Head and Neck Cancer Care
Multidisciplinary Clinic
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Kaiser Permanente  
Santa Clara Medical Center  
710 Lawrence Expressway  
Santa Clara, CA 95051

Kaiser Permanente  
Cancer Treatment Center  
3800 Homestead Road  
Santa Clara, CA 95051
Introduction

Upon learning you have cancer, your world changes. A cascade of emotion often follows for the person who's received the diagnosis, and for those close to them. There will be many questions. Your Kaiser Permanente cancer care team understands and is committed to helping you through this journey.

At Kaiser Permanente, specialized teams provide care and treatment to patients with cancer. Our skilled specialists and support staff perform thousands of treatments every year. Our advanced equipment and techniques help ensure that you receive the highest quality of care. Treatment breakthroughs develop frequently, and Kaiser Permanente brings the benefits of those treatments to our members every day.

This booklet is for you, to support you and those close to you during this journey. It provides information about head and neck cancer, what to expect, and how we can work together to make your treatment as comfortable and successful as possible. Our Kaiser Permanente Cancer Care website and our new internet site, My Doctor Online, link you to many other resources. We direct you to some of these resources in this booklet. Please ask questions and discuss any concerns you may have with members of your cancer care team. We are here to help you and those close to you.

Your Kaiser Permanente Cancer Care Team

“You are the main decision maker and the key person on your medical team. Stay involved… it's a sign of health.”

Mike L. — Tongue cancer survivor
Head and neck cancer is a broad term used to refer to cancers that begin in the head and neck area. They include cancers of the oral cavity, larynx (voice box), the nasal cavity, paranasal sinuses, salivary glands, and mouth. Most are found in squamous cells made up of the moist, mucous surfaces that line the mouth, throat, and sinuses. These cancers are called Squamous Cell Carcinoma.

Other types of cancer arise from structures called glands in the head and neck region, such as the salivary glands. These cancers are often different from the typical head and neck cancer, and thus have different treatments associated with them. Nasopharyngeal cancer, a third type, arises from the lining of the nasopharynx, an area between the nose and throat.

Head and neck cancer is the sixth most common cancer worldwide (1). The American Cancer Society estimates 53,640 new cases of head and neck cancer will be diagnosed in the United States during the year 2013 (2). And, the National Cancer Institute estimates head and neck cancer to comprise about 3% of all cancers diagnosed in the United States (3). Head and neck cancers are nearly twice as common among men as they are among women (4). Head and neck cancers are also more commonly diagnosed among people over the age of 50 than among younger people.

The table below lists common areas of head and neck cancer.

<table>
<thead>
<tr>
<th>Type</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral cancers</td>
<td>lips, mouth, gums, and tongue glands that make saliva</td>
</tr>
<tr>
<td>Salivary cancer</td>
<td>the pharynx (area at the back of the throat, including the back of the sinus cavity, mouth, and tonsil areas)</td>
</tr>
<tr>
<td>Pharyngeal cancer</td>
<td></td>
</tr>
<tr>
<td>Nasopharyngeal cancer</td>
<td>nasal and sinus cavities, the nose, and connecting tissue</td>
</tr>
<tr>
<td>Laryngeal cancer</td>
<td>vocal cords or voice box (larynx)</td>
</tr>
</tbody>
</table>

**Comprehensive Cancer Care online kp.org/santaclara/cancercare**

Our Comprehensive Cancer Care website is created by our own Cancer Specialists to bring you a broad range of up-to-date cancer treatment information, and news from the field of cancer care.

**kp.org/mydoctor**

Kaiser Permanente’s mydoctor online website gives you access to your own health information and education resources, including self-help programs, videos, and research. Set up your own secure account to email your doctor, make appointments, order medications, and view your own medical information. Sign up at your doctor’s home page, or call our Member Website Support at 1-800-556-7677.

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(2) Amer. Cancer Soc., Cancer Facts and Figures 2012
Pharynx  The pharynx is subdivided into Nasopharynx, Oropharynx, and Hypopharynx.

Nasopharynx  The nasal cavity and paranasal sinus cavities with connecting tissue.

Oropharynx  The tonsils, base and back of the tongue areas, retromolar trigone (the small area of the lower jaw behind the wisdom teeth), and back wall of the throat.

Hypopharynx  The cavity and surrounding tissues connecting the mouth and nasal passages with the top of the esophagus. It also includes the larynx, or voice box.
Anatomy of the Oral Cavity

The mouth, or oral cavity, includes the following:

- Front two thirds of the tongue
- Gingiva (gums)
- Buccal mucosa (the lining of the inside of the cheeks)
- Floor (bottom) of the mouth under the tongue
- Hard palate (the roof of the mouth)
- Soft palate (the muscular back portion of the roof of the mouth)
- Lips
- Teeth
Cancer is a term used for diseases in which abnormal cells divide without control and are able to invade other tissues. Cancer cells can spread to other parts of the body through the blood and lymph systems.

“What is Cancer?”

“Most of all, remember there is hope. There is life after learning you have cancer.”

_Ken N._ — Oropharynx cancer survivor

Our bodies are made up of many types of cells. Normal cells grow and divide in a controlled way to produce more cells as they are needed to keep the body healthy. When cells become old or damaged, they die and are replaced with new cells. However, sometimes this orderly process goes wrong. The genetic material (DNA) in a cell sometimes becomes damaged or changed. When this happens, cells may grow and divide out of control and form a mass of tissue known as a tumor. If the tumor grows and spreads, then it is called cancer.

Not all tumors are cancerous; tumors can be benign (not cancerous) or malignant (cancerous). Benign tumors can often be removed and, in most cases, do not come back. Cells in benign tumors do not spread to other parts of the body. In malignant tumors the abnormal cells can invade nearby tissues and spread to other parts of the body. The spread of cancer from one part of the body to another is called metastasis.

There are three ways that cancers spread in the body:

**Through tissue:** Cancer invades the surrounding normal tissue.

**Through the lymph system:** Cancer travels in the lymph fluid to other parts of the body.

**Through the blood stream:** Cancer travels in the blood to other places in the body.

Most cancers are named for the organ or type of cell in which they start. For instance, a cancer that starts in the breast is called breast cancer. When cancer cells break away from the primary (original) tumor and travel through the lymph or blood to other places in the body, another (secondary) tumor may form. This process is called metastasis. If the breast cancer cells spread to the bones, the cancer cells in the bones are still breast cancer cells. The disease is called metastatic breast cancer, not bone cancer.

Doctors may not always find where the cancer first began to form. When tests cannot find a primary tumor, it is called an occult (hidden) or unknown primary tumor. In some cases, the primary tumor is never found.
Risk Factors for Head and Neck Cancer

Smoking is a leading cause of head and neck cancer.
If you smoke, we strongly encourage you to quit.
Continued smoking can cause greater treatment side effects, as well as jeopardize the success of your cancer treatment.

We can help you quit.
Kaiser Permanente can help with counseling, medications, classes, and online programs. Look for tobacco cessation at kp.org/santaclara/cancercare.
For more information call the Health Education Department at 1-408-851-3800.

There is an increased risk of developing cancer when various risk factors exist in a person’s life. The most common risk factors for developing head and neck cancer include:

- Smoking or other tobacco use
- Alcohol abuse
- Age 50 or older
- Exposure to radiation sources
- Exposure to certain viruses

Smoking, tobacco exposure, and drinking alcohol are the most common causes of head and neck cancer. Smoking by itself greatly increases the risk of head and neck cancer. Chewing tobacco or betel nuts may raise the risk of cancers in the mouth, gums, and tongue. Drinking alcohol along with smoking or chewing tobacco makes the risk even greater.

Exposure to two common viruses is associated with development of cancers of the head and neck: The Epstein-Barr Virus (EBV) and the Human Papilloma Virus (HPV). Epstein-Barr Virus is associated with nasopharyngeal carcinoma.

