FAST FACTS: CHRONIC GVHD OF THE MOUTH

Learning more about your disease and treatment options can help you make informed medical decisions.

READ ON TO LEARN ABOUT:
• Chronic graft-versus-host disease (GVHD) of the mouth
• How to ease symptoms of chronic GVHD of the mouth
• How chronic GVHD of the mouth can be treated
• When to call your doctor

WHAT IS CHRONIC GVHD OF THE MOUTH?
• Chronic GVHD of the mouth happens when the donor’s cells attack the saliva (spit) glands and soft tissues in your mouth.
• Glands in your mouth make saliva that helps your mouth stay moist and smooth. Saliva also helps you swallow your food and helps protect your teeth from decay. If the glands are destroyed or don’t work because of chronic GVHD, your mouth may be very dry and you may get more cavities.
• Chronic GVHD of the mouth can cause white patches, redness, pain, sores and mucoceles (painless bumps in the mouth). It may make eating painful or cause taste changes. It might cause your mouth to be more sensitive to spicy foods, acidic foods (like orange juice or tomatoes) and carbonated drinks (like soda or ginger ale). It can also make your lips chapped and sore.
• Chronic GVHD can also cause scarring over time that makes it difficult to open your mouth wide.

WHAT CAN I DO TO DECREASE SYMPTOMS?
• Drink water often to keep your mouth moist and reduce dryness. Do not get dehydrated.
• If you have difficulty swallowing due to dry mouth, take small bites, chew food completely and drink fluids frequently while eating.
• If swallowing is still difficult, talk to your doctor. Chronic GVHD can also make your esophagus very dry. Your esophagus is the tube that moves food from your mouth to your stomach. A very dry esophagus can cause difficulty swallowing.
• Suck on sugarless candy or chew sugarless gum to decrease the feeling of a dry mouth.

HOW CAN I KEEP MY TEETH AND GUMS HEALTHY?
• Keep your teeth clean. Brush your teeth at least 2 times each day with a soft toothbrush. If toothpaste bothers your mouth, use toothpaste made for sensitive teeth or for use by children.
• Floss once every day.
• See your dentist for regular cleanings. Ask your dentist if you need to take medicines before dental work to prevent infections.
• You may need fluoride treatments more often to protect your teeth from cavities.

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People with chronic GVHD of the mouth have a higher risk of cavities and gum inflammation (redness and swelling). Any mouth inflammation may make GVHD worse. So, it is important to keep your teeth and gums healthy.

WHAT OTHER TREATMENTS ARE AVAILABLE?

- Prescription immunosuppressant medicines (medicines that hold back your immune system) for your mouth may help reduce inflammation and make it easier to eat and drink. Examples include steroid solutions that you swish and spit or gels that you apply to painful areas. These treatments can cause yeast infections of the mouth so tell your doctor if you notice new white patches in your mouth or throat pain.
- Pain medicines taken before eating and topical anesthetics (medicine that you put directly on painful areas) can decrease pain.
- Prescription medicines that help your body make more saliva may help ease dryness. Examples include cevimeline or pilocarpine.
- Ask your doctor or pharmacist if any of your other medicines could be making your dry mouth worse. Some medicines, like pain medicines, antihistamines, antidepressants and sleeping pills, may cause dry mouth.

WHAT ELSE SHOULD I KNOW?

- Symptoms of chronic GVHD of the mouth often get better with treatment.
- Severe dry mouth is often permanent.
- Some infections can cause symptoms similar to chronic GVHD. Your dentist or doctor may need to do tests to see if you have an infection.
- People with chronic GVHD have a higher risk of mouth cancer. See your dentist every 6 months and report any changes in the color or texture of your mouth. For example, a sore that doesn’t heal or a new bump in your mouth.
- You cannot spread GVHD of the mouth to other people by kissing or sharing food.

WHEN SHOULD I CALL MY DOCTOR?

- Your mouth gets more dry.
- You have a hard time opening your mouth wide.
- Your mouth or throat hurts.
- You notice any new bumps or changes in your mouth.

OTHER RESOURCES TO HELP YOU LEARN MORE

Be The Match® has a variety of free resources to help you after transplant.

Visit BeTheMatch.org/patient-survive and choose the resources that best meet your needs.

Here are some you might find helpful:

TOOLKIT: After Transplant Care Guidelines
WEBCAST: Living Now—Your Role in Managing Your Chronic GVHD

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