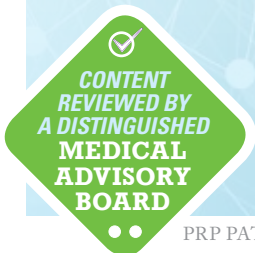


FREE take one

IMMUNOTHERAPY for the treatment of **HEAD & NECK** *Cancers*



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Society for Immunotherapy of Cancer
www.sitcancer.org

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For more information on cancer immunotherapy...

Visit sitcancer.org/patient for patient resources from the Society for Immunotherapy of Cancer (SITC)

FOR MORE INFORMATION SEE PAGE 13

Immunotherapy offers new hope with more treatment options

Learning you have head and neck cancer can feel overwhelming. Give yourself time to digest the news, and then focus on learning as much as you can about your exact diagnosis. Knowing key information will better prepare you to make well-informed decisions with your doctor. This guide explores head and neck cancer, the immune system, the types of immunotherapy approved to treat certain head and neck cancers and ways to help manage your treatment.

The ability to harness the potential of the immune system to treat cancer is offering people with head and neck cancer a new treatment option, which is improving patient outcomes and giving them an enhanced quality of life. Immunotherapy is a very different way of treating cancer. It uses the body's own immune system to recognize and attack cancer cells that may have been hiding and targets them for destruction. It is a systemic treatment, which means the drugs travel through your bloodstream to all parts of your body. The hope is that this therapy targets the cancer cells to kill them and keep them from dividing.

Head and neck cancer describes a variety of malignant (cancerous) tumors that affect the oral cavity (mouth), pharynx (throat), larynx (voice box), nose, sinuses, salivary glands and thyroid. Most of these cancers begin in the squamous cells, or the thin cells that line the moist tissues inside of the nose, mouth and throat, while other cancers form in the cells of the salivary glands and thyroid (see *Types of Head & Neck Cancer*, page 4).

The type of tissue in which the cancer begins and the location in the body where it first develops is referred to as the primary site. In advanced disease, cancer cells may break away from the primary tumor and are carried in the lymphatic channels or bloodstream until they get trapped in nearby lymph nodes or organs. Metastatic cancer occurs when malignant (cancerous) cells spread to distant sites such as the liver, lungs or bones. These are known as metastases. Regardless of location, the metastases are still considered head and neck cancer and are treated as such.

Head and neck cancer often recurs (returns) after treatment at the primary site. It may recur in the same or nearby area (local or regional spread) or in a distant site after initial treatment. This may return months or years after your initial treatment. Although your treatment plan was designed to elimi-

nate all cancer cells, a few may have remained undetected. If this happens, the remaining cancer cells can multiply and become what is known as recurrent cancer. Keeping follow-up appointments to monitor for a recurrence or a secondary cancer is crucial for detecting and treating head and neck cancers early (see *Know the Risks*, page 2).

WHAT IS THE IMMUNE SYSTEM?

To understand how your immune system can be used to treat cancer, it's helpful to know it's a complex network of cells, molecules, organs and lymph tissues working together to defend the body against germs, microscopic invaders and even cancer cells.

The first job of the immune system is to distinguish between what is part of the body (self) and what is not part of the body (non-self or foreign). Once the immune system determines that a cell is non-self, or foreign, to the body, it begins a series of reactions to identify, target and eliminate the non-self cell. When you scrape your elbow, for example, the skin's protective barrier is broken and harmful non-self substances can easily enter the body (see Figure 1).

The lymphatic system, which is made up of the spleen, thymus, adenoids and tonsils and lymph nodes, is a driving force in the immune system. Lymph, a clear fluid, is circulated throughout the body through the lymph nodes. It collects and filters bacteria, viruses, toxins and chemicals, which are circulating in the lymphatic system and bloodstream. Lymph nodes are located throughout the body, with large concentrations near the chest, abdomen, groin, pelvis, underarms and neck. The immune system recognizes abnormal cells or germs by "seeing" specific proteins, or other molecules, that are called antigens.

Lymph contains lymphocytes, a type of white blood cell that attacks infectious agents. The two main types of lymphocytes are B-lymphocytes (B-cells) and T-lymphocytes (T-cells).

B-cells develop in the bone marrow and mature into either plasma cells or memory cells. Plasma cells make antibodies to fight germs and infection. Memory B-cells help the immune system remember which antigens attacked the body so they can recognize them and respond if they return.

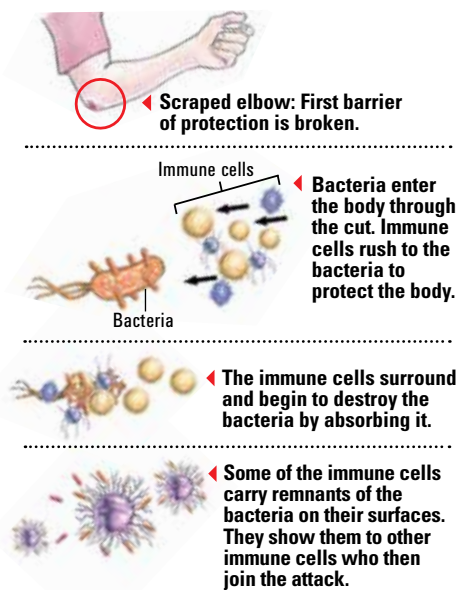
T-cells also develop in the bone marrow and mature into four types: helper, killer, regulatory and memory T-cells. Each responds to non-self or foreign antigens in different ways.

HOW THE IMMUNE SYSTEM ELIMINATES CANCER

The normal process for an immune response begins when B-cells and helper T-cells identify a threat (non-self antigen) and alert the rest of the immune system. The body then ramps up its production of T-cells to fight and destroy the non-self cells.

The immune system uses the same process to recognize and eliminate cancer as it does to remove other non-self cells, but the process is more complicated. Cancer cells are created by the body, so the normal ways to find and fight invading cells from outside the body aren't always effective. The immune system may have difficulty identifying cancer cells as non-self. It may still see them as part of the body and not coordinate an attack. If the body can't tell the difference between tumor cells and normal cells, the tumor cells may be able to evade

FIGURE 1
▲ NORMAL IMMUNE RESPONSE



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► SITC Guidelines: The Society for Immunotherapy of Cancer (SITC) offers guidelines for medical professionals regarding the recommended use of immunotherapy treatment and immune-related adverse event management. Guidelines for head and neck cancers and several others are currently available at → www.sitcancer.org/guidelines

or “hide” from the immune system.

Additionally, cancer cells can change and use multiple methods to escape or trick the immune system. One way is to produce proteins on their surface to hide from the immune system, like camouflage. Another is to create their own messengers (cytokines), which means that the cancer cells can communicate and confuse other immune cells, allowing the cancer to take control of certain parts of the process the body uses to regulate the immune response. This means that even if the immune system recognizes the cancer, it may not be able to successfully start or sustain an attack long enough to kill the cancer cells.

The longer the cancer cells face a weakened immune response, the more they're able to adapt, and the easier it is for them to manipulate immune cells inside the tumor's location (sometimes called the tumor microenvironment). Immunotherapy offers the immune system reinforcements to keep up its fight.

IMMUNOTHERAPY AS A POTENTIAL TREATMENT PATH

The first immunotherapy drugs for head and neck cancers were approved in 2016 to treat recurrent or metastatic head and neck squamous cell carcinoma (see *Treatment Options*, page 6). They are considered a significant leap forward in treating this cancer.

To receive immunotherapy, you may be required to meet certain criteria. One requirement may be biomarker testing because some types of immunotherapy are approved to treat cancer that expresses a protein called programmed cell death-ligand 1 (PD-L1). If

there is a large amount of this protein in/on your tumor, immunotherapy alone may be used. If there is not, chemotherapy may be combined with immunotherapy. If you have a pre-existing autoimmune disorder, such as rheumatoid arthritis or lupus, be sure to discuss it with your doctor.

It's important to note that immunotherapy is not effective for every person, even if it is approved for that person's cancer type. Doctors and scientists are involved in clinical trials to learn why (see *Clinical Trials*, page 8). Research is seeking to find more types of immunotherapy that may be used for head and neck cancers to improve effectiveness and to determine the best candidates for this treatment option. Ask your doctor if you should consider a clinical trial.

Other treatments used to treat head and neck cancer include the following:

- Surgery is the removal of the tumor and surrounding normal tissue.
- Chemotherapy involves drugs to stop the growth of cancer cells. How it is given depends on the type and stage of the cancer.
- Radiation therapy is the use of high-energy radiation to kill cancer cells or stop them from growing.
- Targeted therapy includes drugs or other substances to attack cancer cells directly, usually by targeting a specific abnormal gene, protein or receptor.

Depending on the type and stage of your cancer and characteristics such as previous treatments, age and general health, your doctor will recommend a treatment plan. ■



KNOW THE RISKS

People who have been diagnosed with head and neck cancer have an increased chance of developing another primary cancer, making it important to be aware of certain risk factors.