In recent years, the Human Papilloma Virus (HPV) has been associated with cancer in the head and neck, cervix, and anogenital areas of the body. HPV-related head and neck cancers most commonly involve the oropharynx, including the tonsils and the base of the tongue. The risk of HPV exposure increases with the number of sexual partners you have and engaging in oral sex. HPV can lead to oropharyngeal cancer in both men and women.
Other known risk factors for head and neck cancer include:

- Eating preserved fish or vegetables, and especially salted fish products of east Asia.
- Exposure to inhaled products like wood dust, asbestos, radiation, nickel, and other metals.

Common symptoms of head and neck cancer are:

- A lump, lesion, or sore that does not heal
- A mass in the neck
- Change in voice
- Trouble swallowing
- White or red patches in the mouth, or on the gums or tongue that don’t go away
- Unusual bleeding or pain in the mouth
- Frequent nosebleeds
- Frequent headaches
- Swelling under the jaw bone
- Loss of muscle function or feeling in the face
- Ear pain or hearing loss
- Trouble breathing

“Embrace the support system being offered. Listen and learn from others who have been through the process.”

Ken N. — Oropharynx cancer survivor
Diagnosing Head and Neck Cancer

One of the most effective tools in the fight against head and neck cancer is early detection and prompt treatment. When cancer is found early, there is a better chance of a successful treatment outcome.

Most commonly, a head and neck surgeon will make the diagnosis of head and neck cancer. Important parts of the evaluation may include:

**Endoscopy**: The endoscope is a lighted tube with a small camera that is moved into and through the nose or mouth for a more thorough exam inside your mouth and throat. The endoscope may also be used to examine your airway (bronchus) and swallowing tube (esophagus). At times, this is done under anesthesia.

**Computed tomography (CT) scan**: This scan creates a series of X-ray images of the head and neck area.

**Magnetic resonance imaging (MRI)**: This scan creates detailed pictures of soft tissues in the head and neck region.

**Positron emission tomography (PET)**: This whole-body scan helps detect the extent of cancer in the head and neck, as well as possible spread of the cancer to other parts of the body. At Kaiser Permanente, the PET scan is combined with a CT scan and called a PET/CT. It will still be called a PET scan.

**Fine-needle aspiration (FNA)**: This procedure uses a small needle to remove a sample of tissue or lymph node material in the affected area. This does not require surgery and can often help make a cancer diagnosis.

**Biopsy**: This procedure removes a sample of tissue from the body. The tissue is sent to a pathology laboratory for analysis to see if cancer cells are present in the tissue sample. A biopsy can be done either in the office with a local anesthetic, or in the operating room under general anesthesia.
If cancer is confirmed, it is important to learn the stage (or extent) of the disease. Tests are done to discover the size of the tumor and determine if the cancer has spread to other parts of the body. Staging will help guide the plan of treatment, give a prognosis, or estimate of expected treatment results. In general, the lower the stage, the earlier the cancer has been detected.

**TNM staging system**

A more specific staging description is provided by using a process called TNM staging. The designations assigned to a cancer using this system determine how a plan for treatment of the cancer will be created. TNM is a widely used system and details a combination of three factors to describe the cancer:

**T Stage:** The size of the primary tumor.

**N Stage:** Indicates if cancer has spread to lymph nodes and how many lymph nodes are involved.

**M Stage:** Describes spread of the cancer to other parts of the body, known as distant metastasis.

Below is an example of how we stage head and neck cancer.

<table>
<thead>
<tr>
<th>Pre-cancerous stage</th>
<th>Stage 0</th>
<th>Abnormal cells have been found but have not yet become cancerous. This stage is often called carcinoma in situ.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early stage</td>
<td>Stage I</td>
<td>Tumors are generally small and have not spread to any nearby lymph nodes.</td>
</tr>
<tr>
<td></td>
<td>Stages II and III</td>
<td>Tumors are larger than Stage I cancers and may involve lymph nodes.</td>
</tr>
<tr>
<td>Advanced stage</td>
<td>Stages IVa and IVb</td>
<td>Tumors are more advanced and involve more lymph nodes than Stage III cancers.</td>
</tr>
<tr>
<td></td>
<td>Stage IVc</td>
<td>Cancer has spread to other organs outside of the head and neck region. This is the most advanced stage of head and neck cancer.</td>
</tr>
</tbody>
</table>
Numbers associated with each letter (TNM) show the measure of the tumor size and the extent to which cancer may have spread to other parts of the body.

Below is a description of each factor used in TNM staging.

<table>
<thead>
<tr>
<th>Primary tumor (T)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>TX</td>
<td>Tumor cannot be assessed.</td>
</tr>
<tr>
<td>T0</td>
<td>No evidence of tumor found.</td>
</tr>
<tr>
<td>Tis</td>
<td>Abnormal cells have been found but have not become cancerous. This stage is often called carcinoma in situ.</td>
</tr>
<tr>
<td>T1, T2, T3, T4</td>
<td>Cancer cells have been found. Level of T staging based on size and/or extent of tumor. (T1 tumor size is 2 cm or less and T3 is greater than 4 cm.)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lymph nodes (N)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>NX</td>
<td>Lymph nodes cannot be assessed.</td>
</tr>
<tr>
<td>N0</td>
<td>Cancer cells not found in the lymph nodes closest to the cancer site.</td>
</tr>
<tr>
<td>N1, N2, N3</td>
<td>Cancer cells found in the surrounding lymph nodes. N staging level based on number of lymph nodes involved, size, and extent of the cancer.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Distant metastasis (M)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>MX</td>
<td>Tumor cannot be assessed to see if cancer cells have spread from the primary site to distant organs and/or lymph nodes.</td>
</tr>
<tr>
<td>M0</td>
<td>Cancer cells have not spread to distant organs and/or lymph nodes.</td>
</tr>
<tr>
<td>M1</td>
<td>Cancer cells found in distant organs and/or lymph nodes.</td>
</tr>
</tbody>
</table>
The Tumor Board

Assembling the best possible treatment plan requires specialists from many different fields. A collaboration of our dedicated cancer specialists, The Tumor Board reaches consensus to recommend the treatment plan that best suits your needs. Not all cancer cases are reviewed by the Tumor Board.

If your case does go to the Tumor Board your doctor will meet with you to explain the findings of the Tumor Board. You will discuss the treatment plan, descriptions of the therapies to be used, and side effects that can be expected from treatment. Every effective cancer treatment has benefits and side effects.

Cancer treatment team

At Kaiser Permanente, we understand the complexity of cancer and how it may affect you. We have brought together a multidisciplinary cancer treatment team to provide you the best possible care. This team will follow you through your cancer treatment and after. We hope you will feel comfortable with all members of our team and we encourage you to communicate any of your questions or concerns with us. Members of your treatment team include:

- Head and Neck Surgeon
- Licensed Clinical Social Worker
- Maxillofacial Surgeon
- Medical Oncologist
- Medical Assistant
- Oncology Nurse
- Palliative Care Specialist
- Pathologist
- Physical Therapist
- Plastic Surgeon
- Radiologist
- Radiation Oncologist
- Registered Dietitian
- Speech Therapist
Successful treatment will be encouraged by taking good care of ourselves. Try to improve your general health habits before your treatment begins. Taking good care of ourselves can help avoid treatment side effects, encourage more rapid healing; and increase the likelihood of successful outcomes. Before treatment begins, please look at this booklet section entitled, “Self-Care: Before, During, and After Treatment.”

Many promising treatment options exist for head and neck cancer. Your treatment will be tailored to account for your particular situation. Your doctors will determine a course of treatment based upon where the cancer is located, its stage, and your overall health. The most common treatments used to fight head and neck cancer are:

**Surgery:** An operation to cut out and remove the cancer; may include reconstructive surgery.

**Chemotherapy:** The use of medications to kill cancer cells throughout the body.

**Radiation therapy:** The use of painless, invisible, high-energy beams to the tumor site, killing cancer cells.

**Combination therapy:** Treatments using any combination of the above therapies.

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**After treatment**

You will probably begin feeling better about two weeks after finishing radiation treatment. Effects from chemotherapy are often gone within a few days. Radiation and chemotherapy take time to work. We may not see the maximum result until a few months after your treatment is completed. It could take months or even years to recover your normal energy level and feel like yourself again.

