Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

Resources for Head and Neck Cancer Survivors

This information includes resources to help people who have survived head and neck cancer manage the side effects of treatment, improve quality of life, and receive emotional support. It includes tips from other survivors, as well as from healthcare providers who treat people with head and neck cancer.

Always check with your healthcare provider before trying anything in this resource. You may also want to check with your insurance provider to see which services are covered.

Managing symptoms

Dry mouth

When radiation treatment is used near your mouth or throat, your salivary glands (glands that produce saliva) are affected. This may cause your mouth to become dry. How long this lasts depends on the type of treatment you're having. However, there are ways to reduce the discomfort. Below are suggestions that may help when you have dry mouth.

- Keep a glass of water at your bedside to drink during the night.
- Use a bedside humidifier.
- Drink plenty of liquids.
- Keep your mouth and lips hydrated with moisturizers such as Surgilube®, olive oil, cocoa butter, or Aquaphor®.
- Moisten your food with lots of gravy, sauces, or juices.
- Chew sugar-free gum or suck on sugar-free sour candies. They can help you

make saliva.

- Try taking 1 teaspoon of coconut oil or tasteless, liquid aloe vera by mouth at bedtime to sooth your throat. This can help keep your mouth and throat moist.

You should try to avoid:

- Drinks with caffeine (such as coffee and soda)
- Chocolate
- Tobacco (such as cigars and cigarettes)
- Acidic foods and drinks (such as citrus fruits, lemon juice, vinegar, and tomatoes)
- Hot and spicy foods
- Starchy foods (such as potato, bread, and rice)
- Alcohol-based mouthwashes

For more information, see the table "When Your Mouth Is Dry" in the resource *Eating Well During Your Cancer Treatment* (www.mskcc.org/pe/eating-cancer-treatment).

Try a saliva substitute

Tell your healthcare provider if you have dry mouth. They can recommend a saliva substitute for you to try. Saliva substitutes can help keep your mouth moist. You can buy most of these without a prescription at your local pharmacy. Here is a list of some oral saliva substitutes:

- Entertainer's Secret®
- Moi-Stir® Oral Spray
- Mouthkote® Oral Moisturizer
- Colgate Optimoist®
- Salivart® Oral Moisturizer
- Xero-Lube®

- Biotene® Oral Balance®
- OraHealth XyliMelts
- SmartMouth Dry Mouth Mouthwash

Sore mouth

If your mouth is sore or if you're having trouble swallowing, eating soft foods may help. These foods include:

- Milkshakes
- Custards or puddings
- Yogurt
- Scrambled eggs
- Mashed vegetables

Avoid foods that may irritate your mouth, such as:

- Spicy foods
- Salty foods
- Acidic foods and drinks (such as citrus fruits, lemon juice, vinegar, and tomatoes)

For more information, please see the table "When Your Mouth Is Sore" in *Eating Well During Your Cancer Treatment* (www.mskcc.org/pe/eating-cancer-treatment).

Problems with swallowing

You may have some difficulty swallowing. This could be due to a loss of important nerve function after radiation therapy, surgery, or a combination of treatments. Some survivors can swallow liquids such as liquid nutritional supplements (such as Ensure®) or soups. Others can swallow puréed or soft, wet foods.

Here are some ways to help yourself with swallowing:

- Mix your food with sauces.
- Consider blending your favorite foods.
- Eat a few small meals or snacks during the day instead of having 3 large meals.

For more information about helping yourself with swallowing, read the "Exercises" section in *Radiation Therapy to Your Head and Neck: What You Need To Know About Swallowing* (www.mskcc.org/pe/rt_head_neck_swallowing)

Percutaneous endoscopic gastrostomy (PEG) tube

If you can't swallow at all, your doctor may recommend that you have a percutaneous endoscopic gastrostomy (PEG) tube. In this procedure, a tube is inserted through the abdominal (belly) wall into the stomach. Nutritional liquids are poured into the body through the tube. Your healthcare provider can tell you more about this process.

If you're having trouble swallowing, discuss it with your healthcare provider. It may also be helpful to meet with a speech or swallowing therapist.

Loss of speech or difficulty speaking

You may have lost your speech or have trouble speaking if your treatment affected your larynx (voice box), tongue, or other parts of your mouth and throat. Your healthcare team will work with you and discuss your options after treatment. It may be helpful to meet with a speech or swallowing therapist.

Dental changes

If your treatment has affected your salivary glands, you may have changes with your teeth. When your body isn't making saliva, bacteria will stay in your mouth and on your teeth longer. This increases your risk of tooth decay.

It's important for you to take good care of your teeth and gums after your treatment. This is also referred to as "dental hygiene." See your dentist regularly if you aren't making saliva or have had radiation therapy to your head or neck.