- Human papillomavirus (HPV) is particularly associated with cancers of the oropharynx (back of the throat), including the tonsils and base of tongue. HPV vaccines are now available to help prevent HPV-related cancer and other conditions.
- Cigarette smoking
- Chewing tobacco
- Excessive use of alcohol
- Poor dental hygiene
- Prolonged exposure to the sun, which is linked to cancer of the lip

The risk is higher for people who use both tobacco and alcohol than for people who use only one or the other.

For more information about reducing your risk of head and neck cancer, talk with a member of your health care team or use the following resources.

- **American Cancer Society:**
866-QUIT-4-LIFE (866-784-8454)
- **American Lung Association:**
800-LUNGUSA (800-586-4872)
- **American Society of Clinical Oncology:**
www.cancer.net
Health Risks of E-cigarettes, Smokeless Tobacco and Waterpipes
HPV and Cancer
Stopping Tobacco Use After a Cancer Diagnosis
- **National Cancer Institute:**
www.cancer.gov
Alcohol and Cancer Risk
- **Smokefree.gov:**
877-44U-QUIT (877-448-7848)
- **U.S. Department of Health and Human Services:**
800-QUIT-NOW (800-784-8669)

Staging Brings Treatment Plan Into Focus

➔ **Staging is how doctors determine the extent** of your cancer, where it is located and whether it has metastasized, or spread, to nearby organs, tissue, lymph nodes or other parts of your body. These factors are used to classify the cancer and help your doctor develop a personalized treatment plan for you.

The TNM staging system, developed by the American Joint Committee on Cancer (AJCC), is typically used to stage head and neck cancers. This system classifies the cancer by tumor (T), node (N) and metastasis (M). The T category describes the size and location of the primary tumor. The N category describes lymph node involvement, indicating whether the lymph nodes show evidence of cancer cells. The number and location of these lymph nodes are important because they show how far the disease has spread. The M category describes distant metastasis (spread of cancer to another part of the body), if any.

Once the cancer has been classified, an overall stage is assigned. Head and neck cancers may be staged as Stage 0 through Stage IV. Stage 0 (also known as “in situ”) is a precursor of an invasive cancer. Stages I and II are generally confined to the local area where the cancer is found, and Stage III has

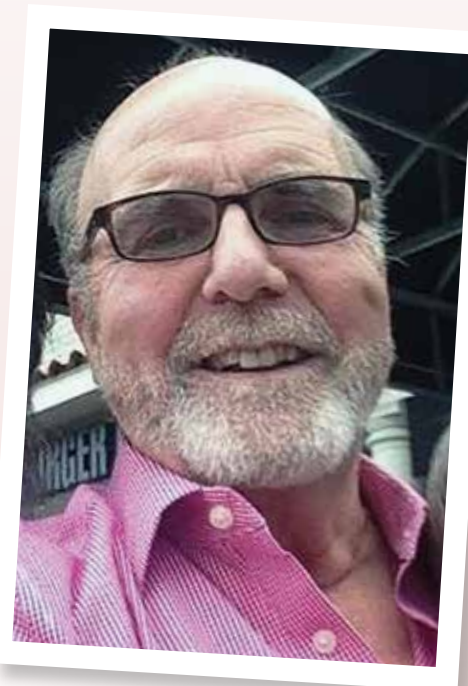
spread to the regional lymph nodes in the neck. Stage IV is further divided into Stages IVA, IVB and IVC. Stage IVA and IVB are locally or regionally advanced disease, and Stage IVC has spread to distant sites, such as the liver, lungs or bone. These basic stages are designed to group patients who have a similar prognosis (outlook). This grouping allows doctors to more accurately predict survival outcomes for patients depending on the type of treatment they receive.

The staging tables for the types of head and neck cancer discussed in this guide are available online. For throat cancer, staging differs for HPV+ and HPV- diagnoses, and thyroid cancer staging differs by type. Look carefully at the table headlines to ensure you view the information that applies to you.

- PatientResource.com/Head_and_Neck_Laryngeal.aspx
- PatientResource.com/Head_and_Neck_Oral.aspx
- PatientResource.com/Head_and_Neck_Salivary.aspx
- PatientResource.com/Head_and_Neck_Sinus_Nasal.aspx
- PatientResource.com/Head_and_Neck_Throat.aspx
- PatientResource.com/Head_and_Neck_Thyroid.aspx

Out of Tragedy Comes Resilience and Compassion

When John Brislin, an avid biker and golfer, broke his neck in October 2017, he was surprised to learn that the tests showed he also had cancer at the base of his tongue. Adjusting to all of this news at once was difficult, but he had his neck plated and then began cancer treatments. Currently, he has no evidence of cancer and is back riding bikes, golfing and enjoying time with his wife and family. He volunteers at Friend for Life Cancer Support Network to help other head and neck cancer survivors.



➔ **In October 2017, I was riding my bike at a park** where vehicles aren't allowed. Pathways and bridges have barriers to prevent cars from entering, and unfortunately I hit one of them. I immediately began losing feeling from the neck down. People nearby helped me call my wife and son, but I was so worried that I jumped into my car and drove myself to the ER.

The ER doctor wanted to do a CT of my neck, but I am very claustrophobic and refused at first. After being given morphine, I finally agreed. The CT scan confirmed I broke the C2 vertebra in my neck and that I had cancer at the base of my tongue. I was shocked. I had experienced pain in my mouth off and on in the past, but I didn't think it was anything serious and didn't see a doctor.

I wasn't a good candidate for cancer surgery because of my broken neck. I had to get vertebrae C2 through C5 plated before my doctor would start treatment with chemotherapy and radiation. Next, I had the procedure to put in a port for the chemotherapy. Then I was fitted for a thermoplastic mask for the radiation treatments. Considering my claustrophobia, I was concerned, but my nurses were very helpful. They recommended watching videos online to get familiar with what would happen. I was still very nervous for the first fitting. The radiation technicians were really sweet and kind to me through the fitting and all of my treatments.

The first radiation treatment was only 8 to 10 minutes long. Eventually I got used to it and could count down the time I had left, which allowed me to relax and zone out during the treatment.

My doctor warned me that the side effects could make it difficult to eat, and he suggested I get a G-tube (feeding tube). I resisted, and I bet him a bottle of wine that I could get through it without the tube. I completely lost my sense of taste, but I continued eating out of habit. Overall, I tolerated the chemotherapy fairly well with no nausea, just a weird feeling all over and a swollen neck.

The treatment worked but a routine follow-up CT showed a suspicious spot in my nasal cavity. The doctor was unable to remove it surgically, and he had a committee of doctors review my case. They couldn't positively confirm it was cancer, but they agreed it should be treated as cancer. My doctor offered me immunotherapy.

Taking immunotherapy was so much easier than chemotherapy. It was given as an infusion that took less than an hour. The only real side effect was diarrhea, but my doctor had warned me about it and prescribed medications to counteract it. Now, the spot seen on my last scan is gone, and I continue to be monitored every three months. I have regained my strength, ride my bike again and golf a few times a week. I don't worry about a recurrence because if I have one, I know I'll start treatment again.

My family and friends from my hometown supported me through everything, but the most help came from the father of my son's friend in Colorado, who also had head and neck cancer. It helped to talk to someone who had gone through something similar, and I realized I wanted to be there for others.

My nurse therapist recommended I volunteer for Friend for Life Cancer Support Network, an organization made up of cancer survivors and caregivers who provide compassionate, one-on-one support to others diagnosed with cancer and their loved ones. Now I talk with other people about head and neck cancer and offer my support as they work through their diagnoses. When talking to other survivors, I've learned that you need to be respectful of their time and space. Some may want to talk more than others. Go at their pace.

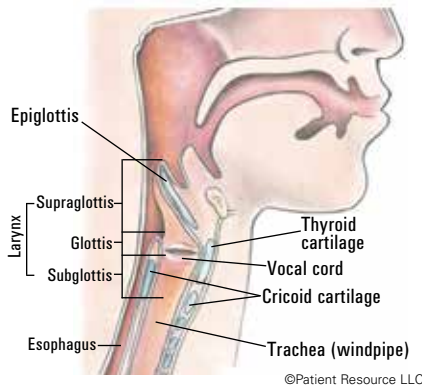
Another way I help others is by sharing my experience with first-year students in medical school. It helps them to ask questions and better understand the issues surrounding head and neck cancer patients.

Be sure to ask your doctor plenty of questions. Don't let the negative thoughts build up in your mind. Share your concerns with your health care team. They are there to help you.