Your follow-up tests, procedures, and appointment schedules will meet standards set by the National Comprehensive Cancer Network Guidelines. You will meet with your Oncologist one month after treatment has stopped. After radiation treatment, you will be seen every two months during the first year. If you receive chemotherapy or surgery, you will meet with your primary Oncologist periodically depending on how you are doing. In some cases your doctor will order more tests or scans to check your response to treatment.
Surgery is one of the most common treatment options for head and neck cancers. If you have surgery, your Head and Neck Surgeon will remove cancerous tissue and some tissue surrounding the tumor (a cancer resection), to create a clear, cancer-free area. If your cancer has affected nearby lymph nodes, they may be removed as well.

Lymph nodes are part of the lymphatic circulatory system. Cancer cells can sometimes travel in lymphatic fluid and become lodged in lymph nodes. To prevent further spread of the tumor, the neighboring lymph nodes may need to be removed. The removal of lymph nodes in the neck is called a neck dissection. This might be done as a separate surgery.

Before any surgery is performed, you and your Head and Neck Surgeon will review your case. You will be informed of the parts of the body involved, the stage of the cancer, your expected hospital stay, follow-up care, and possible cosmetic and functional results from the surgery. Sometimes more than one surgery is needed as part of the surgical treatment plan.

Your cancer surgery will be performed under general anesthesia, meaning that you will be asleep during the operation. Sometimes, treatment may cause you to have trouble breathing. If this is the case, your surgeon may suggest a procedure to help you breathe. A breathing tube may be inserted through your mouth into your lungs to make it easier for air to pass. At times there may be too much swelling or mucus to do this and a tracheotomy may be needed. A tracheotomy is a procedure that creates a new airway by cutting into the trachea, or windpipe, through the front of the neck. A tube is placed through the opening and into the trachea to allow free air flow for breathing. This opening may be temporary or permanent, depending on how you are doing. In addition, as you go through treatment, you may receive a feeding tube to deliver nutrition. In most cases, the breathing and feeding tubes are temporary. We remove them when you have recovered from your treatment.

The length of your hospital stay can vary depending upon the type of procedure that we perform. Simple surgical procedures can be done in an outpatient setting, allowing you to return home the same day. More complex procedures may require a longer hospital stay or a stay in the hospital Intensive Care Unit (ICU).

Prepare for surgery online video
kp.org/mydoctor
Search for “anesthesia for an adult emmi”
Maxillofacial surgery

If your cancer involves the bones of your face, Maxillofacial Surgeons, who specialize in surgeries of the jaw bones and bones of the face, may be part of your surgery team.

Plastic and reconstructive surgery

Reconstructive surgery may help rebuild areas affected by the initial surgery. The procedures may be cosmetic, to improve appearance, or to repair a defect left by cancer removal. Reconstructive surgery may also be done to make physical adjustments to improve functions, such as chewing and speaking. Often, the reconstructive surgery is done at the same time as the cancer resection or sometimes it may be performed as a separate surgery.

Reconstructive surgical options vary depending upon the extent of the prior surgery, and can include:

- **Primary closure**: Closure of a wound using simple sutures (stitches).
- **Split thickness skin grafting**: Skin layer from another part of your body, such as the thigh, is used to create an additional closure for the surgical wound. This is helpful for large but superficial surgical sites.
- **Regional flap**: Tissue is repositioned on the neck or chest area to cover the surgical wound site.
- **Free flap**: A transplant of skin and soft tissue from a distant site. If bone is needed to reconstruct the jaw, the bone may be taken from one of the bones in your leg.
- **Maxillofacial prostheses**: Restoring or reconstruction of oral or maxillofacial defects with bio-compatible synthetic devices.


**Side effects of surgery**

Possible side effects will be discussed with your doctor. There are many options to manage the severity of side effects. Some side effects from surgery may include:

- Difficulty chewing or swallowing
- Changes in speech
- Swollen areas in the face or neck
- Prolonged swelling in areas where lymph nodes have been removed (lymphedema)
- Numbness in areas where nerves may have been removed or damaged
- Weakness and stiffness in the neck and shoulders

Swelling in the face and neck area, usually goes away within a few weeks. However, if lymph nodes are removed (neck dissection), swelling may last for a longer period of time. The surgery can slow the flow of lymph fluid, which may collect in the tissues. This is called lymphedema. The shoulders and neck may also feel weak and stiff after a neck dissection. Physical therapy, including appropriate exercises and treatments, may help with these problems. Regardless of the side effects, we will help you manage them.

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**After surgery**

Your Head and Neck Surgeon will often be your primary doctor to follow you throughout your cancer journey and after. The pathology report from your surgery will help your Head and Neck Surgeon determine if further surgery, chemotherapy, or radiation therapy are needed. After you have completed treatment, your Head and Neck Surgeon will arrange for regular follow-up visits.
If chemotherapy is part of your treatment, you will meet with your Medical Oncologist to discuss chemotherapy options.

Chemotherapy medications are designed to kill cancer cells. Each cancer has its own prescribed treatment regimen. The type of cancer, the location of the cancer, the size of the tumor, and the spread of cancer cells all determine which drugs or combination of drugs are used. Chemotherapy may be given before radiation treatment, during radiation treatment, or after radiation treatment has been completed. Kaiser Permanente has a dedicated infusion center where the chemotherapy is given.

Chemotherapy is usually given as an intravenous (IV) infusion. It is given in cycles with breaks between treatments. This allows the body to recover before the next treatment. You might receive a treatment once a week or you might have a few weeks between treatments.

Chemotherapy Orientation Class

This class is for newly diagnosed patients and family members. We introduce you to chemotherapy treatment, what to expect and how to cope. Please call the Oncology Department for schedule information. 1-408-851-4325.

Chemotherapy Treatment Plan Examples

<table>
<thead>
<tr>
<th>Plan 1: Chemotherapy every 3 weeks</th>
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</thead>
<tbody>
<tr>
<td>Chemo Day #1</td>
</tr>
<tr>
<td>Chemo Day #22</td>
</tr>
<tr>
<td>Chemo Day #43</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Plan 2: Chemotherapy each week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chemo Day #1</td>
</tr>
<tr>
<td>Chemo Day #8</td>
</tr>
<tr>
<td>Chemo Day #15</td>
</tr>
<tr>
<td>Chemo Day #22</td>
</tr>
<tr>
<td>Chemo Day #29</td>
</tr>
<tr>
<td>Chemo Day #36</td>
</tr>
</tbody>
</table>
Instructions for chemotherapy patients

- Before each chemotherapy session, you will need to have blood tests done at the laboratory. The tests should be done two business days before each chemotherapy appointment. Your blood can be taken at any Kaiser Permanente Laboratory. If you have a central line, such as an Infusa-Port or PICC line, the Laboratory Department will not be able to draw blood from these IV sites. The Infusion Center nurses can draw blood from special IV sites. An appointment is required for blood draws at the Infusion Center.

- Drink plenty (64 ounces) of non-caffeinated, non-alcoholic beverages the day before treatment, the day of treatment, and during the three days following treatment.

Prepare for chemotherapy online video
kp.org/mydoctor
Search for “chemotherapy emmi”
• Avoid high doses of any over-the-counter pain medicines, unless given permission by your doctor.
• Avoid people who are sick if possible. Wash your hands well after you contact anyone who is sick.
• Prevent pregnancy during your cancer care. Always use a reliable birth control method while in treatment.
• Report any of these problems to your care team:
  o Fever (101°F or higher) or signs of infection
  o If you feel ill
  o Redness, blistering, or pain where the IV was inserted into the skin
  o Severe mouth or throat tenderness that prevents drinking
  o Diarrhea that you cannot control with Imodium
  o Constipation that does not improve with use of laxatives or stool softeners
  o Bleeding that does not stop easily
  o Jaw tightness
  o Loss of balance, dizziness, or passing out
  o Any other concerning symptoms
• People receiving chemotherapy may have low levels of the drug in their body fluids (e.g., blood, urine, saliva). These usually disappear within hours after treatment. The level of drug is low and is not considered to be a health risk to others. Keep pregnant women and children away from any contact with your body fluids. Soiled clothes and linens should be washed separately.

