



If you or a loved one has head and neck cancer, you may be feeling overwhelmed. You may have a lot to process and many doctor visits. It can seem like your health care team is speaking another language. If you have decisions to make about your treatment, it helps to know what to expect with a diagnosis of head and neck cancer.

This booklet gives an overview of how head and neck cancer is diagnosed and treated, and how to cope. We hope this booklet will help you learn more about your options, know what questions to ask, and begin to take control of your cancer and your life.

TALKING ABOUT CANCER

You will hear many words used to describe head and neck cancer. Some key ones to know are:

DYSPHAGIA (*dis-FAY-jee-uh*):

Difficulty swallowing.

LARYNGECTOMY (*LAYR-in-JEK-toh-mee*): The surgical removal of the larynx (voice box).

G-TUBE (*JEE-toob*): A tube inserted through the wall of the abdomen into the stomach. It can be used to give drugs and liquids, including liquid food.

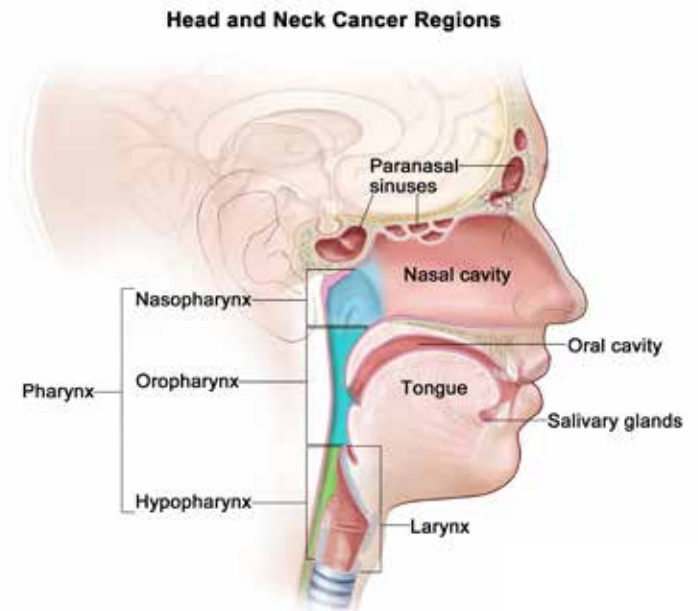
STOMA (*STOH-muh*): An opening or hole in your neck made by surgery. You breathe through this hole after you have laryngectomy surgery.

TRACHEOSTOMY (*TRAY-kee-OS-toh-mee*): An opening surgically created through the neck into the trachea (windpipe) to allow direct access to the breathing tube.

What is Head and Neck Cancer?

There are five main types of head and neck cancer, each named according to the part of the body where it develops:

- **Oral cancer** (oral cavity, in the mouth)
- **Pharyngeal cancer** (pharynx, back of the throat)
 - **Oropharyngeal cancer** (oropharynx)
 - **Hypopharyngeal cancer** (hypopharynx)
 - **Nasopharyngeal cancer** (nasopharynx)
- **Laryngeal cancer** (larynx, voice box)
- **Nasal cavity and paranasal sinus cancer**
- **Salivary gland cancer**



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This booklet doesn't cover thyroid and esophageal cancer because they are treated differently. For more on those cancers, see: www.CancerSupportCommunity.org/thyroid-cancer and www.CancerSupportCommunity.org/esophageal-cancer

Risk Factors:

- Drinking alcohol
- Using tobacco — cigarettes, pipes, chewing tobacco, and cigars
- Increasing age — most head and neck cancers occur in people older than 45
- This cancer is more common in men than women
- Some head and neck cancers, primarily those occurring in the tonsils and the base of the tongue in the oropharynx, are related to the human papillomavirus (HPV), which can also cause cervical cancer. The Epstein-Barr Virus (EBV) is linked with an increased risk of nasopharyngeal cancer

Head and neck cancer accounts for about four out of every one hundred (4%) of all cancers in the United States. About 65,000 people (47,650 men and 17,040 women) develop head and neck cancer each year.

These cancers most often begin in the cells that line the inside the mouth, the nose, and the throat (squamous cells). Head and neck cancers also sometimes begin in the salivary glands.