One thing to remember about cancer is that once you have it, you're a member of that community forever. You're also surrounded by some of the nicest people who want to help you. ■

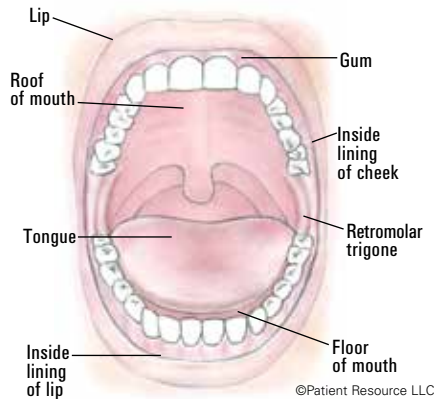
» Head and neck cancers:

LARYNGEAL CANCER



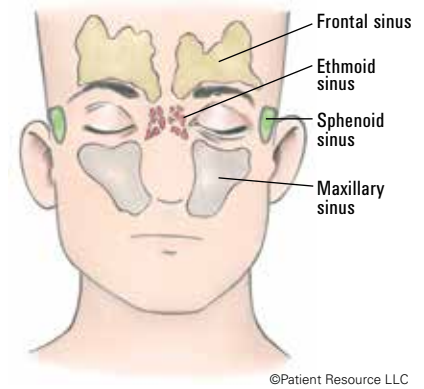
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ORAL CANCER



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SINUS AND NASAL CANCER



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▲ Often called the voice box, the larynx is a small, hollow organ in your throat that houses your vocal cords. The cartilage walls of the larynx form your Adam's apple directly in front of the vocal cords, protecting them. Though only about 2 inches long, the larynx has three parts: the glottis (or vocal cords) is in the middle with the supraglottis above and the subglottis below.

Cancer of the larynx, also called laryngeal cancer, typically develops in the lining in thin, flat cells called squamous (SKWAY-mus) cells. Symptoms may include hoarseness or other voice changes, a persistent sore throat, a constant cough, ear pain, a lump in the throat, painful swallowing, trouble breathing or coughing up blood.

Clinical guidelines for laryngeal cancer treatment recommend a comprehensive pre-treatment evaluation for all patients. This should include a baseline assessment of voice, breathing and swallowing function, as well as counseling to thoroughly discuss each treatment option and its benefits, risks and potential effects on your quality of life.

▲ The oral cavity includes your lips, gums, lining inside the lips and cheeks, hard palate (front part of the roof of the mouth), the front two-thirds of your tongue and the floor of the mouth underneath it, and the retromolar trigone (the small space behind each wisdom tooth).

The majority of head and neck cancers begin in the oral cavity. The tongue is the most common site. Oral cancers typically form from squamous (SKWAY-mus) cells, which line the moist surfaces of the mouth. Early-stage symptoms may include minor mouth pain, bleeding, jaw swelling or a white or red patch (ulcer) on the gums, tongue or lining of the mouth. Because there is no recommended routine screening for oral cancers and these symptoms can signal many other conditions, oral cancers are frequently not diagnosed until late stage.

Cancers that form in the back of the mouth, including the base of the tongue, posterior (rear) roof of the mouth and tonsils, are considered throat cancer (see *Throat Cancer*, page 5).

▲ The nasal cavity begins above the roof of the mouth, dividing in front to form the two nasal passages inside your nose and curving down in the back to meet your throat. The paranasal sinuses are hollow spaces inside the bones surrounding the nose, and they are named for the bones: the frontal, ethmoid, sphenoid and maxillary sinuses.

The nasal cavity and paranasal sinuses work together to filter, moisten and warm the air you breathe before it reaches your lungs. Cells in the sinuses make mucus to keep the nose from drying out.

Cancer affecting this area is typically squamous (SKWAY-mus) cell carcinoma, most commonly in the maxillary sinuses. Symptoms may include persistent sinus-related blockage, pressure, pain or headaches; a recurring sore inside the nose; nosebleeds; pain or swelling near the eyes; vision or hearing changes; facial numbness; a lump on the face or neck, inside the nose or on the roof of the mouth; or loose teeth, pain in the upper teeth or dentures that no longer fit well. A small number of nasopharyngeal cancers, especially in people of Asian descent, may be caused by the Epstein-Barr virus (EBV)*.

→ QUESTIONS TO ASK YOUR MEDICAL TEAM

- ▶ What is the goal of my treatment? _____
- ▶ How will my treatment be administered? IV or oral? Should I do anything to prepare? _____
- ▶ How often will I have treatments? How long will they last? _____
- ▶ Will I be able to work, travel and continue my regular activities during treatment? _____

Understanding the basics

SALIVARY GLAND CANCER

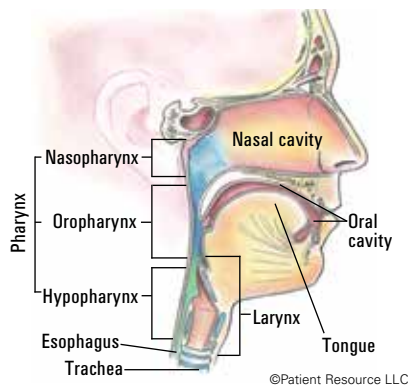


▲ **Salivary glands** make saliva to help you swallow, chew and digest food and to keep your throat moist. You have a set of three major glands inside and near your mouth on each side of your face. The parotid glands are in front of your ears, the submandibular glands are below your jaw and the sublingual glands are under the floor of your mouth. You also have hundreds of microscopic minor salivary glands in the moist linings throughout your oral cavity, nose, paranasal sinuses, pharynx (throat) and larynx (voice box).

Many tumor types can develop in the major salivary glands, although many are not malignant (cancerous). Tumors in the minor glands are relatively rare but are more often malignant.

Salivary gland cancer may be found during a routine dental visit or physical exam. Symptoms may include a lump in an ear, cheek, jaw, lip or inside the mouth; fluid draining from the ear; trouble swallowing; difficulty opening the mouth wide; facial numbness or weakness; or persistent facial pain.

THROAT CANCER



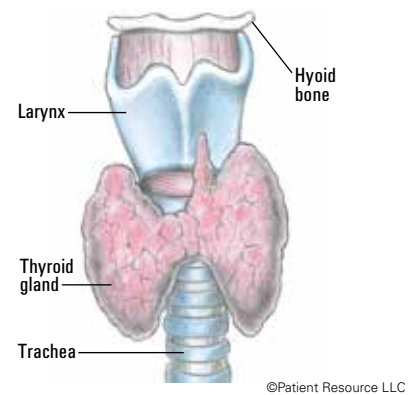
▲ **The throat, or pharynx**, is a hollow tube about 5 inches long that starts at the back of the nasal cavity and leads to the esophagus.

Throat cancer often starts in the squamous (SKWAY-mus) cells that line its mucus membranes. These cancers may be more specifically referred to by the affected region. Nasopharyngeal cancer begins in the nasopharynx behind the nose. This diagnosis may be linked to the Epstein-Barr virus (EBV)*. Oropharyngeal cancer occurs in the oropharynx, the middle region that includes the soft palate (back of the roof of the mouth), base of the tongue and tonsils. The majority of oropharyngeal cancers are related to the human papillomavirus, or HPV (see *Know the Risks*, page 2). Hypopharyngeal cancer starts in the hypopharynx, the lowest region.

Symptoms may include a persistent sore throat; painful swallowing; difficulty moving the tongue, fully opening the mouth, swallowing, breathing or speaking; ear pain or decreased hearing; voice changes; or a lump in the back of the mouth, throat or neck.

**Also known as human herpesvirus 4, it is one of the most common human viruses.*

THYROID CANCER



▲ **The thyroid** is a butterfly-shaped gland in your neck just below the larynx (voice box). It produces hormones that control your heart rate, body temperature, growth and metabolism (how quickly food is changed into energy). The parathyroid glands (not shown), which are four pea-sized organs on the back of the thyroid, produce hormones controlling blood calcium levels.

The primary types of thyroid cancer are anaplastic, follicular, medullary and papillary, which is the most common. Papillary and follicular are sometimes referred to as differentiated thyroid cancers and are staged as such. Their cells look similar to normal cells when viewed under a microscope, and they tend to spread and grow slowly. In contrast, medullary and anaplastic thyroid cancer cells are undifferentiated or poorly differentiated, meaning they don't resemble normal thyroid cells. Both tend to grow and spread more quickly, and anaplastic thyroid cancer is very aggressive.

Symptoms may include a lump, swelling or pain in the front of the neck; hoarseness or other voice changes that don't go away; trouble swallowing or breathing; or a constant cough not related to a cold. ■

► **How will we know if the treatment is working?** _____

► **Will I be able to receive other types of treatment if immunotherapy fails at some point?** _____

► **What side effects are possible, and what can I do to manage them?** _____

► **Will treatment affect my fertility? What steps can we take to preserve my fertility?** _____

► **Whom do I call with questions after hours or in an emergency?** _____

Immunotherapy unlocks the immune system's potential

This therapy is providing doctors with a new view of how to treat certain types of cancer. First approved in 2016 by the Food and Drug Administration (FDA) for metastatic and recurrent head and neck cancers, immunotherapy offers a transformative new treatment option for a disease that has not had many new medications approved in recent years.

Immunotherapy trains the immune system to enhance its response to cancer. It has the potential for a lasting response that can extend beyond the end of active treatment.

Scientists have discovered multiple ways to engage or boost the immune system with immunotherapy. Research is ongoing in clinical trials to improve the existing therapies and to explore new ones.