The key to dealing with side effects ...

is prevention. Be prepared to deal with them before they occur. Take advantage of the experience and knowledge of the clinic staff to help you. Discuss side effects early in your treatment process. Usually, once the best method is found to control side effects, the side effects do not become worse with future treatments, with the exception of fatigue.
Infusion center appointments

Your infusion treatments are held separately from appointments with your Medical Oncologist. The Oncology Nurse will administer your treatment and explain the treatment process. If you have any questions or concerns, or feel ill during your treatment, please speak with your Nurse. At the end of each treatment session, the Center staff will give you your next appointment time. Your infusions are coordinated with the Radiation Oncology Department if necessary.

If you feel anxious arriving for your first treatment, be sure to let the clinic staff know what you are feeling. They can help patients through fear and anxiety. Let them help. Think of ways you have successfully faced stressful situations in the past. Future visits will feel more familiar.

Your treatment appointments may last several hours. You may relax in a large comfortable chair or lie on a bed, if appropriate. You will remain in your own clothes and you may want to bring a sweater if you tend to feel cold. We encourage you to bring books or magazines to read, and projects like knitting or writing. The medical center is Wi-Fi accessible, so you can use the internet during treatment. You may listen to your own music or meditation recordings by bringing your own player and headphones. A friend or family member may attend with you to keep you company.

Our goal is to keep your treatment sessions safe and comfortable. Very little activity will take place during your treatment. You will be able to use the restroom. Some small snacks are available, but the Center does not provide meals.

Side effects of chemotherapy

Each person tolerates chemotherapy differently. It is difficult to predict a person’s tolerance and side effects. We hope you do not suffer any side effects from chemotherapy. However, we want you to be aware and prepared for the most common side effects so that they can be dealt with quickly. Most side effects can be minimized with medications.

Lowered blood counts: Lower red blood cells causes anemia, resulting in fatigue and pale skin. Lower white blood cells is called neutropenia and can reduce the body’s ability to fight infection. Low platelet counts can result in easy bruising and bleeding.

Nausea and vomiting: Nausea and vomiting can be controlled with medications.

Constipation or diarrhea: These are normally managed with medications.

Impaired kidney function: Drink plenty of liquids before and after chemotherapy infusions.
Neuropathy: Numbness, burning, or tingling in fingers or toes usually resolves over time.
Sterility: If you plan to have children, talk with your doctor before you start your treatment.
Hair loss: This usually happens two to six weeks after starting treatment. The loss may vary from slight thinning to complete loss. The hair usually grows back after treatments are completed.
Skin changes: Sensitivity to the sun will require protection. Discoloring or thickening of the skin may occur and sometimes returns to normal.
Tenderness and sores: The mouth, throat, esophagus, or lips may feel especially tender.
Vein changes: Some discomfort may occur at the infusion site.
Fatigue: You will feel tired and experience a loss of stamina.
Emotional changes or moodiness: Some emotional experiences may feel unusual and can be caused by nervous system changes from treatment.
Sexual function: Sexual desire or ability may decline during the treatment period.

Alternative medicine and treatments

We advise caution before using complementary and alternative medicines, especially during chemotherapy and radiation therapy.

Many herbal supplements have potential interactions with chemotherapy and radiation therapy. We advise you to be an informed consumer rather than trying treatments based on commercial advertisements for products in stores or online.

Avoid any supplements that claim to have anti-oxidant properties.

Some supplements to avoid during chemotherapy and radiation therapy include: St. John’s Wort, Ginkgo extracts, Chaparral, and food supplements that are metabolized in the liver, such as grapefruit juice, milk thistle, goldenseal, cat’s claw, cannabinoids, licorice, chamomile, and wild cherry. Supplements that may cause liver damage include birch oil, blessed thistle, kava, germander, DHEA, turmeric, and more.

For more information: kp.org/santaclara/cancercare search for alternative medicine
Radiation Therapy

The Kaiser Permanente Cancer Treatment Center provides highly specialized external beam radiation treatments. Radiation therapy is the use of invisible, high-energy rays to destroy cancer cells. A Radiation Oncologist will oversee your therapy and a Radiation Therapist will administer your treatment.

BEFORE TREATMENT CAN BEGIN

You MUST have a complete dental exam performed by your Dentist. This must be done as soon as possible. Dental work or tooth extractions must be done right away in order to heal before treatment can begin. Your dentist will order fluoride gel trays that you will use every day.

If you have had surgery, planning your radiation therapy may be delayed a few weeks to allow for healing.

Radiation can be used with or without chemotherapy. Radiation therapy can be effective before surgery to shrink a cancerous tumor and make it easier to remove. It can be used after surgery to prevent any remaining cancer cells from multiplying. Radiation can also help reduce pressure, pain, or bleeding caused by cancer.

During treatment you will receive radiation to the area needing treatment, killing cancer cells. Some nearby healthy cells will be damaged by the radiation. You will recover after treatment is completed. Some of the healthy cells damaged during treatment (e.g., salivary gland tissue or taste buds) may not return to normal function and may contribute to long-term side effects, such as dry mouth and altered sense of taste.

The treatments last only a few minutes and you will be able to walk and drive afterward. When treatment is completed each day, the radiation machine is turned off. You will not be radioactive. You will not be a danger to others.

Prepare for radiation therapy online video

kp.org/mydoctor

Search for “radiation therapy emmi”
Cancer Treatment Center

At the Cancer Treatment Center (CTC) you will meet members of your cancer treatment team, including your Radiation Oncologist, Oncology Nurse, and Registered Dietitian. The team’s assessment of your cancer and recommendations for your treatment will be discussed.

An appointment will be made for a CT simulation. You will be positioned on the treatment table and we will determine the ideal position for you to be in during your radiation treatments. We will map your anatomy with use of the CT scanner. These planning steps will ensure that you are positioned accurately during each treatment session.

You will be fitted for an immobilization mask. A warm plastic sheet with “fishnet” holes will be placed over your face. When it cools, it will harden to the shape of your face. The sheet is completely porous and does not block breathing or sight. The mask may extend to the shoulders for some patients.

Credit: National Cancer Institute

When your mask is fitted it will cover your face and you will need to stay still. If you think you may feel uncomfortable lying still on the treatment table during your visits, please discuss this with us. The CTC staff has experience working with patients through this process and will do everything possible to assure that your treatment visits are efficient and comfortable.
The Cancer Treatment Center uses a range of state-of-the-art radiation therapy equipment.

- Three-dimensional conformal radiation therapy (3D-CRT)
- Image-guided radiation therapy (IGRT)
- Intensity-modulated radiation therapy (IMRT), using RapidArc™
- Stereotactic radiosurgery (SRS)
- Electronic portal imaging device (EPID)
- Multileaf collimator (MLC)
- On-board imager (OBI)
- High-dose rate (HDR) brachytherapy

**Radiation treatment visits**

The usual course of treatment lasts about six to seven weeks and is given once each day, Monday through Friday. Generally, your treatment time will be the same length for each visit.

Please arrive 15 minutes before your scheduled appointment to give yourself time to change from your clothes to a treatment gown. Once you have changed your clothes, you will lie on the treatment table and be carefully positioned for treatment. You should lie very still while receiving the treatment. The radiation beams must be directed to the exact position of the area being treated. To keep you still during treatment, your immobilization mask will be fastened to the table. Your mask will be used during each of your radiation treatments.

You will be alone in the treatment room during treatment. The Radiation Therapist will be outside the room watching you on a video screen. They can talk with you using an intercom. During radiation treatment you will not notice the beam. The radiation beam does not hurt.