Diagnosis & Staging

Your doctor will do a physical exam and ask you many questions. It is important to describe how you have been feeling and any changes you have noticed, such as pain, difficulty swallowing, mouth or throat sores, or changes in your voice.

TESTING

Your doctor may order some of these tests:

- **Endoscopy** — a thin, lighted tube is inserted through the nose to look at the

back of your nose and throat. This may be done at the doctor's office, often after using numbing spray.

- **Biopsy** — a sample of tissue is removed to check for cancer.
- **Fine needle aspiration** — this is a type of biopsy done with a small needle to see if you have cancer. It is often used to assess lumps in the neck.
- **Biomarker testing/Molecular testing** of the tumor — Your doctor may want to test your tumor for P16 or HPV. In certain kinds of head and neck cancer (oropharyngeal squamous cell carcinomas), knowing this test result will help your doctor decide on the treatment that is best for you. The tumor may also be assessed for the Epstein-Barr Virus (EBV). This can cause cancers in the nasopharynx (upper part of the throat behind the nose).
- **Fiberoptic endoscopic evaluation of swallowing test (FEES)** — a thin, lighted tube is inserted through your nose and down your throat so that the health care provider can watch how you swallow from inside.

IMAGING

Your doctor may also use the following diagnostic tests:

- **Ultrasound**
- **CT Scan**
- **MRI**
- **PET or PET-CT scan**
- **Modified barium swallow studies** — a series of x-rays taken after you swallow a barium drink.

STAGING

Each cancer is “staged” based on the size or location of the tumor (T), how much it has spread to nearby lymph nodes (N), and if it has spread to more distant parts of the body (M). Stage can range from Stage 0 to Stage IV (4). Generally, the lower the number of your stage, the smaller it is and the less it has spread. Stage 4 cancers are very advanced. They may either be very large local tumors, or may have spread to numerous lymph nodes in the neck and/or to distant parts of your body. HPV-related cancers of the oropharynx can only be Stage 4 if they have spread to areas outside of the head and neck.

Treatment Planning

After being diagnosed with head and neck cancer, you and your doctor will discuss treatment options. It is important for you to be included in the treatment planning throughout your cancer experience.

When you talk to your doctor about your treatment options, ask about the goals of each option and how each option might affect you. Ask about:

- What will give you the best chance of a cure?
- How will your treatment affect your work, family, and social relationships?
- Will you be able to do the things you enjoy?
- How will your appearance and your ability to eat, swallow, or talk be affected?
- How will the short-term and long-term side effects affect your everyday life?

TIPS FOR TREATMENT PLANNING:

- Take someone with you to appointments for support and an extra set of eyes and ears. You can also use your cell phone to record your conversation with your health care provider.
- Talk to your health care team or financial navigator about ways to manage treatment cost before you start treatment.
- Write down your questions before each doctor’s visit. Keep a journal of your side effects.
- Learn the words that doctors use to talk about head and neck cancer. This can help you better understand your test results and treatment options.
- Before you start treatment, meet with a speech pathologist, physical therapist, and occupational therapist so they can evaluate you. They can give you exercises to do throughout your treatment so you recover more quickly.

KEY MEMBERS OF HEAD AND NECK CARE TEAM

- Surgeon (otolaryngologist/head and neck surgeon)
- Reconstructive/plastic surgeon
- Medical oncologist
- Radiation oncologist
- Oncology nurse, nurse practitioner, or physician assistant
- Oncology registered dietitian (An expert on diet and nutrition for cancer patients. Will have “RD”, or “RDN”, or “RD, CSO” after their name.)
- Patient navigator or nurse navigator
- Pain/palliative care specialist (helps relieve side effects)
- Speech language pathologist (helps with speech, voice and swallowing problems)
- Physical therapist, occupational therapist, or lymphedema therapist
- Oncology social worker or therapist to provide emotional support and a financial counselor to help you find financial support

- Dentist or Prosthodontist (dentist with special training in replacing missing teeth and jaw structures)

TALK TO YOUR HEALTH CARE TEAM ABOUT QUESTIONS AND CONCERNS SUCH AS:

- Side effects, like nausea, mouth sores, or problems swallowing or chewing
- If you cannot eat or drink regularly or have consistent pain when doing so
- Inability to complete normal tasks
- Ongoing weight loss
- Dental problems
- Feelings of depression or anxiety

If you are facing a cancer treatment decision, Cancer Support Community’s *Open to Options*® program can help you prepare a list of personalized questions to share with your doctor. Our *Open to Options*® specialists can help you create a written list of specific questions about your treatment plan for your doctor. Call 888-793-9355 to schedule an appointment or to find a Cancer Support Community near you.