Current immunotherapy, used alone or in combination with other treatments, is typically given as an intravenous (IV) infusion. Immunotherapy may be used as first- or second-line therapy. First-line therapy is the first treatment given for a disease. When used by itself, first-line therapy is the one accepted as the best treatment. Second-line therapy is given when the first-line therapy doesn't work or stops working.

INTRODUCING IMMUNE CHECKPOINT INHIBITORS

The type of immunotherapy approved by the FDA for head and neck cancer is immune checkpoint inhibitors, which prevent the immune system from slowing down. They target the proteins PD-1 (programmed cell death protein 1) and PD-L1 (programmed cell death-ligand 1), which are proteins found on cells of the immune system and cancer, respectively. Normally when these proteins interact, the immune system is shut down. The checkpoint inhibitors block this activity and boost the immune system's cancer-fighting response.

A primary function of the immune system is to determine which cells or substances are self or non-self (see *Overview & Staging*, page 1). The immune system generally makes enough white blood cells to fight non-self cells, such as bacteria and viruses, and is able to mobilize into larger numbers of infection-fighting cells only if the body is infected with a specific non-self organism. The way the immune system does this is by being ready to recognize non-self cells or microorganisms through their proteins, which are referred to as antigens. When the immune system is alerted to the threat of an antigen, such as through proteins found on bacteria

or viruses, it ramps up production of T-cells (part of the white blood cells), that then attack and destroy the cells carrying the protein antigens. After an attack, the immune system must slow down so that the T-cells don't begin attacking healthy cells. It does this through the use of checkpoints, a set of biological checks and balances that regulate the immune system.

Checkpoints keep the immune system "in check." This process happens at the cellular level between protein ligands and their protein receptors. To understand how this occurs, it's important to know that the surface of each cell is not completely round and smooth. Cells are covered with receptors and ligands, which work like puzzle pieces. Protein ligands have "tabs" that stick out, and receptors have "spaces" that curve inward. When the puzzle pieces fit together (known as binding), chemical signals and information are exchanged between cells in a biochemical reaction. When the correct proteins and receptors connect, a series of signals is sent to slow down an immune response so it doesn't continue to attack healthy cells.

Several checkpoint receptors that slow down the immune system have been identified, and two are present in head and neck cancer. When they combine, the reaction signals it's time to slow down.

- **PD-1** is a receptor that signals T-cells to die and to reduce the death of regulatory T-cells, which slow down the immune system after an immune response, and to regulate T-cells that attack normal, healthy cells. PD-1 can cause the immune system to slow down only if it connects with one of its ligands, such as PD-L1.
- **PD-L1** is a protein that, when combined with PD-1, sends a signal to reduce the production of T-cells and enable more T-cells to die.

The goal of immune checkpoint inhibitors is to prevent PD-1 and PD-L1 from connecting so that the immune system does not slow down. However, cancer cells are smart and try to hide from the immune system. One of the ways a cancer cell can outsmart the im-

mune system is by producing PD-L1 on its own surface and using it as camouflage so that T-cells will see it as a normal cell. T-cells expect only normal cells to produce PD-L1, so when a T-cell encounters PD-L1 on a cancer cell, it is tricked into signaling the immune system to slow down.

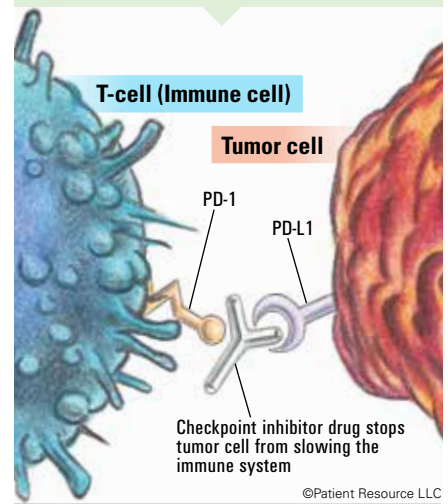
Checkpoint inhibitor drugs prevent these connections, and the immune cells continue fighting the cancer. Immune checkpoint inhibitors currently approved for head and neck cancer target and block PD-1 or PD-L1. If either checkpoint is blocked, the immune system continues to attack antigens and cancer cells without slowing down.

MOLECULAR TESTING

In many cancer types, doctors test biomarkers to diagnose a cancer, help plan treatment, find out how well treatment is working, or make a prognosis. Biomarkers are molecules produced by cancer cells or other cells in the body in response to cancer. They are also known as tumor markers, molecular markers, biological markers or serum markers. Testing for biomarkers is known as molecular testing and may identify specific genes, proteins or molecules associated with the tumor that can be measured in the tumor tissue, blood, plasma, urine, cerebrospinal fluid or other bodily fluids or tissues.

IMMUNE CHECKPOINT INHIBITORS

An immune response is controlled with checkpoints, which are the "brakes" of the immune system. If the checkpoints PD-1 and PD-L1 connect, the immune system slows down and becomes less efficient at finding and attacking cancer cells. Immune checkpoint inhibitors prevent PD-1 and PD-L1 from connecting, enabling the immune system to continue working hard to eliminate cancer cells.



The biomarkers tested in head and neck cancer are mainly used to determine if there's a link with the human papillomavirus (HPV), which may affect prognosis. They may also be tested to find out if you are a good candidate for immunotherapy. Research and clinical trials are underway to find biomarkers that may be used to detect, diagnose and determine prognosis. The hope is that finding more molecular markers will lead to early detection of the disease so it can be treated earlier. Your doctor may test for the following.

- **PD-L1 expression** may be tested to determine if the tumor cells or immune cells in the tumor microenvironment contain a higher level, which may mean you could be a good candidate for immune checkpoint inhibitors. Research has shown that people with a high level of PD-L1 expression sometimes respond better to immunotherapy. In addition, the level of expression will help your doctor determine whether to give immunotherapy alone or in combination with chemotherapy. Not everyone with a high PD-L1 expression should be given immunotherapy.

Not all people who receive immunotherapy respond. In some cases, people with high expressions do not respond to immunotherapy. Some people with a low PD-L1 expression do respond but less

often. More research is needed to explore why this happens so immunotherapy is not given to someone who may not respond to it.

- **Tumor mutational burden (TMB)** is an assessment of the number of genetic mutations in a tumor. It can also help doctors determine if you might respond to immunotherapy. It is believed that the higher the TMB level is, the more likely you are to respond.
- **(MSI-H) or deficient mismatch repair (dMMR)** may be tested to determine if the cancer is caused by genes that have problems repairing themselves. MSI-H describes cancer cells that have a greater than normal number of genetic markers called microsatellites, which are short, repeated sequences of DNA. Every time a cell reproduces itself, it makes a copy of its genes and DNA. During the process, errors in duplication can be made, much like a misspelled word. The body normally corrects the error, but sometimes it isn't caught and fixed. It then becomes a mutation that is reproduced in later versions of the cell. Cancer cells that have large numbers of microsatellites may have defects in the ability to correct mistakes that occur when DNA is copied. High levels may qualify you for certain types of immunotherapy.

FDA-APPROVED IMMUNOTHERAPIES FOR HEAD & NECK CANCER

Immune checkpoint inhibitors

- ▶ nivolumab (Opdivo)
- ▶ pembrolizumab (Keytruda)

As of 8/22/19

Inform your doctor if you have an autoimmune disease, such as Crohn's disease, ulcerative colitis, rheumatoid arthritis, psoriasis or lupus. An autoimmune condition means you have an overactive immune system and introducing immunotherapy may increase potential safety risks and life-threatening toxicities. Also let your doctor know if you've received immunotherapy before because previous treatments may affect your doctor's treatment decision. ■

ADDITIONAL RESOURCES

- ▶ **Society for Immunotherapy of Cancer:** www.sitcancer.org
- ▶ **American Cancer Society:** www.cancer.org
Immune Checkpoint Inhibitors to Treat Cancer
- ▶ **American Society of Clinical Oncology:** www.cancer.net
Head and Neck Cancer: Treatment Options
Tumor-Agnostic Treatment for Cancer: An Expert Perspective
Understanding Immunotherapy
- ▶ **CancerCare:** www.cancercare.org
Immunotherapy

GLOSSARY

These definitions may help you during discussions and shared decision-making with your health care team.

Antibody: A protein made by B-cells when the body's immune response is triggered by antigens (foreign substances such as abnormal proteins in cancer cells, bacteria, viruses and toxins).

Antigens: Foreign substances that trigger the body's immune response, including abnormal proteins in cancer cells, bacteria, viruses and toxins.

B-cells (B-lymphocytes): Immune cells (white blood cells) that make proteins to mark cancer cells and certain foreign substances for other immune cells to destroy.

Immune cells: White blood cells, such as B-cells and T-cells, that help the immune system defend the body against cancer, infectious diseases and other threats.

Immune checkpoint inhibitor: A type of immunotherapy that blocks certain recep-

tors or proteins (such as PD-1 or PD-L1) on some immune cells to keep the body's immune response in check (in balance). Blocking these proteins or receptors allows certain immune cells (T-cells) to destroy cancer cells unchecked.

