. If you cannot write down the answers, ask the person who accompanies you to do that for you. If you have a mobile device, ask if you can use it to take notes. Writing notes will help you review the information later.

**Record your visit if your doctor allows it.** Recording the conversation with your doctor gives you a chance to hear specific information again or share it with family members or friends. Incorporate other health care professionals into your team. Your

medical oncologist is an essential member of your health care team. There are other health care professionals who can help you manage your diagnosis and treatment as well:

- Your primary care physician should be kept updated about your cancer treatment and any test results.
- Your local pharmacist is a great source of knowledge about the medications you are taking; have all of your prescriptions filled at the same pharmacy to avoid the possibility of harmful drug interactions.
- Make sure your oncology teams knows of any other medical conditions you have, or any pain you are experiencing, so that they can consult with your primary care physician or your specialist if needed. Be sure you communicate all therapies you receive, including supplement use and alternative care modalities such as acupuncture, massage, etc.



## Questions to Ask Your Doctor about Mouth Sores

**Research shows that patients who have good communication with their doctors are more satisfied with their medical care and have better control of treatment side effects such as mouth sores and pain. Your doctor and the members of your oncology team are trained to address your concerns.**

Research shows that patients who have good communication with their doctors are more satisfied with their medical care and have better control of treatment side effects such as mouth sores and pain. Your doctor and the members of your oncology team are trained to address your concerns.

Here are some questions to help you start the conversation:

- Is my treatment going to cause oral mucositis?
- How serious is it likely to be?
- Is there anything I can do to prevent it?
- What will you do to help me manage it?
- What steps, such as a dental check-up, do I need to take?
- How long before mouth sores heal?

Remember, there is no such thing as over-communication. Your health care team wants to know about how you're feeling overall, which includes your level of pain, your energy level, your appetite, and your mood and spirits.



# CancerCare Can Help

Receiving a diagnosis of cancer can be very difficult, and adjusting to the necessary changes in your life can be challenging.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide support and education, help in navigating the complicated health care system, and provide information on support groups and other resources.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or explore our website, [www.cancercare.org](http://www.cancercare.org)

You will likely also build your own personal support network, comprised of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store; ask a friend who's a good listener to come over for a chat.

To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit [www.cancercare.org](http://www.cancercare.org).

## MORE ABOUT ORAL MUCOSITIS

### Frequently Asked Questions

**Q: Is there any way to prevent mouth sores after receiving radiation or chemotherapy?**

A: When it comes to radiation, newer technologies are helping to spare healthy tissues and reduce damage to the lining of the mouth. As discussed elsewhere in this booklet, there are effective ways to manage this side effect and lessen its symptoms. However, at the moment there is no known way to prevent mouth sores completely, including those caused by chemotherapy. That's why it is important to ask your health care team whether your particular treatment may cause mouth sores and if so, to work closely with the different members of your team to manage them.

Seeing your dentist for screening before starting cancer treatments is especially important. He or she can recommend the type of toothbrush and mouthwashes to use during treatments. Keeping in close touch with your dentist and medical oncologist will enable you stay on top of any mouth sores you may develop.



**Q: My mouth sores developed after I received radiation to my jaw. I also have a lot of mucus build-up in my mouth. How can I deal with this?**

A: Although an increased level of mucus in your is not the same as oral mucositis, the increased mucus can make the oral mucositis worse. There are a number of things both you and your doctor can do to control mucus:

- Rinse and gargle often with a salt and baking soda mixture. Stir half a teaspoon of table salt and half a teaspoon of baking soda into a quart of plain water.
- Use a humidifier at night to help thin out the mucus.
- Ask your doctor about cough syrups that contain chlorpheniramine. These products can reduce secretions.
- Your doctor may also recommend cough medicines that contain guaifenesin, such as Robitussin DM or Humibid, to thin the mucus.
- If the secretions become very heavy, your doctor may need to order a portable suction machine that you can use to remove the mucus.

**Q: My dentist tells me that I need a root canal. Is it okay to have this done during my cancer treatment?**

A: In order to make that decision, your dentist needs to consult with your oncologist about the status of your blood counts, including your white blood cells. These cells are important to the immune system for fighting infection. If your white cell count is low, it is probably best to delay the root canal and treat any tooth pain or infection with antibiotics and pain medication first. When the white blood cells return to a safe level and your oncologist feels it is safe for you to have the root canal, you can have the procedure. But before you go ahead, be sure to discuss it with your cancer care team.

## Resources

### General Cancer Organizations

#### CancerCare

800-813-HOPE (4673)

[www.cancercare.org](http://www.cancercare.org)

#### American Cancer Society

800-227-2345

[www.cancer.org](http://www.cancer.org)

#### Cancer.Net

**(Patient information from the American Society of Clinical Oncology)**

[www.cancer.net](http://www.cancer.net)

#### National Cancer Institute

800-422-6237

[www.cancer.gov](http://www.cancer.gov)

#### Partnership for Prescription Assistance

888-477-2669

[www.pparx.org](http://www.pparx.org)



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