QUESTIONS TO ASK YOUR HEALTH CARE TEAM

- What type of head and neck cancer do I have? Where is the tumor located? What stage is the cancer? What does this mean?
- What are my treatment options?
- What treatment plan do you recommend? Why?
- Does your institution have a multidisciplinary tumor board and will my case be presented there to get input from other providers?
- What is the goal of each treatment? Is it to get rid of the cancer, help me feel better, or both?
- What are the possible side effects of each treatment, in the short term and the long term?
- Will this treatment affect my ability to eat, swallow, smell, taste, or speak?
- Will I need physical therapy, speech therapy, and/or another type of rehabilitation (rehab) after finishing treatment?
- How much experience does this center have in treating people with head and neck cancer?
- Should I see other specialists before treatment, such as an oncologic dentist or a speech pathologist?
- How will this treatment affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- Could this treatment affect my ability to become pregnant or have children?
- If I'm worried about managing the costs of cancer care, who can help me?
- Where can I find emotional support for me and my family?

Getting a Second Opinion

Consider getting treatment or a second opinion at a major cancer center or university hospital with a dedicated head and neck cancer team that treats a large number of patients. You may have to travel for this, if you don't live in a major city.

Talking with a second doctor can help you understand your cancer and how to better treat it, or reassure you that the first treatment recommended is best. Let your doctor know if you want a second opinion.

Treatment Options

Many cancers of the head and neck can be cured, especially if they are found early. Treatment depends on:

- The type and stage of cancer
- Possible side effects
- Your preferences
- Your overall health
- How treatment might affect the way you feel, look, talk, eat, and breathe

Each of these treatments may cause side effects.

For more information on coping with side effects, visit www.CancerSupportCommunity.org/SideEffects.

Surgery

During surgery, the goal is to remove the tumor and some healthy tissue that surrounds it. Depending on the location, stage, and type of the cancer, some people may need more than one operation. Surgeries can include:

- Standard surgery to remove the tumor and a “margin” of healthy tissue around it.
- Laser or robotic surgery which goes through your mouth to remove the cancer.
- Lymph node dissection or neck dissection. (Removal of the lymph nodes in the neck, which may be done at the same time as removal of the tumor.)

LARYNGECTOMY

This is a surgery that removes the larynx (voice box). Your doctor may offer this as a treatment for cancer of the larynx (laryngeal cancer).

If you have this surgery, you will need to learn a new way to speak because your voice box will be removed. Your nose and mouth will be permanently separated from your windpipe and lungs, and you will be breathing through a new opening in your neck called a stoma. Having a laryngectomy changes lung function, including increased mucus and coughing.

After a laryngectomy or other surgery in your neck, parts of your neck and throat may feel numb because your nerves have been cut. If lymph nodes in your neck were removed, your shoulder and neck may become weak and stiff. Talking with your doctor about what to expect during your recovery can help you cope with side effects.

RECONSTRUCTIVE (PLASTIC) SURGERY

Reconstructive (plastic) surgery can help restore your appearance. It can also help with chewing, swallowing, breathing, and other functions. These procedures may use nearby or distant tissue from your body to help replace what was removed to get rid of the cancer.

Radiation

There are two types of radiation used for head and neck cancer. External-beam radiation therapy is given from a machine outside the body. Internal radiation therapy (brachytherapy) is given using implants.

