



CANCERcare®
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A Team Approach to Treating Head and Neck Cancer

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Find out about:

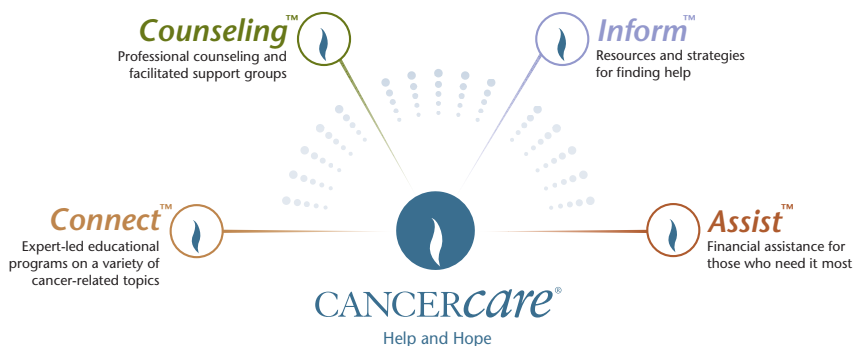
- Treatment options
- Head and neck specialists
- Quality of life
- The importance of a support network



CANCERcare®

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CancerCare's services are provided free of charge to anyone affected by cancer

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CancerCare is a national nonprofit organization that provides free professional support services to anyone affected by cancer: people with cancer, caregivers, children, loved ones, and the bereaved. CancerCare programs—including counseling, education, financial assistance, and practical help—are provided by trained oncology social workers and are completely free of charge. Founded in 1944, CancerCare now provides individual help to more than 90,000 people each year, in addition to the more than 1.4 million people who gain information and resources from its website.

Contacting CancerCare

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A Team Approach to Treating Head and Neck Cancer

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INTRODUCTION

page 2

- **THE TREATMENT TEAM**, page 2
- **UNDERSTANDING TREATMENT OPTIONS**, page 3
- **TARGETED TREATMENTS**, page 6
- **A WORD ABOUT SWALLOWING AND SPEECH**, page 10
- **COPING WITH CANCER**, page 10

FREQUENTLY ASKED QUESTIONS

page 12

GLOSSARY (definitions of blue boldfaced words in the text)

page 14

RESOURCES

page 16

This patient booklet was made possible by a charitable contribution from Bristol-Myers Squibb.

You can benefit most from a team of experts.

Each year, more than 40,000 adults in the United States develop head and neck cancer. This cancer can occur in the mouth, throat, voice box, salivary glands, nose, and sinuses. Most types of head and neck cancer develop in **squamous cells**. These thin, flat cells form the lining of many parts of the head and neck.

Men are about twice as likely as women to develop this type of cancer. But in both men and women, the leading cause of head and neck cancer is tobacco use, including cigarettes, cigars, pipes, chewing tobacco, and snuff. In fact, people who smoke are six times more likely to develop cancer in the mouth and throat than nonsmokers. Drinking alcohol and smoking together raises the risk of head and neck cancer.

The Treatment Team

Many types of head and neck cancer can be treated effectively, especially when found early. For the best possible treatment, it's important to meet and consult with a team of specialists who can help you choose the best course. Often, one doctor—usually your surgeon—will coordinate this team effort.

Treatment for head and neck cancer can affect your appearance as well as your ability to eat, talk, and breathe. Your team can help you manage these changes. Key members of the team include a:

- **Head and neck surgeon** to evaluate and remove tumors and coordinate your care before, during, and after treatment
- **Reconstructive (plastic) surgeon** to improve appearance or function

- **Radiation oncologist** to treat the cancer with radiation
- **Medical oncologist** to treat the cancer with chemotherapy (anti-cancer drugs)
- **Speech pathologist** to help you improve your ability to talk and swallow, if these functions are affected
- **Dentist and/or a prosthodontist** who can replace teeth and parts of the jaw, to maintain good oral health
- **Dietitian** to make sure you eat the right foods to maintain your strength
- **Physical therapist** to ensure that muscles—especially those in the head and neck affected by surgery—continue to function properly and stay strong
- **Psychologist and/or oncology social worker** to help you deal with the emotional and practical concerns of having cancer.