Immune-related adverse events (irAEs): The immune system's potential over-reaction to immunotherapy agents. In rare cases, irAEs can rapidly become life-threatening without swift medical intervention.

Immune system: A complex network of cells, tissues and organs and substances that helps the body fight infections and other diseases, such as cancer. Includes white blood cells and organs and tissues of the lymph system, such as bone marrow, spleen, thymus, tonsils, lymph nodes and lymph vessels.

Lymphocytes: Immune cells (white

blood cells) in lymph tissue and blood that help the immune system fight cancer. The main types are B-lymphocytes (B-cells) and T-lymphocytes (T-cells).

PD-1 (programmed cell death-1): A receptor protein found on certain immune cells (T-cells) that binds with another protein (PD-L1) to keep the body's immune response in check.

PD-L1 (programmed death-ligand 1): A protein found on normal cells that binds with a receptor protein (PD-1) on T-cells to keep the immune response in check. PD-L1 is also found on cancer cells and some immune cells, and an abundance of this protein helps cancer cells avoid being detected and destroyed by the immune system's T-cells.

Receptors (immune receptors): Surface molecules on immune cells that bind to the surfaces of other immune

cells. This interaction typically produces signals that help cells communicate and regulate specific functions in the immune system.

T-cells (T-lymphocytes): Immune cells (white blood cells) that can directly kill cancer cells. T-cells play a significant role in helping the immune system fight infection, cancer and other diseases. Some T-cells have regulatory functions and may block immune responses.

Tumor microenvironment: An area that surrounds and sustains a tumor. It is made up of normal immune cells, signaling molecules and blood vessels.

White blood cells: Immune cells (B-cells and T-cells) made in the bone marrow and found in the blood, spleen and lymph tissue. They help the body fight infection, cancer and other diseases as part of the immune system.

HEALTH CARE TEAM

Audiologist: Medical specialist who treats and manages hearing problems.

Medical oncologist: Doctor who treats cancer using drug therapies.

Multidisciplinary medical team: Medical professionals, each with a specialized role in your treatment plan, who work closely together to ensure you receive the best care possible.

Nutritionist/dietitian: A licensed

specialist who helps you understand how to stay nourished during and after treatment.

Oncologic dentist or oral oncologist: A dentist or oral medicine provider who specializes in dental and oral care for people with cancer.

Otolaryngologist or otorhinolaryngologist: A surgeon who specializes in certain diseases of the head and neck (also known as an ear, nose and throat specialist, or ENT).

Patient navigator: Team member or liaison who guides patients from diagnosis through survivorship and communicates with the health care team. May or may not be a nurse or other licensed professional.

Psychologist/psychiatrist/therapist: Mental health professional who helps cancer patients and loved ones address emotional, psychological and behavioral needs. Psychiatrists are physicians and can prescribe mood medications.

Rehabilitation specialist/physical therapist: Health care professional who helps patients improve physical strength and movement.

Speech-language pathologist: Health care professional who helps patients regain function for speaking, swallowing and using oral motor skills during and after treatment.

Some definitions courtesy of the website of the National Cancer Institute (www.cancer.gov)

Today's head and neck cancer therapies began as clinical trials

Extensive research is taking place across the country to find new and more effective methods of harnessing the body's immune system to treat head and neck cancer. This is accomplished through structured research studies called clinical trials. Such crucial research fuels advances that continue to transform cancer care, giving more people the chance to live longer, better quality lives after diagnosis.

Clinical trials exploring potential immunotherapy treatments are currently studying at least a dozen new targets for immune checkpoint inhibitors; therapeutic cancer vaccines; new immunotherapy agents, used alone and in combination with different types of treatments; and neoadjuvant (pre-surgery)

immunotherapy, among other strategies. Researchers are also looking for new ways to reduce immunotherapy-related side effects (see *Supportive Care*, page 10).

Ask your doctor about clinical trials and discuss whether this treatment option is right for you. If a trial is recommended but

isn't close to home, don't rule it out before checking into resources that may help with transportation and lodging (see *Assistance*, page 12).

You can also search for clinical trials online and enlist friends and family to help. Online search tools to navigate through thousands of research studies can be confusing. The mock search site below outlines the process in easy steps. Before you begin, have your exact diagnosis, pathology report and details of previous treatments handy to help determine if you meet eligibility requirements. ■

Searching online for a clinical trial

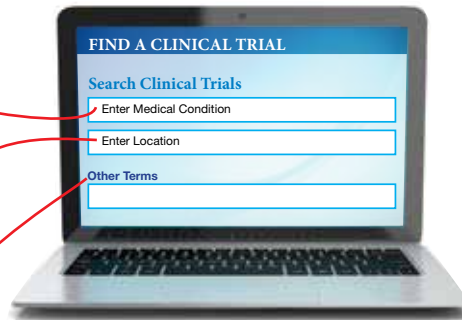
➔ Be an active participant in your own care by looking online for available trials. These step-by-step instructions will help guide you. Once you feel comfortable with the search process, use the list of resources below, and on page 12 to find clinical trials that may apply to you.

STEP 1 FILL IN YOUR INFORMATION

YOUR DIAGNOSIS: For example, enter "throat cancer." To create more options, you can also search for "pharyngeal cancer" or "HPV+ throat cancer" and compare results.

DESIRED LOCATION: If you prefer a clinical trial close to home, enter your address. Add other locations if you're willing and able to travel for treatment.

OTHER TERMS: You can refine your search by adding a treatment type such as immunotherapy, a specific drug or a National Clinical Trial (NCT) identifier. During your research, you may notice that an NCT identifier is assigned to each clinical trial. Identifiers begin with the letters "NCT" followed by eight numbers.



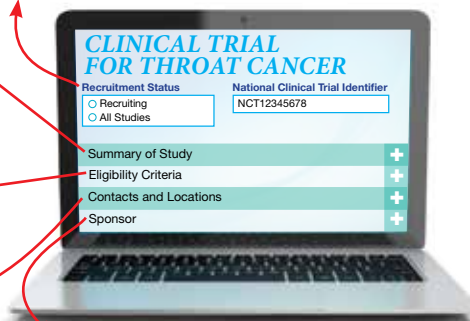
STEP 2 READ YOUR SEARCH RESULTS

RECRUITMENT STATUS: This indicates whether the trial is actively seeking patients, not yet recruiting or otherwise inactive. The status will change, so check for updates.

SUMMARY OF STUDY: Here you'll find details about the purpose of the clinical trial and the treatment being studied. This section is usually written for health care providers, so it may be difficult to understand. In that case, print out the information to discuss with your doctor.

ELIGIBILITY CRITERIA: This outlines the conditions you must meet to be eligible for the trial, such as the stage of disease, sites of metastasis, overall health requirements and previous treatments.

CONTACTS AND LOCATIONS: This may contain contact information for the clinical trial investigators, staff or sponsors who may be able to provide more details about the study. Trial locations may be included.



SPONSOR: This is the organization responsible for the clinical trial. It may be a pharmaceutical or biotechnology company, a university, the National Cancer Institute or others.

What a clinical trial can do for you...

In some situations, a trial may offer the best option among treatments you're considering. Additionally, you may benefit from the following:

- ▶ Access to leading-edge treatments that aren't yet available for your type or stage of disease.
- ▶ An alternative strategy if the cancer becomes resistant to your current treatment.
- ▶ Another option if your type of cancer is rare and doesn't have as many standard treatments available.
- ▶ A higher level of care because you will be closely monitored by your regular oncologist and the clinical trial medical team. This extra attention may help identify and then treat side effects or other problems earlier.
- ▶ Being an active partner in your care.

Keep in mind the decision to participate is always yours. If the trial doesn't meet your expectations at any time or for any reason, you may leave the trial and return to standard-of-care treatment. A clinical trial will not jeopardize your care.

And what you can do for a clinical trial...

- ▶ Your involvement is an opportunity to help advance cancer treatments. Not all participants have the same experience, even if the treatment is the same, and all the information gathered from a trial is valuable.
- ▶ Many survivors look for opportunities to give back. You may feel a sense of accomplishment at being able to contribute to the future of cancer care.

CLINICAL TRIAL RESOURCES

ACCESS: cantria.com/access / **AccrualNet:** accrualnet.cancer.gov

ACT (About Clinical Trials): www.learnaboutclinicaltrials.org / **Cancer Research Institute:** www.cancerresearch.org

Center for Information & Study on Clinical Research Participation: www.searchclinicaltrials.org / **CenterWatch:** www.centerwatch.com

ClinicalTrials.gov: www.clinicaltrials.gov / **Head and Neck Cancer Alliance:** www.headandneck.org / **Lazarex Cancer Foundation:** www.lazarex.org

National Cancer Institute: www.cancer.gov/clinicaltrials / **National Cancer Institute (NCI) Contact Center** (cancer information service): 800-422-6237

National Institutes of Health (NIH) (interested in participating in a clinical trial): 800-411-1222 / **Support for People with Oral and Head and Neck Cancer:** www.spohnc.org

Giving your body the nutrition it needs during and after treatment

To maintain a healthy body, you must eat and drink enough foods that contain key nutrients. When you have cancer, your body needs extra nutrients to prevent weight loss, maintain your strength and energy, tolerate the physical and emotional side effects of treatment better, reduce your risk of infection and recover faster. Head and neck cancer treatment makes this especially difficult because of the challenges you may have with eating and swallowing. Read on to learn how good nutrition can help you navigate treatment and enjoy an overall better quality of life.