Make sure your dentist is aware of your treatment history and how this will

impact your dental screenings and treatment. If you need to have teeth removed at any point in your lifetime, you must see a dentist who knows about the long term side effects of radiation. It's important to contact MSK's dental department before having any procedures, especially any teeth removed after having radiation to your head and neck. For more information, or to make an appointment, you or your local dentist can call MSK's dental department at 212-639-7644.

Changes in your appearance

Your appearance may have changed after your treatment. This may cause new or upsetting feelings for you. Many people find it helpful to talk with a counselor to cope with these feelings. For more information or to make an appointment, call MSK's Counseling Center at 616-888-0100.

Reconstructive surgery may be an option for you. For more information about reconstructive surgery or prosthetics, talk with your healthcare provider.

Pain

Pain is sometimes a part of healing and recovery. It can come and go, or last for months or years after treatment. If you have pain, talk to your healthcare provider. MSK has pain specialists that can help you learn how to manage your pain.

For more information, visit the MSK Pain Management website at:
www.msk.org/cancer-care/palliative-care/pain-management

Improving Your Quality of Life

The Integrative Medicine and Wellness Service

The Integrative Medicine and Wellness Service at MSK offers therapies to patients, their families and caregivers, and members of the community. These are called integrative medicine therapies or complementary therapies. These therapies can be used to help control many symptoms and side effects of cancer and cancer treatment. These therapies include:

- Acupuncture

- Acupressure
- Yoga
- Tai chi
- Massage therapy
- Meditation and other mind-body relaxation therapies
- Music therapy
- Exercise

To find out more about these services, or to make an appointment, call 646-449-1010. You can also visit the Integrative Medicine and Wellness Service website at: www.msk.org/integrativemedicine

Nutritional counseling

It may be hard for you to get the nutrition you need after treatment. The challenges you face will depend on the type of cancer you had and the kind of treatment you received.

We recommend that you meet with a dietitian who can work with you to make sure that you get the nutrition you need. To schedule an appointment with an outpatient dietitian, call 212-639-7071.

Smoking and alcohol use

MSK has specialists who can help you quit smoking or other tobacco use. For more information about our Tobacco Treatment Program, visit www.msk.org/tobacco or call 212-610-0507.

If you're concerned about your alcohol use, we can help you. For more information, call the Counseling Center at 646-888-0200.

Getting emotional support

Many head and neck cancer survivors feel sadness, fear, anger, anxiety, or depression. These feelings can come about before, during, and after your cancer treatment. MSK has many professionals who can help you cope. They

include social workers, psychiatrists, chaplains, and patient-to-patient volunteers.

You may notice feelings of anxiety now that your treatment is finished. Many people are also afraid that their cancer will return. These feelings can be overwhelming and difficult to explain to those not affected by cancer.

Emotional support is key to your recovery process. Talk to your healthcare provider if you think you're having these feelings. They can help you find the emotional support you need to get through this time.

MSK support services

Counseling Center
www.msk.org/counseling
646-888-0200
Many people find that counseling helps them deal with emotions during cancer treatment. Our counselors provide counseling for individuals, couples, families, and groups. They can also prescribe medications to help with anxiety or depression.

Resources for Life After Cancer (RLAC) Program
646-888-8106
At MSK, your care doesn't end after treatment. The RLAC Program offers support services for cancer survivors and their families. The services include seminars, workshops, and support groups to address topics related to cancer survivorship including insurance, employment, emotional concerns, and caregiver issues.

The RLAC Program also offers a support group for survivors of head and neck cancer called Head, Neck, and Oral Cancers: Moving Forward. In this group, you will have a chance to discuss your needs and concerns with other survivors and healthcare team members. To register, call 646-888-8106.

Additional resources

The following are resources outside of MSK that you may find helpful.

American Cancer Society (ACS)

www.cancer.org
800-227-2345
ACS offers information and services about cancer and cancer care.

Cancer*Care*

www.cancercare.org
800-813-4673
275 Seventh Avenue (Between 25th and 26th Streets)
New York, NY 10001
Cancer*Care* provides counseling, support groups, educational workshops, publications, and financial assistance.

Cancer Information Service (CIS)

www.cancer.gov/contact/contact-center
800-4-CANCER (800-422-6237)
CIS provides information about cancer, including diagnosis, treatment, prevention, and clinical trials.

National Cancer Institute (NCI)

www.cancer.gov
800-4-CANCER (800-422-6237)
The NCI website has detailed information on specific types of cancer.

Support for People with Oral and Head and Neck Cancer (SPOHNC)

800-377-0928
www.spohnc.org
SPOHNC is a self-help organization that gives support to people with head and neck cancer. They send out a monthly newsletter and offer support through a survivor-to-survivor network. There are local chapters in New York State.

The Oral Cancer Foundation

www.oralcancerfoundation.org

The Oral Cancer Foundation is a national public service organization that offers education, research, advocacy, and patient support activities.

If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

Resources for Head and Neck Cancer Survivors - Last updated on October 7, 2025
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