Understanding Treatment Options

As with most cancers, there are three main treatments for head

Signs and Symptoms

The warning signs of head and neck cancer:

- Painless white or red patch in the mouth
- Hoarseness or change in voice
- Sore throat or a mouth sore that does not heal
- Painless lump in the mouth or neck
- Difficulty chewing, swallowing, or breathing
- Frequent nose bleed, particularly on one side of the nose
- Hearing loss or ear pain, particularly in one ear
- Blood in saliva or phlegm
- Weight loss or fatigue

Risk Factors for Head and Neck Cancer

- **Tobacco use** Chewing tobacco increases risk.
- **Heavy alcohol use**
- **Too much sun exposure** Sunlight increases the risk of cancer on the face, especially the lips.
- **Gender** Men are about twice as likely as women to develop head and neck cancer.
- **Age** Risk rises in people over age 40.
- **Ethnicity** People of African descent are at higher risk for some types of head and neck cancer.
- **Toxic substances** Exposure to environmental toxins, such as asbestos, certain metals (including nickel and cadmium), wood dust, paint fumes, and some industrial chemicals, can raise risk.
- **Stomach acid** Even if you don't have heartburn, acid rising from the stomach (what doctors call "reflux") can harm throat tissues.

and neck cancer: surgery and radiation, which can be used alone or in combination, often with chemotherapy.

SURGERY

Surgery to remove tumors is a common treatment of head and neck cancer. In addition, head and neck surgeons often perform a **neck dissection**. For this procedure, the surgeon removes groups of **lymph nodes** from the sides or middle of the neck, where head and neck cancer often spreads. Finding tumor cells in the lymph nodes helps determine further treatment.

Reconstructive surgery is often done to improve a person's appearance or to make it easier to eat, drink, chew, swallow, or talk. Most reconstructive, or plastic, surgeons use some type of **flap**—a piece of tissue removed from one part of the body and reinserted into another. For example, a flap can be used to

rebuild areas of the tongue or lining of the mouth that had to be removed during treatment.

Recent advances allow surgeons to reconstruct areas of the head and neck where skin, bone, muscles, nerves, or blood vessels were damaged or removed during surgery. For instance, experts have developed dental implants to which bone and connective tissues can attach. This allows the body to hold the implant securely, restoring a more normal appearance and function to the mouth and jaw. This technology has improved the quality of life of people whose cancer has damaged bones of the mouth and face.



RADIATION

Several new technologies have made radiation treatment more effective:

- **Intensity modulated radiation therapy (IMRT)** allows the use of many radiation beams of differing intensity. This creates a “cloud” of radiation that targets the tumor more effectively than traditional radiation, while reducing damage to nearby tissues.
- **Radiosensitizers** are drugs taken by mouth or through a vein. These agents “sensitize” cancer cells so that radiation is more likely to destroy them.
- **Radioprotectors** are drugs designed to protect the normal cells near tumors from the harmful effects of radiation. For example, the drug amifostine (Ethyol) protects the salivary

glands of the mouth, reducing the dry mouth that is a common side effect of radiation.

CHEMOTHERAPY

Chemotherapy can help shrink tumors as well as prevent head and neck cancer from returning after surgery or radiation treatment. It can reduce the chance that the cancer might spread to other parts of the body. Chemotherapy often makes it possible to preserve organs, such as the voice box, that previously would have been removed surgically. In addition, chemotherapy helps decrease symptoms and prolong the lives of patients whose disease has reached a more advanced stage.

Targeted Treatments

Newer types of drugs being studied now for head and neck cancer are not like traditional chemotherapy drugs, which attack tumors but harm healthy tissues as well. The new agents work by specifically targeting cancer cells. These targeted treatments stem from our better understanding of what makes cancer cells grow. To rid the body of tumors, they take advantage of subtle differences between cancer cells and normal cells. The side effects from targeted treatments are often milder and different from side effects that result from chemotherapy.

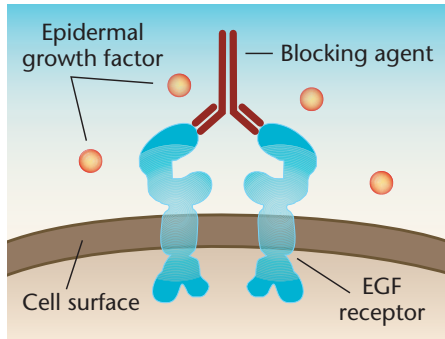
BLOCKING AGENTS

A number of these targeted drugs such as erlotinib (Tarceva) and cetuximab (Erbix) are designed to block a **receptor** on a cancer cell. On each cell's surface, the job of receptors is to serve as portals or "doorways" for specific molecules. The molecules that enter these doorways help the cell to function or grow.