THE BENEFITS OF WORKING WITH A DIETITIAN

To ensure you are able to get the nutrition you need, it is crucial to connect with a registered dietitian who has expertise in treating cancer patients. Along with helping you understand how to give your body the nutrients it needs, your dietitian may also function as a liaison between you and your medical team, relaying or explaining information and serving as an advocate for you. He or she is also a valuable educational resource and can talk with you regarding misinformation about nutrition, fad diets and “miracle” cures.

You will meet with a dietitian very soon after diagnosis to begin evaluating your nutritional needs and to prevent weight loss. After learning about your physical limitations, listening to your concerns, such as not being able to drink enough and how to handle taste changes, and considering foods you can tolerate and your taste preferences, your dietitian will develop a personalized nutrition plan for each phase of treatment with these goals in mind:

- Prevent your treatment from being interrupted due to poor nutrition.
- Ease the side effects of treatment.
- Improve your overall quality of life.

Your plan goals will be adjusted throughout treatment to address your changing

physical capabilities and nutritional needs. You will be closely monitored for signs of malnutrition so that you don't lose lean body mass and develop other complications.

BE AN ACTIVE PARTICIPANT

Once your plan is in place, here are a few ways you can contribute.

- When stocking your kitchen, stick to the guidelines your dietitian created. During a time when you may feel you have little control, it helps to know you are in charge of your own nutrition.
- Blending fruits and vegetables into easy-to-swallow smoothies and soups gives you necessary nutrients.
- Carry snacks and drinks with you at all times to enjoy while waiting for appointments, riding in the car, etc.
- Increase calories to your meals by adding extra fat, such as ice cream, cheese, avocado, extra virgin olive oil, honey, sauces and gravies.
- Drink plenty of water. Keep a glass of water handy during mealtime to make swallowing easier. In general, your body needs it to function and to prevent dehydration, which can lead to other problems.
- Let others know your dietary needs. Well-meaning friends may bring over foods that can't be eaten during or after treatment.



▲ Blend nutritious smoothies.



▲ Make the meal colorful.

Offer suggestions about the types of foods you can have. People want to help and knowing that they're bringing something that goes along with your treatment plan will make them feel good.

- Supplements may help maintain your nutritional status. Several prescription and over-the-counter products can provide nutrition in a small amount of food or liquid. Popular versions include protein powders that can be added to smoothies, milkshakes and high calorie/high protein drinks. ■

ADDITIONAL RESOURCES

- ▶ **Society for Immunotherapy of Cancer:** www.sitcancer.org
- ▶ **American Society of Clinical Oncology:** www.cancer.net
Nutrition Recommendations During and After Treatment
The Role of Oncology Dietitians in Cancer Care
- ▶ **Head and Neck Cancer Alliance:** www.headandneck.org/nutrition
- ▶ **Oncology Nutrition Dietetic Practice Group:** www.oncologynutrition.org
- ▶ **PearlPoint Nutrition Services:** www.pearlpoint.org



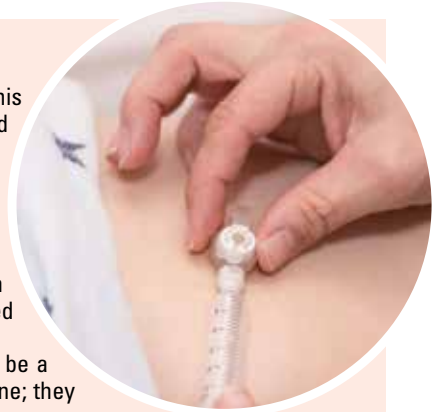
Explaining Enteral Nutrition (Tube Feeding)

→ **If you are unable to eat or not able to get enough nutrition**, you may need a feeding tube. This can be temporary or permanent. It may be your single source of nutrition, or it may be used to add nutrients until you can eat enough by mouth.

A tube may be placed directly into your abdomen and into the stomach or intestine. What goes into the feeding tube is not food as we know it but a nutritional mixture to maintain strength and get the right nutrients needed to continue the healing process. That liquid formula is delivered through the tube directly into your gut. It can be given in several “meals” throughout the day (also called bolus feeding), or a specific amount can be delivered over a certain amount of time through the use of a special pump. In the hospital, your health care team will manage this for you. If you need to continue (or begin) this type of feeding at home, you will be trained on the process.

During this time, dental care is still very much needed and shouldn't be forgotten. There can be a tendency to assume if nothing is going into the mouth that the teeth and gums are fine if left alone; they are not. Brushing, flossing and caring for gums remains a priority.

You may also want to talk to your doctor or pharmacist about whether some or all of your medications can be given through the feeding tube.



Tap into the resources that will help you live your best life

A *valuable tool for managing* the physical and emotional side effects, as well as the social, practical and spiritual concerns that are part of treating head and neck cancer, is supportive care. Research has shown that receiving this type of assistance, also referred to as palliative care, as early as possible after diagnosis improves quality of life and may make it easier to stick with and complete scheduled therapies. Ask your nurse navigator about the supportive care resources that may be best suited for you and your treatment plan.

IMMUNE-RELATED ADVERSE EVENTS

Severe side effects aren't common, but they can occur with immunotherapy. Called immune-related adverse events (irAEs), they can develop rapidly, becoming severe and even life-threatening without swift medical attention (see Table 1). They can occur if treatment overstimulates the immune system. This may cause inflammation, redness or swelling, which can be painful. You may not be able to physically feel these symptoms at first, so it's important to schedule and keep all medical appointments as irAEs may be diagnosed based on routine laboratory tests and X-rays. Be sure to contact your medical team if symptoms occur between appointments. Remain alert to the possibility of irAEs for up to two years after treatment ends, and report symptoms immediately to your doctor.

PHYSICAL SIDE EFFECTS

Immunotherapy for advanced stage head and neck cancer may be used with or after other treatments, such as surgery, radiation therapy and drug therapies, and each may have side effects. When therapies are combined, the symptoms may be more intense. Your doctor can advise you when to call the office or seek emergency care.

Following are some common side effects and suggestions to help make you more comfortable.

Decreased appetite is common because head and neck cancer treatment may make eating difficult. In addition, chemotherapy and immunotherapy can be associated with loss of appetite. Choose high-calorie easy-to-eat foods, such as pudding, milkshakes or cream-based soups. Use butter, oils and milk in food to increase calories.

Diarrhea can significantly affect your quality of life. If severe, it can lead to dehydration and loss of essential nutrients. Follow a diet of clear liquids so the lining of your intestines can heal. Slowly add low-fiber foods, such as white rice or boiled potatoes, to your diet. In time, you may be able to anticipate bouts of diarrhea and plan accordingly. If you have a special occasion, your doctor may be able to adjust your treatment to help you avoid this side effect during the event. Avoid accidents by knowing where to find clean restrooms at places you frequent and along routes you travel.

Fatigue during cancer treatment occurs primarily because the body needs extra energy to repair the healthy tissue damaged by treatment. It lasts longer than typical fatigue, is more severe and may not be relieved by sleep. Regular exercise is proven to fight fatigue. Even a daily 10-minute walk can make a difference. Get eight hours of sleep every night and take naps as needed, limiting them to 20 or 30 minutes each. Save your energy for people and activities most important to you.

Lymphedema occurs when lymph nodes are removed or damaged during treatment, causing swelling in that part of the body as lymph fluid builds up in tissues. People who have had lymph nodes surgically removed and then the same area irradiated or treated with radiotherapy are at an increased risk. Consider meeting with a certified lymphedema specialist before treatment begins to learn how to reduce your risk of developing lymphedema and what to do if it occurs.

Nausea and vomiting are much easier to prevent than to control, so ask your doctor about antiemetics (anti-nausea drugs) before treatment begins. Severe cases can lead to dehydration. Eat smaller, more frequent meals, drink plenty of water and avoid unpleasant odors. Try peppermints or ginger-flavored lozenges. Non-drug approaches include progressive muscle relaxation, guided imagery, acupuncture, self-hypnosis and biofeedback.