“Encouragement is so very important.”  *Ken N.*  — Oropharynx cancer survivor
**Side effects of radiation therapy**

While the radiation beam is painless, radiation to the head and neck does have side effects. The most common side effects are sore throat, mouth sores, dry mouth, taste changes, skin reddening, blistering, and skin peeling. Your doctor will discuss side effects and care with you. Please note that the consent form you are signing does include a list of possible side effects.

After two to three weeks of treatment, you will start to notice side effects. These side effects will gradually worsen throughout treatment and peak one to two weeks after treatment ends. Side effects will slowly improve over the following months.

Drinking alcohol and smoking only irritate your mouth and throat during treatment and greatly decrease the chance for successful treatment of your cancer. If you smoke or drink alcohol, try to quit. Talk to your doctor about the resources available to you.

**Mouth and throat pain:** You will gradually develop a sore mouth and throat. Pain can be severe enough to make swallowing food, water, and saliva difficult. You will receive topical numbing agents and prescription pain medications to manage pain. We encourage patients undergoing treatment to continue swallowing to preserve swallow function.

**Dry mouth:** You will develop dry mouth (xerostomia) that may remain for months to years after treatment. Most patients say their saliva improves over time, but never reaches a normal level. It is helpful to take frequent sips of water through the day and with meals to keep your mouth moist and help with swallowing. Discuss strategies to help with dry mouth and preserve saliva production with your Radiation Oncologist.

**Difficulty swallowing:** You will have trouble swallowing and may need to change to a soft or pureed diet. Drinking liquid nutrition supplements can help you meet your nutrition needs when eating is challenging. A feeding tube (PEG tube) may be recommended if severe swallowing problems are anticipated.

**Loss of appetite:** You may lose your appetite. Try eating smaller, more frequent meals using nutrient-dense foods to meet your nutrition needs. Make sure that nausea and vomiting is well-controlled with medications.

**Changes in taste and smell:** Your sense of taste and smell will change during treatment. You may completely lose taste during treatment making eating very challenging. Taste begins to improve within a few weeks of completing treatment but may never return to normal.

**Thick saliva:** Staying well-hydrated will help relieve the thick saliva in your mouth and throat. Your team can recommend over-the-counter products to manage thick saliva.
Weight loss: Losing weight is common during head and neck cancer treatment. It is helpful to try to gain weight before starting treatments. During treatments your weight will be monitored closely. Excessive weight loss is associated with muscle wasting, weakness, fatigue, and slow recovery.

Reddened skin: Your skin will become red, similar to sunburn. We recommend the use of over-the-counter moisturizers to prevent damage to the skin. In rare cases, the redness gets worse and can peel, ooze, or even bleed. Your nurse or doctor will recommend appropriate products to minimize discomfort and promote healing.

Changes in diet: Your diet will change during treatment. You may need to eat soft food or drink liquid supplements and avoid foods that are irritating to your sensitive mouth and throat. The Registered Dietitian will follow you closely through treatment to assist with any nutrition challenges.

Hair loss: You may have hair loss in areas of the treatment field. In men, facial hair may disappear. In some cases, the hair does re-grow months to years after finishing treatment.

Fatigue and tiredness: You will feel very tired. Fatigue may last for many months after treatment is completed.
Clinical Trials

Clinical trials are cancer research studies that involve people. The studies test new ways to prevent, detect, diagnose, or treat cancer. People who take part in cancer clinical trials have an opportunity to contribute to scientists’ knowledge about cancer and to help in the development of improved cancer treatments.

Kaiser Permanente has received national recognition for participating in numerous clinical trials with national and international clinical trial organizations. All of our Medical and Radiation Oncologists are investigators on our cancer research team. We at Kaiser Permanente believe that you should understand all of your treatment options, including participation in a cancer clinical trial.

For more online information about clinical trials
kp.org/santaclara/cancercare
scroll down to the feature called, Is a clinical trial right for you?
We very much encourage you to take good care of yourself. Take time for yourself. Pay attention to reducing stress in your life. Try to improve your general health habits before your treatment begins. Taking good care of ourselves can help avoid treatment side effects, encourage more rapid healing, and increase the likelihood of successful outcomes.

**Head and neck support group**

A diagnosis of head and neck cancer and its treatment bring many physical and mental challenges that stretch beyond the course of therapy. The support of fellow survivors can replace feelings of uncertainty and helplessness with a sense of control which can have a powerful effect on health and recovery. During Head and Neck Support Group meetings, survivors become a source of information, encouragement, and support to other newly diagnosed patients, caregivers, family members, and friends of head and neck cancer survivors. Ask your care providers for information about the support group meetings.

**Healthy eating**

Weight loss and poor appetite are common for patients with head and neck cancer. Chemotherapy and radiation cause multiple side effects that affect appetite and one’s ability to eat enough nutrients through the course of treatment.

You will meet with a Registered Dietitian to discuss your nutrition needs before starting treatment, through therapy, and beyond.

**Basic guidelines:**

- Eat regular meals and include snacks between meals to optimize intake.
- Include protein rich food with every meal.
- Include a variety of fruits and vegetables daily to obtain vitamins and minerals.
- Drink enough fluids to stay hydrated.
- Adjust the consistency of food when you experience discomfort or pain with swallowing.
- As taste perception changes, you will have to experiment with different flavors to suit your palate.
- Discuss any new side effects that you experience with your care team, as there are many options to manage these.

If you are taking over-the-counter supplements, check to ensure that your particular supplements do not contain antioxidants (Vitamin A or Beta Carotene, Vitamin C, Vitamin E, Lycopene or Selenium) that exceed 100% of the Recommended Daily Intake or Daily Value. Large doses of antioxidants can interfere with your treatment and is not recommended while undergoing chemotherapy and radiation therapy. Antioxidants protect cells from damage or

“The state of my mind was the most important thing that I had. Self-care was a big part of it.”

*Mike L.* — Tongue cancer survivor
oxidation. They may keep cancer cells safe from oxidative cancer treatments. You may still include a variety of fruit, vegetables, and grains (foods that contain antioxidants) in your diet.

**Feeding tube**

Your doctor may suggest that a feeding tube be put in place before you begin your treatment. This will provide temporary access to nutrition and hydration when eating and drinking is difficult due to the side effects of treatment.

We encourage you to take some food and liquids by mouth to maintain your swallow function. This will help you transition back to eating regular food soon after finishing treatment.

**Oral care**

Continuing good dental hygiene during and after cancer treatment can reduce complications such as cavities, mouth sores, and infections. It is important to clean the mouth after eating. The following are guidelines for every day oral care during and after treatment:

- Brush your teeth and gums with a soft toothbrush 2 or 3 times a day for about 2 minutes.
- Use mild-tasting toothpaste with fluoride, or baking soda-based toothpaste.
- Floss gently once a day.
- Use alcohol free mouth wash, baking soda, or salt water rinses.
- Use prescription fluoride treatment daily. Your dentist will order dental trays.

- Over-the-counter products are available to manage chronic dry mouth.
- Use lip care products to prevent dry and cracked lips.

**Jaw exercises**

Trismus is trouble opening the mouth. Trismus can affect your ability to eat, talk, or take care of your oral health. To strengthen your jaw muscles try the following:

- Open your mouth as wide as possible 20 times in a row. Repeat this 3 times a day.
- Place the palm of both hands under the jaw. Apply light pressure to the lower jaw as it opens to create resistance when you open your mouth. Gently push the hands up while opening your mouth.

**Speech therapy**

Some patients benefit from speech therapy. Difficulty swallowing and speaking may increase during treatment due to inflammation and scar tissue. Range of motion in the neck may also be affected. Physical Therapists and Speech Therapists work to regain the ability to chew, swallow, speak, and move the head and neck. This service may be accessed before, during, and after treatment.

**Skin care**

To help keep your skin moisturized, apply aloe vera or calendula followed by the recommended moisturizers in the radiation field 3 times per day. Begin moisturizing on the first day of radiation and then seven days
a week. **Do not apply any lotion 2 hours before your treatment time.** You may apply moisturizers immediately after treatment. Continue moisturizing 2 to 4 weeks after radiation therapy has finished.