Chemotherapy

There are many different chemotherapy drugs that doctors can use against head and neck cancer. The most commonly used drugs include:

- cisplatin (Platinol®)
- carboplatin (Paraplatin®, Onxol®)
- fluorouracil (Acrucil®)
- methotrexate (Rheumatrex®, Trexall®)
- paclitaxel (Taxol®)
- docetaxel (Docefrez®, Taxotere®)

Your doctor may recommend chemotherapy along with your radiation therapy to increase the tumor's sensitivity to treatment. The combination of radiation plus chemotherapy is called chemoradiation.

Targeted Therapy

Targeted therapy is a type of cancer treatment that targets a specific error (mutation) that is helping the cancer grow, divide, and spread. In head and neck cancer, drugs that block EGFR like cetuximab (Erbix®) can help stop or slow tumor growth. These drugs may be used alone or combined with radiation therapy.

For more advanced cancers, doctors may prescribe a combination of the targeted therapy and standard chemotherapy drugs.

Immunotherapy

Immunotherapy is a treatment that helps your immune system fight the cancer better. Two immunotherapy drugs, known as checkpoint inhibitors, are approved for head and neck cancer:

- pembrolizumab (Keytruda®)
- nivolumab (Opdivo®)

These drugs may be used alone or in combination with chemotherapy. For information about the side effects of immunotherapy, visit www.CancerSupportCommunity.org/immunotherapy-side-effects.

Clinical Trials

Be sure to ask about clinical trials. Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's newest treatments were studied in yesterday's clinical trials. Today's clinical trials may become tomorrow's newest treatments. For more information on clinical trials, visit www.CancerSupportCommunity.com/ClinicalTrials.



DAVE & THEA'S STORY

When Thea's husband, Dave, was diagnosed with oral squamous cell carcinoma, she was nervous but determined to stand by him. A difficult surgery and radiation left Dave with severe side effects and a tough road ahead. Thea dedicated herself to his recovery. "Dave is my family. I've got to keep him around."

When Dave was in the hospital and rehab, Thea visited daily. "I watched the nurses to learn how to care for him," she says. Thea spoke up when she had concerns about his care. When Dave couldn't talk, Thea bought him a white board and acted as his voice on phone calls with his grown children. She also learned to prepare meals he could eat.

Dave found ways to make eating work. He uses sauces or toppings to make up for his dry mouth/lack of saliva. While waiting to get dental implants, he cut his food into small, evenly-sized pieces and drank everything through a straw. He also avoided acidic foods, which hurt sore places in his mouth caused by radiation.

During and after his recovery, Thea and Dave attend weekly support groups for head and neck cancer patients and caregivers.

Palliative (Supportive) Therapy

Palliative therapy is designed to prevent or manage side effects of cancer and its treatment. It can include:

- Working with your rehab team (speech-language pathologist, physical therapist and occupational therapist) to learn exercises you can do before surgery to prevent problems in swallowing, swelling, and reduced range of motion in the upper body, neck and jaw. This team will also work with you after surgery.
- Diet counseling, including meal planning, feeding tube formula help, and plans for healthy eating after treatment.
- Speech/language therapy, which can help with swallowing and speech problems by providing ongoing treatment and exercises.
- Learning how to care for your stoma (the new opening created in your windpipe if you had a laryngectomy).
- Working with your dentist to care for and protect your teeth if you have significant oral surgery or radiation therapy.
- Managing pain and other side effects such as dry mouth.

Coping with Head and Neck Cancer

Head and neck cancers can have a big impact on your life. It can affect your speech, swallowing, and breathing. It can affect your self-image if you look different after treatment.

DEALING WITH STIGMA

Smoking, using tobacco products, drinking alcohol, and getting the HPV virus are risk factors for head and neck cancers. If this may have caused your cancer, you may feel judged or to blame. In addition, treatment side effects can cause changes to your appearance and ability to eat. This can leave you feeling self-conscious in social situations. There are strategies for coping with these feelings.

To combat blame, shame and stigma:

- If you smoked, used tobacco products, or drank heavily, forgive yourself. You cannot change the past.
- If someone asks whether you smoked, ask them, “Why do you ask?” Often people are just trying to distance themselves from their own risk of cancer and may not realize how they sound.
- If you hear negative remarks, use the opportunity to educate the speaker. If you ever smoked, you might say, “Yes, head and neck cancer can be caused by smoking, but there are other causes as well.” If you never smoked, use this as a teaching moment and say, “Many people who have never smoked still get head and neck cancer.” If someone mentions head and neck cancer being caused by HPV, you might say “Did you know that most people will have the HPV virus at some point in their lives?”
- Find support from other people with head and neck cancer. You might learn ways they have found to cope with stigma,



changes in body image, or feelings of guilt and focus on living today.