Blocking agents used to fight head and neck cancer target the receptors that receive epidermal growth factor. Hence, they are known as **epidermal growth factor receptors**, or **EGFRs**.

When growth factor enters the cell via the EGFRs, it encourages the cell to grow, divide, and possibly spread as cancer. By binding to the EGFRs, the targeted drugs prevent the receptor from taking in growth factor—and thus prevent the cell from growing into a tumor.

Cetuximab and erlotinib have been approved for use in other cancers, and now cetuximab is also approved for use in head and neck cancer. Because these drugs specifically target cancer cells, they do not have the toxic side effects, such as nausea and vomiting, of many anti-cancer drugs. They can cause an acne-like skin rash or other allergic reaction or—in the case of erlotinib—diarrhea, but generally not more than that.



On the surface of the cancer cell, a receptor, shown here in blue, provides an entry point or doorway for epidermal growth factor. This growth factor encourages cells to grow, divide, and possibly spread as cancer.

CUTTING OFF TUMORS' BLOOD SUPPLY

Another type of targeted treatment in clinical trials for head and neck cancer is bevacizumab (Avastin), which takes advantage of one of the things we know about how tumors grow: Tumors need to have a blood supply, much like normal tissues.

Blood vessels grow in several ways. One way is through the presence of a protein called **v**ascular **e**ndothelial **g**rowth **f**actor, or **VEGF**. This protein stimulates blood vessels to grow in tumors. When tumor cells spread through the body, they release VEGF to grow new blood vessels. These blood vessels supply oxygen, minerals, and other nutrients to feed the tumor.

The Importance of Clinical Trials

There's no question that clinical trials have led to advances in cancer treatment, creating a brighter future for all people with cancer. Clinical trials are the standard by which we measure the worth of new treatments and quality of life as patients go through those treatments. For this reason, doctors and scientists urge patients to take part.

Your doctor can guide you in making a decision about whether a clinical trial is right for you. Here are a few things you should know:

- Often, patients who take part in clinical trials gain access to and benefit from new treatments.
- Before you participate in a trial, you will be fully informed as to the risks and benefits of the trial.
- No patient receives a placebo or "dummy pill" if there is a standard treatment available for the disease. Most trials are designed to test a new treatment against a standard treatment to find out whether the new treatment has any benefit.
- You can stop taking part in a clinical trial at any time for any reason.

Bevacizumab works by stopping VEGF from stimulating the growth of new blood vessels in tumors. Because normal tissues have an established blood supply, they are less affected by the drug. As with cetuximab and erlotinib, the side effects of bevacizumab are generally mild and different from the side effects that result from chemotherapy.

Doing research on these drugs is so important to finding an effective treatment of head and neck cancer. See the box above and our list of resources on page 16 for more information on joining a clinical trial.

Preserving Dental Health

Treatments for head and neck cancer can affect the health of the teeth and gums. Ideally, people with head and neck cancer should see the dentist at least two weeks before starting any treatment, especially radiation. A number of techniques can be used to maintain oral health before, during, and after treatment, including:

- **Pre-radiation fluoride treatment** Because radiation can cause tooth decay, people about to undergo cancer treatment can be given high doses of topical fluoride to reduce damage to the teeth and gums.
- **Denture check** Dentures should be evaluated for proper fit before cancer treatment. Adjustments can then be made to reduce the risk of injury to the gums and mouth tissues during treatment.
- **Mouth care** Radiation can cause cavities, mouth sores, dry mouth, taste changes, and jaw bone stiffness. While undergoing radiation, it's important to keep the mouth moist and clean. Rinse your mouth several times a day with one-quarter teaspoon of baking soda and one-eighth teaspoon of salt dissolved in one cup of warm water. It also helps to rinse frequently with plain water. To keep your mouth healthy, avoid acidic, spicy, or crunchy foods, as well as tobacco and alcohol (including mouth rinses that contain alcohol).
- **Post-treatment plan** Even after you finish treatment, especially radiation, it's important to see your dentist regularly.



A Word About Swallowing and Speech

Many people who are treated for head and neck cancer experience some kind of difficulty swallowing and speaking. Both of these side effects can be managed effectively, especially when diagnosed early. That's why it is so important to meet with a speech pathologist as part of your team care.

In some cases, patients are not even aware they are having difficulty swallowing. But if this important function has been harmed by radiation or surgery, you run the risk of choking on food, beverages, or saliva. Choking can lead to complications such as the need for tube feeding or even pneumonia, which can be life-threatening.

