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MANAGING

Oral Mucositis

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CancerCare
National Office
275 Seventh Avenue
New York, NY 10001

Toll-Free 800-813-HOPE (4673)
Phone 212-712-8400
Fax 212-712-8495
Email info@cancercare.org
Web www.cancercare.org

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Editors

Charles L. Loprinzi, MD

Regis Professor of Breast Cancer Research, Mayo Clinic, Rochester

Douglas E. Peterson, DMD, PhD

Professor of Oral Medicine and Chair, Program in Head & Neck Cancer and Oral Oncology, Neag Comprehensive Cancer Center, University of Connecticut Health Center

Melinda Bivins, RD, CSO, LD

Clinical Dietitian, The University of Texas MD Anderson Cancer Center

Carolyn Messner, DSW

Director of Education and Training, CancerCare

Glenn Meuche, MSW

Coordinator, CancerCare

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

Oral mucositis is a serious side effect of some cancer treatments. The term “oral mucositis” refers to mouth sores caused by irritation of the mucosa—the soft tissues that cover the tongue and inside of the mouth. These types of sores aren't always found just in the mouth. They can also affect the upper part of the throat and other parts of the digestive system.

Not every person with cancer develops mouth sores. Generally, those who do have such sores have had bone marrow transplants or been treated with radiation to the head and neck. The cancer treatments most likely to cause mouth sores include doxorubicin (Doxil and others), capecitabine (Xeloda), cisplatin (Platinol and others), fluorouracil (5-FU), methotrexate (sometimes called amethopterin or MTX), and high-dose chemotherapy given before a bone marrow transplant.

Mouth sores can cause pain and infections that make it difficult to swallow, eat, and drink. For this reason, they can also lead to weight loss for 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 IV line or a feeding tube, which could require a hospital stay.

Because mouth sores can be very painful, some patients want to take a break from treatment to let the tissues rest. But stopping treatment, even for a short time, may make your treatment less effective.

It is important that you talk with the 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 treatment. There are also things you can do on your own to help manage this symptom. Once treatment ends, your mouth sores will gradually fade.



How Mouth Sores Develop

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

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 usually begin to heal. Usually, by the third week after treatment stops, the mouth sores and pain disappear. If your treatment has been



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 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.

very aggressive, you may experience more severe mouth sores that last longer.

Typical signs and symptoms of mouth sores include 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; raw feeling in the throat; and pain.

Treatments for Oral Mucositis

Until recently, there were no approved treatments to prevent mouth sores or reduce their severity. However, new research is leading to better ways of treating this side effect.

Current treatment options include the following:

Palifermin (Kepivance) is approved by the U.S. Food and Drug Administration (FDA) for people with blood cancers treated with stem cell transplant and high-dose chemotherapy. These types of patients have a higher chance of developing mouth sores. Doctors call palifermin, a targeted treatment, a promising advance in preventing and healing mouth sores.

“Cold therapy” is a technique that nurses devised for people receiving the chemotherapy 5-FU. Starting five minutes



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.

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?

before getting the drug and continuing for about half an hour, patients suck on ice chips. This closes the blood vessels in the mouth so that they are less affected by the drug as it goes through the bloodstream. (The damaging effects of 5-FU tend to drop off after half an hour.) Cold therapy seems to work best for patients who receive a single, large dose of 5-FU rather than smaller doses delivered over time. Studies show that people who use the ice chips have about half the amount of mouth sores and pain as people who do not use the ice chips. The technique has also been used with other types of chemotherapy.

Controlling Mouth Pain

There are a number of medications available to control pain caused by oral mucositis. You can buy some of them over the counter. Others require your doctor's prescription.

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

Over-the-counter local anesthetics such as Xylocaine, Anbesol, or Orajel 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.

Prescription pain medications such as Gelclair, an oral gel, coat and soothe mouth sores by forming a protective barrier

in the mouth. Gelclair 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 the tissues; and licorice root extract, for flavoring.