For bathing and showering, use lukewarm water with a mild soap that will not dry the skin. Lather the soap gently with your hand, rinse and pat dry. Do not use a washcloth or scrub the skin surface. If the therapists place marks on your skin, do not wash them off. Do not remove any tape therapists might place on your skin. Do not shave any skin in the treatment area.

To avoid irritation to the skin, wear clothing that is loose fitting. Wear wide brimmed hats to protect the skin from direct sunlight.

Skin in the treatment areas should not be exposed to extreme temperatures (hot tubs, saunas, steam, ice packs, or heating pads).

Before swimming in chlorinated pools or the ocean, please ask the nurse or physician for advice.

**Stress reduction**

Stress can be reduced through activities like meditation, massage, journal writing, and exercise. The Health Education Department and Mind-Body Wellness Center offer several free and low cost classes to help reduce stress: Introduction to Meditation, Pathways to Emotional Wellness, Mind-Body Stress Management, Sleep Better, and Breath of Yoga. If you prefer an online format, consider listening to Kaiser Permanente’s online podcast series or enrolling in a video coaching series.

**Physical activity**

Staying active is important for mind-body wellness before, during, and after cancer treatment. Stay as active as you can, or as you feel comfortable. Don’t over-do it. Walking even 10 minutes a day will help maintain your strength and lift your mood. Talk with your doctor about appropriate activity for you.

**Health education resources**

kp.org/santaclara/healtheducation

Kaiser Permanente’s Health Education Department addresses total health. Our resources are both affordable and accessible. They include classes, online and audio-visual products, individual consultation, and a variety of health products for sale or lending. Resources include:

- Chronic conditions education
- HIV and STD test counseling
- Life Care Planning consultation
- Medical Weight Management
- Mind, body wellness
- Nutrition and diet consultation
- Pediatric health
- Tobacco cessation
- Women’s and men’s health
**Pain management**

Pain can affect all parts of your life, but having cancer does not mean living with pain. In fact, there are many methods, both with and without medicine, to manage pain. We are committed to pain management for our members with cancer. Our Oncology Supportive Care Clinic is an excellent resource. Your cancer care team can assist you with contacting this resource as needed.

**Emotional support**

Getting through cancer treatment is often an emotional challenge. Your emotional health can be affected by the cancer treatment itself. Schedule changes, relationship stress, physical challenges, and fatigue will all place emotional stresses on your life. Your emotional stress can affect your physical health. All feelings are normal. Learn to recognize and work with your emotions as part of maintaining your health.

While being told you have cancer is a shock, how you react to the news is very personal. There is no right or wrong way to respond. There are many common reactions and emotions that people experience when they learn they have cancer, as well as during and after treatment.

We encourage you to share and discuss your emotions with those around you and with your cancer care team. There are many people available to support you. Let your care team know what you need. Kaiser Permanente provides services including counseling, support groups, and psychiatric care.

**When it’s time to call for help**

For some people, feelings and emotions can become overwhelming and feel difficult to manage. Please call your care team if you have:

- Loss of appetite or poor sleep that worsens over time.
- Unusual difficulty communicating or making yourself understood.
- Decreased ability to pay attention to your surroundings.
- Prolonged feelings of sadness, grief, or hopelessness.
- Apathy over an extended period of time.
- Wide mood swings between elation and despair.
- Frequent or prolonged feelings of isolation or loneliness.
- Unusual difficulty in sexual relationships.
- Thoughts of hurting yourself.

**Psychiatric Oncology**

Psychiatric oncology is the practice of managing emotional and behavioral effects cancer can have on mental health and physical health. It can be included in all stages of active treatment and follow-up care. Psychiatric medications may be an integral part of your care and treatment. Psychiatrists, Psychologists and Licensed Clinical Social Workers are available for consultation at any time during your care.
The Survive and Thrive program at Kaiser Permanente Santa Clara will nourish and strengthen your mind, body, and spirit in all stages of cancer treatment and survivorship. This unique program is a collaborative partnership of the Mind-Body Wellness Center, the Health Education Department, and the Santa Clara Cancer Treatment Center. Our classes and workshops are open to all cancer patients. Several classes are also open to family members and caregivers. We are here for you as you Survive and Thrive.

**Survivor… Now What?** Moving forward with your new identity as a “Survivor.”

**Mind-Body Stress Management:** Reduce stress, discover new thinking patterns, and enhance your quality of life.

**Mind-Body Wellness Workshops:** Weekend workshops offer inspiration, relaxation, and renewal.

**Cancer Fighting Cooking:** This hands-on cooking class presents ways to incorporate cancer fighting foods into a daily diet.

**Nutrition Basics:** Healthy eating, as well as the powerful benefits that nutritional changes can have on survivorship.

**Restorative Yoga:** Gentle, supported, resting postures, along with breath work and guided meditation will improve circulation and reduce stress. Especially beneficial during treatment.

**Strength Training Body & Mind:** Strengthen the body and inspire your mind.

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For more information call the Mind-Body Wellness Center 1-408-366-4284; or mindbodywellness@kp.org.

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**Cancer Survivors Day**

**Seeds of Hope**

Kaiser Permanente Cancer Survivors Day is held each June to celebrate cancer survivors and help them and their families to continue healthy lifestyle habits. Activities include exercise, stretching, healthy eating demonstrations, and more!

Ask your cancer care team for more information.
You are a survivor when you learn you have cancer. Many people around you will be concerned with your physical well-being. The rest of your life is affected by cancer too. There is no mistake: your life has changed. And that means you will probably be learning to live your life differently than you did before your diagnosis. Life will present new challenges as well as opportunities.

For many people experiencing cancer, reaching out to others with the same experience can be the best support. We find encouragement with each other. Feeling disappointed, alone, and anxious is normal. But you don’t need to stay that way. People get through this. It’s tough. It can be real tough. But we get through it. Acknowledge your experiences and feelings. Much of your welfare may depend on the amount of support around you. Rely on that support. Let people take care of you. Stress and anxiety can delay recuperation.

Please let us know about symptoms or problems: whether you’re feeling better or worse, good or bad.

Your care team can respond when you let us know what is happening in your life.

**Read stories of head and neck cancer patients’ experiences.**

At our cancer care website, select the tab for Survivorship and then choose, “Survivor Stories.”

We want you to have as much control of your life as possible. You are responsible to communicate what you feel and need. You may want to bring a family member with you to appointments to help keep track of details. This can help them manage better as well. Keep a diary of treatments, medications, and side effects. Write questions for your doctor and care team so you won’t forget to ask them.

Remember, the goal of your treatment is to help you move forward with your life. Your treatment experience is temporary. It will probably slow you down for a while, but there is no reason to abandon the things that you enjoy. In fact, those things will continue to give you encouragement. We encourage you to maintain your life as normally as you can. This can help to keep the demands of treatment in perspective. You might feel ill, temporarily. You may need help, temporarily. Your schedule will change, temporarily. When treatment is past, and you’ve had time to recover and feel stronger again, it will be time to move forward with your life.

“Try to find some way to let go of all the discussion going on in your head... quit trying to figure everything out. Rest, relax, right now.”

*Mike L.* — Tongue cancer survivor
None of us do this alone. To varying degrees, we all have spouses, partners, children, relatives, friends, and neighbors who play a vital role in giving us hands-on care, support, and encouragement. Most people think first of giving physical care. Caregivers provide support in many other roles during the patient’s cancer experience. A family caregiver may face the tough job of taking on new roles and challenges as the patient’s needs change over time.

Family members are affected directly, not just through giving support. They deal with their own experience of cancer. They too will have feelings about the changes in circumstances. Providing emotional support and taking over duties and family schedules add complexities and stress to our caregivers’ lives. We count on them to be our close friends and trusted confidants. They need support too.

We can help you take care of our caregivers. Understand that this process is not easy for them either. Encourage them to take time for themselves. Remind yourself to try and enjoy their company, even when you may be feeling down or hurting from a recent treatment. Understand that they travel your path with you. As your care team, we want everyone to get the help they need to see you through.