Neutropenia (low white blood cell count) increases your risk of infection, especially for pneumonia, bronchitis and sinusitis. It also makes infections harder to resolve. Report signs of infection, such as fever, to your doctor right away, and ask how high your fever must be to seek medical care. Wash your hands often with soap, practice good hygiene

TABLE 1
IMMUNE-RELATED ADVERSE EVENTS (irAEs)

Body System	irAE	Symptoms & Signs
Cardiovascular	Myocarditis	Chest pain, shortness of breath, leg swelling, rapid heartbeat, changes in EKG reading, impaired heart pumping function
Endocrine	Endocrinopathies	Hyperthyroidism, hypothyroidism, diabetes, extreme fatigue, persistent or unusual headaches, visual changes, alteration in mood, changes in menstrual cycle
Gastrointestinal	Colitis	Diarrhea with or without bleeding, abdominal pain and cramping, bowel perforation
Liver	Hepatitis	Yellow skin or eyes (jaundice), nausea, abdominal pain, fatigue, fever, poor appetite
Nervous system	Neuropathies	Numbness, tingling, pain, a burning sensation or loss of feeling in the hands or feet, sensory overload, sensory deprivation
Neurologic	Encephalitis	Confusion, hallucinations, seizures, changes in mood or behavior, neck stiffness, extreme sensitivity to light
Pulmonary/lung	Pneumonitis	Chest pain, shortness of breath, unexplained cough or fever
Renal/kidneys	Nephritis	Decreased urine output, blood in urine, swollen ankles, loss of appetite
Skin	Dermatitis	Rash, skin changes, itching, blisters, painful sores

and wear gloves when cleaning or gardening. Avoid crowds, sick people and close contact with small children because a child can look and act well when they are harboring germs that could be harmful to you.

Pain in muscles, bones or joints, or abdominal pain, may occur. Track your pain levels, including when it starts, how long it lasts and if it interferes with daily activities. Contact your health care team if the pain does not go away or worsens.

EMOTIONAL WELL-BEING

Living with cancer challenges you emotionally as well as physically. Don't hesitate to ask for a referral to a patient counselor or mental health professional. Check out cancer support groups locally or online, or reach out to close friends or a spiritual advisor. Contact your doctor about excessive crying or continued feelings of hopelessness or despair. Get immediate medical attention if you have thoughts of suicide or death. A diagnosis of cancer and its treatment is like being on a rollercoaster. There are ups and downs, and they are commonly unpredictable.

Anxiety is often described as feeling nervous, stressed, worried and/or tense. Symptoms may include fast heartbeat, upset stomach, difficulty concentrating, tightness in the chest area, or feeling shaky or dizzy. Try relaxation techniques, such as deep breathing, meditation, muscle relaxation, hypnosis, biofeedback and yoga.

Depression is more complex than just feeling sad and can include feelings of panic, hopelessness and discouragement. It's crucial to talk with your health care team if these feelings last more than a couple of days. Many antidepressants are available, but each has its own side effects. Consider engaging in regular physical activity, breathing exercises or meditation.

Fear is a common reaction before, during and after cancer treatment. One way to combat fear is to learn as much as you can about your cancer and your treatment. Talk to others going through similar treatment. Support groups, both in person and online, may be helpful.

Grief is feeling distress or sorrow due to loss. It is normal to grieve the loss of your

health, your appearance or your ideas of what your future would be without cancer. Allow yourself to feel a full range of emotions. Ask your friends and family for support.

Guilt is the sense that you've done something wrong. You may feel responsible or blame yourself for getting cancer due to decisions you made concerning your health or lifestyle. You may feel you are a burden. You may also feel survivor's guilt if others with cancer don't survive. Talk to a trusted friend or family member or with a therapist about your feelings. ■

ADDITIONAL RESOURCES

- ▶ **Society for Immunotherapy of Cancer:**
www.sitcancer.org
- ▶ **American Society of Clinical Oncology:**
www.cancer.net
Head and Neck Cancer: Treatment Options
- ▶ **Support for People with Oral and Head and Neck Cancer (SPOHNC):**
www.spoync.org
Supportive Care
- ▶ **The Oral Cancer Foundation:**
www.oralcancerfoundation.org
Side Effects



Be Prepared for Dental and Oral Challenges

→ *Treatment to this area of the body may affect vital functions, making preventing and managing dental and oral side effects crucial.*

Having good oral health before treatment may reduce the severity of side effects during and after treatment. If possible, see a dentist before treatment begins to address decayed or infected teeth or other mouth problems. During treatment, your doctor may recommend that you brush your teeth and gums with a soft-bristled toothbrush two or three times each day, use fluoride toothpaste with a mild taste and floss at least once a day unless it causes bleeding or other problems.

Throughout treatment, check your mouth every day. Many dental and oral problems caused by treatment can be seen or felt. Contact your treatment team when you first notice a mouth problem or any changes that concern you, or if an existing problem gets worse.

- **Dry mouth** occurs when the glands that make saliva are damaged, which often occurs after radiation therapy. It can be uncomfortable and increase the risk of cavities and oral infections. Drink eight to 10 cups of liquid a day. Keep a water bottle nearby at all times. Suck on ice chips. Chew sugar-free gum or suck on sugar-free hard candy to stimulate saliva. Drink smoothies and slushies. Avoid soda, fruit juice, caffeine, cigarettes, chewing tobacco and alcohol, which can dry out the mouth.
- **Infections** can be caused by damage to the tissues of the mouth from surgery, radiation therapy, lowered white blood cell count or a weakened immune system. Wash your hands frequently before meals and after using the bathroom. Get plenty of rest. Do not share items such as food, cups, utensils, toothbrushes or makeup.
- **Mouth pain** is common and can affect quality of life. Good hygiene and changes in your diet may help. Try topical medications for pain. Rinse your mouth before applying the medication to the gums or lining of the mouth. Take small bites and chew slowly when eating. Sip liquids with your meals. Eat moist, soft foods, such as applesauce, cooked cereals and scrambled eggs. Avoid alcohol and all forms of tobacco.

- **Mouth sores** are caused by an inflammation of mucous membranes in the mouth. Also called oral mucositis, they can appear as red, burn-like sores or ulcer-like sores and are often caused by chemotherapy or radiation therapy. Ask your doctor about medications to prevent or minimize them. Keep your teeth and mouth clean. Brush your teeth every four hours and at bedtime using a soft-bristled toothbrush. Keep your mouth moist by drinking water or using a water-soluble lubricating jelly.
- **Swallowing problems** (dysphagia) can be caused by physical changes to the mouth, jaw and tongue. Head and neck cancers can also restrict and narrow the esophagus, making it difficult for food or liquid to pass down the throat. You may be referred to a speech therapist, who can teach you techniques to make swallowing easier. Call your health care team right away if you cough or choke while you are eating. Try eating soft or liquid foods. Chop or puree your food in a blender or food processor. Thick fluids may be easier to swallow. Drink high-calorie, high-protein liquids, such as protein shakes, especially if you are unable to eat enough protein-rich food.
- **Taste changes** can occur when the cells in your mouth are damaged from surgery, radiation therapy or chemotherapy. An injury to taste buds or salivary glands may cause foods to taste different, bland or metallic. Use glass cookware, plastic plates and plastic utensils to help reduce metallic taste. Eat cold or room temperature foods. Rinse your mouth with a salt-and-baking soda solution (half teaspoon of salt and half teaspoon of baking soda in one cup of warm water) before meals to try to neutralize bad tastes in your mouth.
- **Tooth decay** may occur. In addition to practicing good dental hygiene, avoid sugary foods and drinks, which can cause cavities. If you use gum or hard candy to help control dry mouth, choose sugar-free options. Sip water to help with dry mouth, which contributes to tooth decay. Ask your dentist about fluoride gel or paste to help prevent cavities, and see your dentist regularly.



Support and financial resources available for you

BASIC LIVING EXPENSES

Bringing Hope Home	www.bringinghopehome.org, 484-580-8395
Cleaning for a Reason (free house cleaning service)	www.cleaningforareason.org, 877-337-3348
Compassion Can't Wait (for single parent families)	compassioncantwait.org, 310-276-7111
Family Reach Foundation	www.familyreach.org, 973-394-1411
Hugs and Kisses	www.hugsandkissesinc.org, 561-819-9471
Life Beyond Cancer Foundation	www.needhelppayingbills.com, 800-282-5223
Team Continuum	www.teamcontinuum.net, 845-200-7094

CANCER EDUCATION

American Cancer Society	www.cancer.org
American Society of Clinical Oncology	www.cancer.net
CANCER101	www.cancer101.org
CancerCare	www.cancer.org
CancerQuest	www.cancerquest.org
Centers for Disease Control and Prevention (CDC)	www.cdc.gov
The Gathering Place	www.touchedbycancer.org
Get Palliative Care	www.getpalliativecare.org
Global Resource for Advancing Cancer Education (GRACE)	www.cancergrace.org
The Hope Light Foundation	www.hopelightproject.com
LIVESTRONG Foundation	www.livestrong.org
National Cancer Institute	www.cancer.gov
National Comprehensive Cancer Network (NCCN)	www.nccn.org
National LGBT Cancer Network	cancer-network.org
NCI Contact Center (cancer information service)	800-422-6237
Oncolink	www.oncolink.org
Patient Power	www.patientpower.info
PearlPoint Nutrition Services	www.pearlpoint.org
Pine Street Foundation	pinestreetfoundation.org
Scott Hamilton Cares Foundation	www.scottcares.org
Triage Cancer	triagecancer.org