Another prescription product specifically for use in the mouth is "magic mouthwash." It contains Maalox to coat the mouth and lidocaine to relieve the pain. Some pharmacies that specialize in cancer care offer their own versions of magic mouthwash.

Opiates, which are stronger prescription drugs for severe pain, should be used if you need them. 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, 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.

A fast-acting opiate called fentanyl citrate (Actiq) is available in a berry-flavored lozenge on a stick. Like a cough drop, the lozenge dissolves in the mouth. The drug is delivered quickly into the bloodstream. This medication is intended only for adults who are already taking other opiates.

Patient-controlled analgesia is also an option for some patients. This refers to the use of a portable pump through which a prescription drug, usually an opiate, flows under the skin or into a vein. If more pain relief is needed, a simple push of a button increases the dose temporarily.





Clinical trials Other options for managing mouth pain may be available through a clinical trial. Ask your doctor if a trial may be right for you. An example of a drug in clinical trials is doxepin (Adapin and others). This is a drug that has been used for depression and is now being studied in people receiving head and neck radiation. A liquid form of doxepin numbs the mouth and helps decrease the pain in patients with mouth sores. Although it is not currently approved by the FDA for treating mouth sores, doctors hope that this drug may someday be used in the same way that dentists use Novocain to numb the mouth.

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 doctor and nurse are your best resource to help prevent and manage this side effect. But there are other important members of the team you should consult: your dentist, a registered dietitian, and an oncology social worker for help with practical and emotional concerns.

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, he or she should check to make sure they fit well. The following are some ways you can care for your mouth before, during, and after treatment:

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. Talk with your dentist about other ways to keep those areas 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. Aim for two or three quarts a day. Talk with your doctor or dietitian about the types of fluids 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.

Making It Easier to Eat

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. There are also things you can do:

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. To do that, 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.

Treat yourself to some ice cream. Because it is soft, high in calories, and contains lots of protein and fluid, ice cream is a good food to eat when you have mouth sores.

Finding Emotional Support

Mouth sores, along with the pain and other symptoms they cause, can bring up many feelings and concerns. It is normal to feel sad or worried about the ways in which mouth sores affect your everyday quality of life, including social situations and mealtimes. Here are some ways to cope with these feelings:

Talk with your family and friends. Just getting your concerns out in the open can make them seem more manageable.

Join a support group. You may benefit from a support group, which can ease the feeling that you are going through this experience alone. People in support groups often help each other find new ways to cope, through suggestions, reassurance, and insights. CancerCare® offers free face-to-face, telephone, and online support groups for people with cancer.

Work with an oncology social worker. These health care professionals provide emotional support to help you cope with your treatment and its side effects, and guide you to resources and practical solutions for problems. CancerCare offers free individual counseling online, over the phone, and in person with oncology social workers on staff.

To learn more about how CancerCare helps, call us at 1-800-813-HOPE (4673) or visit www.cancercare.org.

MORE ABOUT ORAL MUCOSITIS

Frequently Asked Questions

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

A. 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, such as Tussionex or Hycodan. 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 might be best to delay the root canal and treat any tooth pain or infection with antibiotics and

pain medication first. After a few days, 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.

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. And as discussed 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. 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.

Resources

CancerCare

1-800-813-HOPE (4673)
www.cancercares.org

American Cancer Society

1-800-ACS-2345
www.cancer.org

American Pain Foundation

1-888-615-7246
www.painfoundation.org

Cancer.Net

Patient information from the American Society of Clinical Oncology
1-888-651-3038
www.cancer.net

National Cancer Institute

1-800-4-CANCER
www.cancer.gov (search for "oral mucositis" for more information)

National Institute of Dental and Craniofacial Research

1-866-232-4528
www.nidcr.nih.gov

TO FIND OUT ABOUT CLINICAL TRIALS:

National Institutes of Health

www.cancer.gov/clinicaltrials

Coalition of Cancer Cooperative Groups

www.CancerTrialsHelp.org

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