Continue your daily routines and responsibilities as much as possible. You can keep track of medications, go to doctor visits, make appointments, fix meals, clean the house, run errands, and keep up with family activities. It is therapeutic to stay focused on getting on with your life.

**Care for the caregiver**

Caring for a loved one can be both rewarding and stressful. It is easy to put your own needs aside while giving care to someone else. Remember, you need to take care of yourself too. Know your limits, and know when to ask for help. Simple steps, such as setting aside time for yourself each day, journaling, talking to friends, and being active are all ways to care for yourself.

“People are eager to help and my advice is to let them.”

*Ron F.* — Tonsil cancer survivor
Long-Term Side Effects

Some side effects from treatment can last for months or years. Your Oncologist and support staff will continue to work with you to manage ongoing side effects.

**Chronic dry mouth**: Salivary glands might be removed or not return to their normal function.

**Difficulty swallowing or chewing**: Surgery or scarring of tissue may alter organs in the mouth or throat. Changes to muscles, tendons, ligaments, and jaw bones can alter the way we chew or swallow. Speech therapy can help.

**Change of taste or smell**: These senses may change over time. Some taste and smell may return in the months after treatment. Some foods will not taste the same.

**Difficulty maintaining weight**: This can result from reduced appetite or eating less if it is difficult to chew or swallow. Dietitians will give you advice to maintain a healthy weight.

**Dental complications**: If treatment is focused on the jaw, there may be long-term effects that include loss of teeth, risk of infection, and pain or numbness in the jaw. You will need regular dental care for the rest of your life.

**Discolored neck skin**: Some skin colorations may be short term and some may become permanent. Protection of the affected skin from direct sunlight will be important to prevent further discoloration.
Lymphedema: Lymph fluid may gather and cause swelling in the face and neck area.

Firm or “woody” neck: Muscle tissue affected by radiation therapy may feel stiff or thick as a result of scarring.

Pain or numbness of neck skin: Nerve endings may be damaged or destroyed in the skin from surgery or radiation therapy.

Jaw pain: As with chewing, jaw pain may result from changes to muscle, tendon, and ligament tissue following radiation and surgery. This may also result from damage to nerves. Pain and physical impairment, especially with bone implants or replacements, may change how a person chews.

Hearing impairment: Side effects of chemotherapy and radiation, surgical removal of tissue, swelling, and fluid collection in the ear can impair hearing.

Infertility: Some types of chemotherapy can cause infertility. For a woman, this means that you may not be able to get pregnant. For a man, this means you may not be able to get a woman pregnant. Before you begin chemotherapy, talk with your doctor and nurse if you want to have children in the future.

“My lifestyle had changed for the better. I was eating more healthy foods and my body and mind responded positively.”

Ken N. — Oropharynx cancer survivor
Oncology Supportive Care Clinic

The Oncology Supportive Care Clinic focuses on the whole person: body, mind, and spirit. The clinic is designed to provide pain and symptom management with the goal of improving quality of life. Good symptom control enables patients to continue with their favorite activities and to enjoy spending time with their family and friends. The clinic offers individual and family counseling to provide a sense of meaning and a source of strength and comfort. Our team also provides assistance with treatment choices and decisions as well as additional resources. For more information or to refer yourself, call 1-408-851-0537.

Advanced Illness Care Coordination Program (AICCP)

AICCP is a support program for members with advanced illness. The program allows you to work with a Licensed Clinical Social Worker (LCSW) to:

Understand how to work with your doctors and caregivers.
Explore important medical choices and personal care issues.
Identify resources to support you and your loved ones.
Gain peace of mind through planning and preparation.

There is no charge, copayment, or coinsurance for this service. For more information or to refer yourself, call 1-408-851-4305.

Palliative Care

Palliative Care is specialized medical care for people with serious illness. This type of care is focused on providing patients relief from the symptoms, pain, and stress of cancer and to help patients live as well as possible while facing a serious illness. The goal of palliative care is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient’s other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatments.

Hospice Service

Hospice services provide support and care to people who are approaching the end of life. Services may include a nurse, social worker, physician, home health aides, chaplain, and volunteers. Hospice services are normally provided in the home or in a licensed care facility with personal caregivers available around the clock. Visits from hospice staff are intermittent (i.e., once or more times a week), depending on need. Assistance is provided for bathing, pain management, wound care, counseling, spiritual care, and social work.

Kaiser Permanente Health Plan provides for hospice service to all members regardless of age. Services may include a nurse, social worker, physician, home health aides, and volunteers. Hospice services are provided in the home and the patient must live with someone, or have someone caring for them 24 hours a day. Nurses visit at least once each week. Assistance is provided for bathing, pain management, wound care, counseling, spiritual care, and social work.
Life Care Planning Program

Life Care Planning is a process of coming to understand, reflect on, discuss, and plan for times when you may be unable to make your own medical decisions. Effective planning is the best way to make sure your views are respected by your loved ones and health providers. This process provides comfort to those who may need to make end-of-life decisions for you. Good advance care planning improves the quality of your advance directive. Our Life Care Planning Consultants can meet with you to help identify a health care agent in the first steps of Life Care Planning. They can facilitate the next steps with you and your health care agent to discuss your values, goals, and preferences for treatment. Life care planning can also focus on periods in a person’s life when death might occur in the next year, or when someone has a continuing critical illness. Consultation includes discussion of “Physician Orders for Life-Sustaining Treatment,” or POLST form. This document gives immediate care information to emergency responders or emergency room personnel. These can be difficult conversations. There is no easy way to plan for future health care choices. It’s a process that involves thinking and talking about complex and sensitive issues and our Life Care Planning Consultants are here to assist you with this important conversation.

Advance directives

Advance directives are plans you make for your future health care decisions in the event you cannot make these decisions yourself. An advance directive can be oral or in writing. Putting your plan in writing helps people accurately remember your wishes. Advance directives can also make it easier to communicate to health providers who may not know you personally. When completing a written advance directive, two major choices exist. The first is to appoint someone else to make your health care decisions if you are incapable of doing so for yourself. This type of document is called a power of attorney for health care. Typically, such a document also allows you to provide written instructions. The second is to outline instructions about care and treatment preferences at the end of life. This document is a living will, but is known by many names in different places.

Advance Health Care Directive

An Advance Health Care Directive is a formal document that provides for legal witness of your written choice of a health care agent. The directive legally authorizes the health care agent to act on your behalf as a durable power of attorney for health care, if or when you are unable to make decisions for yourself. A copy of an Advance Health Care Directive should be scanned into your medical record to be available in emergencies. You can find more information about advance care planning at kp.org/advancedirective.
Your treatment may affect your physical, mental, social, emotional, and financial well-being. The effects can change from day to day. For some, a serious concern may be whether you can maintain a normal work schedule. With the help of your cancer team and your willingness to manage your side effects, we hope your treatment will disrupt your normal schedule as little as possible.

We will work with you to affect your job as little as possible. You may need to change your regular work schedule or take time from work for recovery from treatments. There are insurance and employment resources to help manage changes. Primary concerns may be maintaining your income and health insurance. Ask your care team Social Workers for further information about California State Disability Insurance (SDI), California Paid Family Leave Program, and the Federal Family and Medical Leave Act (FMLA).

**Member Services Department**

Member Services will help answer your questions and obtain the services or assistance you may need, including:

- Health Plan benefits, premiums and copay explanations
- Member’s enrollment status
- Registration on kp.org
- Getting or replacing a member ID card
- Advance Health Care Directives and Durable Powers of Attorney
- Kaiser Plan coverage while traveling out of the area
- Information regarding health plan documents
- Member suggestions or concerns are received in person or by telephone.
- Member Services Call Center, 1-800-464-4000
- Senior Advantage and Medicare 1-800-443-0815
- Or online: kp.org/memberservices
Release of Medical Information (ROMI) Department

The ROMI Department releases patient medical information by request of the patient.