- You will probably need to take a break from your regular hobbies and social activities during treatment and recovery. Work with your rehab team to try to get back involved in those same hobbies and

social activities, if that is possible. Look for new ways to be social with others. People who are isolated from a social support network may be more at risk for things like depression or stress-related illness.

Life After Treatment

EATING AND SWALLOWING PROBLEMS

Eating healthy before, during, and after treatment is important because it can help prevent weight loss, lack of appetite, and other side effects of treatment. It can also help you feel better and respond better to your cancer treatment. Work with your speech pathologist, medical team, and nutritionist to adjust to changes in diet and regain your ability to swallow. To learn more, see our *Eating Well With Head & Neck Cancer* booklet at www.CancerSupportCommunity.org/HNCEating.



RESTORING SPEECH

After a laryngectomy, it is often still possible to restore speech. It may take some time for you to learn new ways to communicate following treatment. Below are the primary ways to restore speech:

Tracheo-esophageal puncture (TEP)

This is the most common way that surgeons try to restore speech. This procedure creates a connection between the windpipe and esophagus through a small hole at the stoma site. A silicone device called a voice prosthesis is placed in a small hole created between the windpipe and esophagus to create voice. Patients work with a speech-language pathologist to learn to talk using this device.

Electrolarynx

The battery-operated device is placed at the corner of your mouth or against the skin of your neck. When you press a button on the device, it makes a vibrating sound. By moving your mouth and tongue, you can form this sound into words. You'll need training with a speech therapist to learn to use it properly.

Esophageal speech

With training, some people learn to swallow air into the esophagus (the tube that connects your mouth to your stomach) and force it out through their mouth. As the air passes through the throat it will cause vibrations which, with training, can be turned into speech. With the development of TEP speech, esophageal speech is less frequently used.

STOMA CARE

Once you recover from your laryngectomy, you will learn to care for your stoma (breathing hole in your neck). You will need to keep the stoma clean, or else it will get blocked. Your doctor and nurses will teach you how to keep it clean, remove mucus from it, and cover it when you are outdoors. They will also explain how to bathe, exercise, cough, and sneeze with your stoma.

HEAD AND NECK LYMPHEDEMA

This is swelling caused by extra lymph fluid that builds up in tissues. It can occur from tissue damage after radiation therapy. This can affect speech and swallowing function. Head and neck lymphedema is treated with manual lymphatic drainage and, in some cases, compression bandages. If you feel or notice any swelling, let your health care team know immediately.

TRISMUS

This is when your mouth doesn't fully open. It can be caused by tissue damage from radiation. Trismus is treated with exercise therapy and devices to help stretch your mouth opening.

Tips for Living with Head and Neck Cancer

DENTAL CARE

After head and neck surgery, always tell any dentist you see about your treatment. Ask them if they have experience treating head

and neck cancer patients. If they don't, ask for a referral to a dentist who does.

DEPRESSION AND ANXIETY

Many people with head and neck cancer feel overwhelmed. It is normal to feel alone, angry, anxious, or feel a sense of despair. Depression and anxiety can make it difficult for you to cope with symptoms and treatment, and can affect your well-being. Make sure to tell your doctor if you are feeling depressed or anxious. Your health care team can help you get treated for these conditions which can make a huge difference in your daily life.

COST AND EXPENSES

Treatment for head and neck cancer and follow-up appointments can be costly. Keeping up with these costs can be overwhelming. However, there are resources that can help. For tips on how to manage treatment costs and finding financial assistance, visit

www.CancerSupportCommunity.org/Cost or call our Helpline at 888-793-9355. Also visit the Head and Neck Cancer Alliance at www.headandneck.org.