CAREGIVERS & SUPPORT

4th Angel Patient & Caregiver Mentoring Program	www.4thangel.org
CanCare	www.cancare.org
CANCER101	www.cancer101.org
Cancer and Careers	www.cancerandcareers.org
CancerCare	www.cancer.org
Cancer Connection	www.cancer-connection.org
Cancer Hope Network	www.cancerhopenetwork.org
Cancer Information and Counseling Line	800-525-3777
Cancer Really Sucks!	www.cancerrealsucks.org
Cancer Support Community	www.cancersupportcommunity.org
Cancer Support Helpline	888-793-9355
Cancer Survivors Network	csn.cancer.org
Caregiver Action Network	www.caregiveraction.org
CaringBridge	www.caringbridge.org
Center to Advance Palliative Care	www.capc.org
Cleaning For A Reason	www.cleaningforareason.org
Cooking with Cancer	www.cookingwithcancer.org
Cuddle My Kids	www.cuddlemykids.org
Family Caregiver Alliance	www.caregiver.org
Fighting Chance	www.fightingchance.org
Friend for Life Cancer Support Network	www.friend4life.org, 866-374-3634
The Gathering Place	www.touchedbycancer.org
Guide Posts of Strength, Inc.	www.cancergps.org
The Hope Light Foundation	www.hopelightproject.com
Imerman Angels	www.imermanangels.org
Lacuna Loft	www.lacunaloft.org
The LGBT Cancer Project – Out With Cancer	www.lgbtcancer.org
LIVESTRONG Foundation	www.livestrong.org
LivingWell Cancer Resource Center	www.livingwellcrc.org
Lotsa Helping Hands	www.lotsahelpinghands.com
The Lydia Project	thelydiaproject.org
MyLifeLine.org	www.mylifeline.org
Patient Empowerment Network	www.powerfulpatients.org
Patient Power	www.patientpower.info
SHARE Caregiver Circle	www.sharecancersupport.org/caregivers-support

Stronghold Ministry	www.mystronghold.org
Support Groups	www.supportgroups.com
Triage Cancer	www.triagecancer.org
Vital Options International	www.vitaloptions.org
Walk With Sally	www.walkwithsally.org
Well Spouse Association	www.wellspouse.org
weSPARK Cancer Support Center	www.wespark.org

CLINICAL TRIALS

ACCESS	cantria.com/access
AccrualNet	accrualnet.cancer.gov
ACT (About Clinical Trials)	www.learnaboutclinicaltrials.org
Center for Information & Study on Clinical Research Participation	www.searchclinicaltrials.org
CenterWatch	www.centerwatch.com
ClinicalTrials.gov	www.clinicaltrials.gov
Lazarex Cancer Foundation	www.lazarex.org
LIVESTRONG Foundation	www.livestrong.org
National Cancer Institute	www.cancer.gov/clinicaltrials
NCI Contact Center (cancer information service)	800-422-6237

FINANCIAL ASSISTANCE

American Cancer Society (Hope Lodge)	www.cancer.org/treatment/supportprogramsservices/hopelodge
BenefitsCheckUp	www.benefitscheckup.org
Bringing Hope Home	www.bringinghopehome.org
CancerCare	www.cancer.org/financial
Cancer Financial Assistance Coalition	www.cancerfac.org
HealthWell Foundation	www.healthwellfoundation.org
Medicare.gov	www.medicare.gov
NeedyMeds	www.needymeds.com
Partnership for Prescription Assistance	www.pparx.org
Patient Access Network Foundation	www.panfoundation.org
Patient Advocate Foundation	www.patientadvocate.org
Patient Services, Inc.	www.patientservicesinc.org
RxAssist	www.rxassist.org
RxHope	www.rxhope.com
Social Security Administration	www.ssa.gov
Social Security Disability Resource Center	www.ssdrc.com
State Health Insurance Assistance Programs	www.shiptacenter.org

GOVERNMENT ASSISTANCE

Benefits.gov	www.benefits.gov, 800-333-4636
Centers for Medicare & Medicaid Services	www.cms.gov
Eligibility.com (Medicare resources)	eligibility.com/medicare/resources
Hill-Burton Program	www.hrsa.gov/get-health-care/affordable/hill-burton, 800-638-0742
Legal Services Corporation	www.lsc.gov, 202-295-1500
Medicare Rights Center	www.medicarerights.org, 800-333-4114
National Council for Aging Care	www.ncoa.org, 571-527-3900
Social Security Administration	www.ssa.gov, 800-772-1213
Social Security Disability Resource Center	www.ssdrc.com
State Health Insurance Assistance Programs	www.shiptacenter.org
U.S. Department of Veterans Affairs	www.va.gov/health

HEAD & NECK CANCER

Adenoid Cystic Carcinoma Organization International	www.accoi.org
Head and Neck Cancer Alliance	www.headandneck.org
HNC Living Foundation	www.hncliving.org
International Association of Laryngectomees	www.theial.com
Oral Cancer Awareness Foundation	www.4orca.org
The Oral Cancer Foundation	www.oralcancerfoundation.org
Support for People with Oral and Head and Neck Cancer (SPOHNC)	www.spoync.org
Thyroid, Head & Neck Cancer Foundation	www.thancfoundation.org
Your Cancer Game Plan	www.yourcancergameplan.com

IMMUNOTHERAPY

Cancer Research Institute	www.cancerresearch.org
Immuno-Oncology	www.immunooncology.com
Society for Immunotherapy of Cancer	www.sitcancer.org

MEDICAL CARE EXPENSES

CancerCare.....	www.cancer.org, 800-813-4673
Cancer Warrior, Inc.	www.cancerwarriorinc.org, 323-578-5083
Foundation for Health Coverage Education	www.coverageforall.org
Hair to Stay	www.hairtostay.org, 800-270-1897
Patient Access Network Foundation.....	www.panfoundation.org, 866-316-7263
Patient Advocate Foundation.....	www.patientadvocate.org, 800-532-5274
Verna's Purse.....	www.vernaspurse.org, 888-489-8944

MENTAL HEALTH SERVICES

American Psychosocial Oncology Society Helpline.....	866-276-7443
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NUTRITION

American Cancer Society.....	www.cancer.org
CancerCare.....	www.cancer.org
LIVESTRONG Foundation	www.livestrong.org
OncoLink.....	www.oncolink.org
PearlPoint Nutrition Services.....	www.pearlpoint.org
Physicians Committee for Responsible Medicine	www.pcrm.org/health/cancer-resources

PAIN MANAGEMENT

American Chronic Pain Association.....	theacpa.org
American Society of Anesthesiologists.....	www.asahq.org
LIVESTRONG Foundation	www.livestrong.org
The Resource Center of the Alliance of State Pain Initiatives	www.trc.wisc.edu
U.S. Pain Foundation.....	uspainfoundation.org

REIMBURSEMENT & PATIENT ASSISTANCE PROGRAMS

Bristol-Myers Squibb Access Support.....	www.bmsaccesssupport.bmscustomerconnect.com/patient, 800-861-0048
Bristol-Myers Squibb Patient Assistance Foundation.....	www.bmspaf.org, 800-736-0003
Keytruda Patient Assistance.....	www.merckaccessprogram-keytruda.com/hcc/, 855-257-3932
Merck Access Program	www.merckaccessprogram.com/hcc/
Merck Helps	www.merckhelps.com, 800-727-5400
Opdivo with You.....	www.patientsupport.bmscustomerconnect.com/opdivo-with-you-registration, 855-673-4861

STOPPING TOBACCO USE

American Cancer Society.....	www.cancer.org
BecomeAnEx	www.becomeanex.org
Freedom from Smoking.....	www.lung.org/stop-smoking/join-freedom-from-smoking
National Cancer Institute Smoking Quitline	877-448-7848
QuitSTART.....	teen.smokefree.gov
Smokefree.gov	smokefree.gov
SmokefreeTXT.....	smokefree.gov/smokefreetxt

TRANSPORTATION SERVICES

The Air Care Alliance	www.aircarealliance.org, 888-260-9707
Air Charity Network	www.aircharitynetwork.org, 877-621-7177
Family Reach Foundation.....	www.familyreach.org, 973-394-1411
Operation Liftoff.....	www.operationliftoff.com
Patient AirLift Services	www.palservices.org, 888-818-1231
Patient Access Network Foundation.....	www.panfoundation.org, 866-316-7263
Patient Travel Referral Program.....	www.patienttravel.org



Society for Immunotherapy of Cancer

Unsure if immunotherapy is right for you?

The Society for Immunotherapy of Cancer's (SITC) 2019 Patient Course: Understanding Cancer Immunotherapy is a good place to start your inquiry

Whether you are battling cancer or serving as a dedicated caregiver, being informed can be critical to a successful treatment plan.

SITC's Understanding Cancer Immunotherapy is a free, online course that provides resources and basic education about cancer and immunotherapy for patients and caregivers. The course's interactive modules offer easy-to-understand information about immunotherapy as a cancer treatment option by covering the following areas:

- Your treatment options and care providers
- Education on cancer and the immune system
- Types of cancer immunotherapy treatments
- The importance of reporting side effects
- Links to other helpful patient and caregiver resources

To access this self-guided course, please visit www.sitcancer.org/patient



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