To obtain information from a member’s medical record the member completes a request form, identifying the specific information being requested. Only members or their legal agent may authorize release of personal medical information.

To forward non–Kaiser records to a member’s medical file, the member requests information from the non–Kaiser provider be sent to their Kaiser Permanente primary doctor (not to ROMI). The Kaiser Permanente primary doctor reviews outside medical records before approval to send the information to the member’s file.

Kaiser Permanente members applying for disability insurance through the California Employment Development Department (EDD) may request copies of medical records to support their application. Members seeking medically related time off from work or applying for Family Medical Leave (FMLA) may request “Work Status Activity Forms” from their doctor.

Financial Services Department

The Financial Services Department helps Kaiser Permanente Health Plan members with questions regarding their medical bills, payments to their accounts, refunds, and any insurance related issues or questions. The department bills all non–Kaiser plans for patients including: Medicare, Medi-Cal, Third Party Liability (TPL), Coordination of Benefits (COB), Health Maintenance Organization (HMO) and secondary insurance companies. Patient Financial Advisors are available to answer questions regarding alternative payment needs, locate resources and assist during and following a hospital stay.
Online resources

Kaiser Permanente My Doctor Online
kp.org/mydoctor

Kaiser Santa Clara Comprehensive Cancer Care website
kp.org/santaclara/cancercare

National Cancer Institute
cancer.gov

National Institutes of Health
nih.gov

American Cancer Society
cancer.org

Cancer Care
cancercare.org

American Head and Neck Society
headandneckcancer.org

Head and Neck Cancer Alliance
headandneck.org

National Comprehensive Cancer Network
nccn.com

Support for People with Oral and Head and Neck Cancer
spohnc.org

Suggested reading

Autobiography of a Face, by Lucy Grealy

The Cancer Fighting Kitchen: Nourishing, Big-Flavor Recipes for Cancer Treatment and Recovery, by Rebecca Katz

Life, on the Line: A Chef’s Story of Chasing Greatness, Facing Death, and Redefining the Way We Eat, by Grant Achatz and Nick Kokonas


One Bite at a Time: Nourishing Recipes for Cancer Survivors and Their Friends, by Rebecca Katz

KP Preventive Care Mobile App

For your Apple and Android mobile devices, our apps can help you with appointment reminders, health tips, and personalized alerts about the care you and your family need to stay healthy. Download them for free on your iPhone, iPad, or iPod touch.
Glossary

**Adenocarcinoma** — cancer that begins in the gland cells

**Adjuvant therapy** — treatment, such as chemotherapy, that is given after the main treatment for a cancer

**Carcinogen** — any substance that is known to cause cancer

**Carcinoma** — a type of cancer that begins in the lining of the skin or internal organs

**Complete response** — The disappearance of all signs of cancer in response to treatment. This does not always mean the cancer has been cured.

**CXR** — abbreviation for chest X-ray

**Dysphagia** — to have trouble with swallowing

**Edema** — swelling that is caused by extra fluid in tissues

**ENT** — a shortened term for Ear, Nose, Throat

**Epiglottis** — tissue that is located in the throat that covers the glottis when swallowing

**External beam radiation** — a radiation therapy using invisible beams outside the body to treat cancer

**Facial lymphedema** — swelling of the face usually after surgery

**Fibrosis** — scar tissue caused by trauma to tissue

**Fine needle aspiration (FNA)** — a needle used to remove a tissue sample or lymph nodes from the neck

**Fractionation** — dividing the total dose of radiation into smaller, equal doses, delivered over several days

**Gastrostomy tube** — a tube placed through the stomach wall to help with feeding

**GY, Gray** — a unit of measuring the amount of radiation dose

**Head and neck surgeon** — a doctor who is an expert in surgery of the head and neck; otolaryngologist

**Hematology** — the study of blood disorders

**High-dose rate (HDR) brachytherapy** — a method of delivering radiation with implanted radiation seeds

**Hyperbaric oxygen (HBO)** — highly concentrated oxygen used for medical therapy

**Hypothyroidism** — decreased thyroid hormone levels that may be caused from radiation to the neck

**Image-guided radiation therapy (IGRT)** — a process of using imaging to help direct radiation treatment

**Imaging** — any method used to take a picture of the body or its soft tissues such as a CT scan or X-ray

**Immune suppression** — to prevent an immune response by the body

**Immune system** — the body’s natural defense system
**Implant** — a foreign object placed in the human body

**Intensity-modulated radiation therapy (IMRT)** — a treatment mode that changes the beams of radiation to conform to the shape of a tumor

**Intensive Care Unit (ICU)** — a special section in the hospital that provides care to very ill patients

**Intravenous** — any substance that is given through the vein

**Larynx** — an organ in the neck that helps with breathing and speech

**Leukoplakia** — a white patch inside of the mouth or throat that does not go away

**Linear accelerator (LINAC)** — the device most often used to provide radiation treatment

**Lymph fluid** — a clear fluid that helps to fight infections and cancer

**Lymph nodes** — glands in the human body that filter lymph fluid and store white blood cells

**Lymphedema** — the buildup of extra lymph fluid in tissues due to blockage of lymph vessels

**Magnetic resonance imaging (MRI)** — a test using magnetic fields and radio waves to picture the body

**Mandibular** — the lower jaw

**Medical assistant** — a staff member who prepares treatment areas and provides help during treatment

**Medical oncologist** — a doctor who is an expert in cancer care and chemotherapy treatment

**Mucositis** — inflammation of the linings in the mouth and throat often caused by cancer treatment

**Neoadjuvant therapy** — the use of a therapeutic treatment before starting the main cancer treatment

**Neuropathy** — a term used to describe a disorder of the nerves

**Neurotoxicity** — damage to the nerves which may be caused by cancer treatment

**Nuclear medicine** — a field of study that uses radioactive substances to help diagnose and treat diseases

**Observation** — when a patient is monitored without treatment unless symptoms appear

**On-board imager (OBI)** — a device that is used to ensure that the radiation treatment is precise

**Oncologist** — a doctor who specializes in cancer care

**Oncology** — a branch of science that studies tumors and cancers

**Oncology nurse** — a nurse who is an expert in cancer care
Glossary (continued)

**Occupational therapy (OT)** — therapy used to help improve the daily functional skills of a patient

**Palate** — the roof of the mouth

**Palliative chemotherapy** — the use of chemotherapy to help shrink or control cancer with the goal of improving or eliminating distressing symptoms caused by the cancer and to help extend a person’s life.

**Palliative radiotherapy** — the use of radiation therapy to control local symptoms or minimize treatment-related discomfort or toxicity to improve quality of life and to extend life.

**Paranasal sinuses** — the mucous lining within the nose and skull

**Partial response** — incomplete disappearance of all signs of cancer in response to treatment

**Pathologist** — a doctor who is expert in examining tissue samples from the body to help make a diagnosis

**Positron emission test (PET)** — a test that uses radioactive substances to obtain images of the body

**Physical therapist (PT)** — a person who works with patients to improve their movement and strength

**Plastic surgeon** — a doctor who is an expert in surgery to reconstruct or correct form and function to the body

**Precancerous** — a description of abnormal cells that have the ability over time to become cancerous

**Prognosis** — a predicted outcome or estimate of one’s current standing

**Prosthesis** — an artificial device to replace a missing body part

**Prosthodontist** — a dental specialist who makes replacements for teeth or other oral structures

**Radiation dermatitis** — skin inflammation due to radiation

**Radiation oncologist** — a doctor who is an expert in radiation therapy to treat cancer

**Radiation oncology nurse** — a nurse who specializes in care of patients undergoing radiation therapy

**Radiation therapy (XRT)** — the use of ionizing radiation to kill cancer cells

**Radiologist** — a doctor who uses imaging to help make a diagnosis

**Radiosurgery** — a medical procedure that uses non-invasive techniques to treat tumors

**Recurrence** — when cancer has returned

**Refractory** — when cancer is resistant or not responding to treatment

**Regimen** — a regulated schedule or protocol

**Registered Dietitian** — a person who is an expert in nutrition