PHYSICAL ACTIVITY

Exercise is important to keep your body and mind healthy after head and neck cancer treatment. Ask your health care team what exercises — such as walking or chair yoga — you can safely do.

SUPPORT GROUPS

Head and neck cancer support groups near you or online will allow you to talk about your feelings. Other people who have had the same experiences may give you ideas that can help you. Some groups are made up only of people with cancer, while others include spouses, family members, or friends.

TALK ABOUT YOUR APPEARANCE

Prepare how you will answer when someone asks you about the changes to your appearance, your speech, or your eating habits. Practice your answer with caregivers and family members. If you cannot speak, or are concerned about people understanding you, have your answer printed on a card you can hand to someone.

SOCIAL GATHERINGS

Prepare for social gatherings where there will be food. For instance, let your host know in advance it may be uncomfortable for you to sit at a table when everyone else is eating. You could come later after everyone has eaten. If you don't want to eat in public, try to find different ways to be social with friends and family so you don't feel isolated.

TRAVEL

You can continue to travel after you have a laryngectomy, but it takes planning. Bring along a folder with your medical information in case you need to receive medical care while away from home. Also carry a kit with supplies to care for your stoma. If you are flying, keep this in your carry-on bag — don't check it.

Coping for Caregivers

Your family and friends may help you as a caregiver while you are in treatment and recovery. Your caregivers may help you with physical care or emotional support. Some caregivers assist with money matters, insurance, household chores, rides, or making appointments. Caregivers may or may not live with you. However they help, caring for someone who has cancer is not easy. People who do so need support and help.

Caregiving can be a full-time job. A caregiver with another job may miss days of work or have trouble getting work done. Some caregivers take unpaid leave, turn down promotions, or lose benefits. It can be very stressful to care for someone and worry about keeping your job at the same time.

Caregivers are often very focused on their loved one. They may neglect their own health and well-being. It is important for caregivers to take care of themselves. Many caregivers benefit from support groups. They can talk about emotional issues, share concerns, obtain help, and feel less alone. To learn more, visit www.CancerSupportCommunity.org/Caregivers.



TERRY'S STORY

When Terry was diagnosed with stage II laryngeal cancer in March 2015, he was an executive in the plasma industry. He played guitar and piano and sang in a band every week. "I was the funny front man," he says.

Terry, now 65, has gone through 35 radiation treatments, a laryngectomy, and two pectoral flaps (reconstruction surgeries that use skin and some muscle taken from your chest). He's retired, and no longer sings, although he still plays guitar and piano. He also is the family cook.

One of the biggest changes for Terry has been the way he communicates. He uses Tracheo-Esophageal Puncture (TEP) to talk. "I can communicate, but how I talk is not relational," he says. "I can say words but I can't express emotion. I can sound angry, even though I'm a really pretty happy person overall."

To people who are facing a laryngectomy, he says, "I am honest and tell people it's hard, but I'm walking and talking and eating, and I couldn't do that for a long time. I promise, it gets better. Cancer is not a death sentence. You need to find the 'new you.'"

Resources for Head and Neck Cancer

International Association of Laryngectomees — www.theial.com

Head & Neck Cancer Alliance — Helpline: 866-916-5107 • www.headandneck.org

Support for People with Oral and Head and Neck Cancer (SPOHNC) — 800-377-0928 • www.spohnc.org

Cancer Support Community Resources

The Cancer Support Community's (CSC) resources and programs are available free of charge. Call 888-793-9355 or visit www.CancerSupportCommunity.org for more info.

Cancer Support Helpline® — Have questions, concerns or looking for resources? Call CSC's toll-free Cancer Support Helpline (888-793-9355), available in 200 languages Mon - Fri 9am - 9pm ET.

Frankly Speaking about Cancer® — Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs.

MyLifeLine — CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond.

Sign up at www.MyLifeLine.org.

Open to Options® — Need help making a cancer treatment decision? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club.

Services at Local CSCs and Gilda's Clubs — With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation.

Cancer Experience Registry® — Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

Grassroots Network — Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

FRANKLY SPEAKING ABOUT CANCER: HEAD AND NECK CANCER PARTNER



**FRANKLY SPEAKING ABOUT CANCER: HEAD AND NECK CANCER
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