There are some relatively simple tests for swallowing difficulties. A special x-ray called the modified barium swallow (what is known as an "MBS") is one type of test. Another test involves the use of a flexible tube to view the throat and swallowing action. If a problem is found, even years after treatment for head and neck cancer, speech pathologists can design exercises to help correct it. Ideally, any difficulties with speech and swallowing should be identified and treated as soon as possible.

That holds true for speech difficulties as well. Cancer treatment may affect a person's ability to speak clearly, and speech pathologists can help strengthen and maintain the muscles used for speaking. Many patients continue to need the help of speech pathologists even after radiation has ended to deal with "late effects."

Coping with Cancer

Being treated for head and neck cancer can affect your appearance and the way you speak. You're faced with a series of choices that will have a major effect on your life, and maybe you're not sure where to turn. But help is available. Of course,

your most important resources are your health care team, family members, and friends. It is very important to develop good communication with them. You can also turn to these resources:

Oncology social workers and nurse practitioners are specially trained to help you find out more about your treatment options, learn how to navigate the health care system, and get the best care possible. Often, when people are coping with head and neck cancer, they need someone to talk with who can help them and their families sort through the complex emotions and issues that arise. These health care professionals can provide emotional support, help you cope with treatment and its side effects, and guide you to resources. CancerCare offers free counseling from professional oncology social workers on staff.



Support groups Support groups can reduce the feeling that you are going through cancer alone. These groups provide reassurance, suggestions, insight—a safe harbor where you can share similar concerns with your peers in a supportive environment. At CancerCare, people with cancer and their families can take part in support groups in person, online, or on the telephone.

Financial help is offered by a number of organizations, including CancerCare, to help cover the cost of transportation to treatment, child care, or help needed around the home. CancerCare can also refer you to other resources in your community that can provide assistance.

CancerCare's Connect™ booklet *Coping With Cancer: Tools to Help You Live* provides more information on the medical, emotional, and practical concerns faced by people with cancer. Request a copy of this booklet by calling 1-800-813-HOPE (4673).

Frequently Asked Questions

Q My doctor says that, because of my oral cancer, part of my tongue will have to be surgically removed. Will I be able to use my tongue to eat and keep up my weight?

A Even when part of the tongue is removed, most patients can eat and drink with little difficulty. But if treatment does interfere with a person's ability to eat, doctors can surgically insert a tube into the stomach or pass a tube through the nose into the stomach. Special nutritionally complete liquids can be given through these feeding tubes. Often, this is usually a temporary measure. You should know that even when areas such as the tongue, lining of the mouth, or jaw bone have to be removed as part of cancer treatment, reconstructive surgery can rebuild them.

Q I'm concerned that my husband's surgery could leave him disfigured. Can this be avoided?

A It's true that many people undergoing surgery for head and neck cancer can be scarred or even noticeably disfigured. That's why it is so important to have a surgeon who specializes in these sorts of procedures as well as a team of professionals to help patients recover and rehabilitate. The latest surgical techniques for people with head and neck cancer are designed for each individual in order to preserve as much of the organs and tissues as possible. After this type of surgery there are many stages of recovery, with specialists for each: proper wound healing, reconstructive (plastic) surgery when needed, dental care, and physical therapy—all of which help patients regain their quality of life. In some instances, head and neck tumors can be treated with a combination of chemotherapy and radiation, an option you and your husband may wish to discuss with his doctor. It's also important that both you and your spouse cope with the emotional issues that can result

after treatment. Organizations such as CancerCare provide information, counseling, and support.

Q I have cancer of the larynx (voice box). After surgery, will I ever be able to talk again?

A Even if you have a total laryngectomy (removal of the voice box), there are several methods to help you speak again. A speech pathologist can help you decide on the best method.

Q Ever since I had radiation treatment for throat cancer, I feel like I've always got mucus in my mouth. Is that normal?

A Absolutely. Many people who've undergone radiation say they have thick mucus in their mouth. Be sure to tell your doctor about the problem so you can get the right medication to thin the mucus and make it less bothersome.

Q I'm having radiation treatments, and the sores that have developed in my mouth are so painful I can hardly sleep. What can I do?

A Mouth sores, a common side effect of radiation, can sometimes be soothed with ibuprofen (such as Motrin) or acetaminophen (such as Tylenol) for mild pain. Ask your doctor or dentist about viscous lidocaine, a prescription drug. He or she may also suggest you try an over-the-counter mouth wash called UlcerEase. Strong drugs such as **opiates**—a class of drugs that includes morphine—are often prescribed for the pain. Don't resist taking these medications. Although many people fear “addiction” to these powerful drugs, the chances of that happening are very small. Not treating pain leads to unnecessary suffering and slows progress toward better health and feeling more comfortable.

For more information on mouth sores, read the CancerCare Connect™ booklet *Mouth Pain and Discomfort: All You Need to Know About Oral Mucositis*. Order your copy by calling 1-800-813-HOPE (4673).

Glossary

EGFRs Stands for “epidermal growth factor receptors,” portals on a cell’s surface. When growth factor enters the cell via the EGFR, it encourages the cell to grow, divide, and possibly spread as cancer. Some cancer-fighting drugs such as cetuximab (Erbix) and erlotinib (Tarceva) work by targeting EGFRs. Both of these drugs have been approved for use in other cancers, and now cetuximab is also approved for use in head and neck cancer.

flap A piece of tissue removed from one part of the body and reinserted into another. Surgeons often use flaps to repair damage done during cancer treatment.

intensity modulated radiation therapy (IMRT) For this treatment, multiple radiation beams, with differing intensities are used to create a “cloud” of radiation over cancer tumors.

lymph nodes Small “filtering stations” that remove waste and fluids and help fight infections. When invaded by cancer cells, lymph nodes are a jumping-off point from which tumors can spread throughout the body.

neck dissection Surgical removal of lymph nodes located in the sides or middle of the neck, where head and neck cancer often spreads.

opiates A class of drugs that includes morphine. Used to treat severe pain.

prosthodontist A dental specialist who can replace teeth and parts of the jaw.

radioprotectors Drugs designed to protect normal cells near tumors from the harmful effects of radiation.

radiosensitizers Drugs used to “sensitize” cancer cells, making them more vulnerable to radiation.

receptor On each cell’s surface, the job of receptors is to serve as portals or “doorways” for specific molecules. These molecules enter through the doorways of the cell to help it function or grow.

reconstructive (plastic) surgeon A surgeon who can rebuild parts of the head and neck damaged or removed during cancer treatment.

squamous cells Thin, flat cells that form the lining of many parts of the head and neck. Most types of head and neck cancer arise from squamous cells.

VEGF A protein called “vascular endothelial growth factor.” This protein stimulates blood vessels to grow in tumors. When tumor cells spread through the body, they release VEGF and create new blood vessels to supply the tumor cells with oxygen, minerals, and other nutrients.

Resources

CancerCare

1-800-813-HOPE (4673)

www.cancercares.org

American Head and Neck Society

1-310-437-0559

www.headandneckcancer.org

Intercultural Cancer Council

1-877-243-6642

www.iccnetwork.org

National Cancer Institute

Cancer Information Service

1-800-4-CANCER (422-6237)

www.cancer.gov

See this specific link for information on mouth sores and other oral complications: www.cancer.gov/cancertopics/pdq/supportivecare/oralcomplications/patient

National Institute of Dental and Craniofacial Research

1-301-496-4261

www.nidcr.nih.gov/HealthInformation/DiseasesAndConditions/default.htm

Oral Cancer Foundation

1-949-646-8000

www.oralcancerfoundation.org

People Living with Cancer

www.plwc.org

Support for People with Oral and Head and Neck Cancer

1-800-377-0928

www.spoync.org

The Yul Brynner Head and Neck Cancer Foundation

1-843-792-6624

www.yulbrynnerfoundation.org

To find out about clinical trials:

Coalition of Cancer Cooperative Groups

www.CancerTrialsHelp.org

National Cancer Institute

www.cancer.gov/clinicaltrials



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The information presented in this patient booklet is provided for your general information only. It is not intended as medical advice and should not be relied upon as a substitute for consultations with qualified health professionals who are aware of your specific situation. We encourage you to take information and questions back to your individual health care provider as a way of creating a dialogue and partnership about your cancer and your treatment.

All people depicted in the photographs in this booklet are models and are used for illustrative purposes only.

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From the moment of diagnosis, let the hope begin.

When Fran was diagnosed with cancer, she knew that she and her daughter, Rachel, would need support. Both found help and hope with *CancerCare*.

Since 1944, our professional oncology social workers have provided **free** counseling, education and practical help for anyone touched by cancer. *CancerCare* is with you every step of the way.

If we can help you and your family, please call us at 1-800-813-HOPE (4673) or visit www.cancer.org.



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