



# Head and Neck Cancer Care



# Table of Contents

Introduction .....	ii
Head and Neck Cancer .....	1
Anatomy of the Throat and Sinus Cavities .....	2
Anatomy of the Oral Cavity.....	3
What Is Cancer?.....	4
Risk Factors for Head and Neck Cancer.....	5
Diagnosing Head and Neck Cancer.....	7
Cancer Staging.....	8
Multidisciplinary Cancer Treatment Team .....	9
Treatments for Head and Neck Cancer .....	10
Head and Neck Surgery .....	12
Chemotherapy.....	15
Radiation Therapy .....	20
Clinical Trials.....	25
Self-Care: Before, During, and After Treatment .....	26
Survivorship .....	31
Family and Caregivers .....	32
Long-Term Side Effects .....	33
Palliative Care and Oncology Supportive Care Clinic.....	35
Life Care Planning .....	36
Hospice .....	37
Insurance and Employment.....	38
Member Services Department .....	38
Release of Medical Information (ROMI) Department.....	39
Financial Services Department.....	39
Resources .....	40
Suggested Reading.....	40
Glossary.....	41

# Introduction

Learning you have cancer is overwhelming. Your world changes, and a cascade of emotions often follows, affecting you and those close to you. You may also have many questions. Your Kaiser Permanente cancer care team will help you through this journey. We created this booklet to support you and your loved ones. 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.

Specialized Kaiser Permanente care teams will provide treatment and support for you. 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 care. Treatment breakthroughs develop frequently, and Kaiser Permanente brings the benefits of those treatments to our members every day.

We welcome your questions. Please discuss any concerns you have with your cancer care team. We are here to help you and those close to you.

“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



Head and neck cancer is a broad term we use to refer to cancers that begin in the head and neck area (see Table 1). They include cancers of the oral cavity, larynx (voice box), the nasal cavity, paranasal sinuses, salivary glands, and mouth (see Figures 1–2). Most are found in the moist, mucous surfaces that line the mouth, throat, and sinuses composed of squamous cells. So these cancers are called squamous cell carcinoma.

Other types of cancer arise from glands in the head and neck region, such as the salivary glands. These cancers are often different from the typical head and neck cancer, so they have different treatments. Nasopharyngeal cancer, for instance, affects the lining of the nasopharynx, an area between the nose and throat.

Head and neck cancer is the sixth most common cancer worldwide.<sup>1</sup> The National Cancer Institute estimates head and neck cancer makes up 3 percent of all cancers diagnosed in the United States.<sup>2</sup> Head and neck cancers are nearly twice as common among men as they are among women.<sup>3</sup> Head and neck cancers are also more commonly found in people over the age of 50.

**Table 1. Common areas of head and neck cancer.**

Cancers	Location
Oral cancers	Lips, mouth, gums, and tongue
Salivary cancer	Glands that make saliva
Oropharyngeal cancer	Pharynx (area at the back of the throat, including the base of the tongue, tonsils, and the back of the sinus cavity)
Nasopharyngeal cancer	Behind the nose and above the throat, and connecting tissue
Laryngeal cancer	Vocal cords or voice box (larynx)

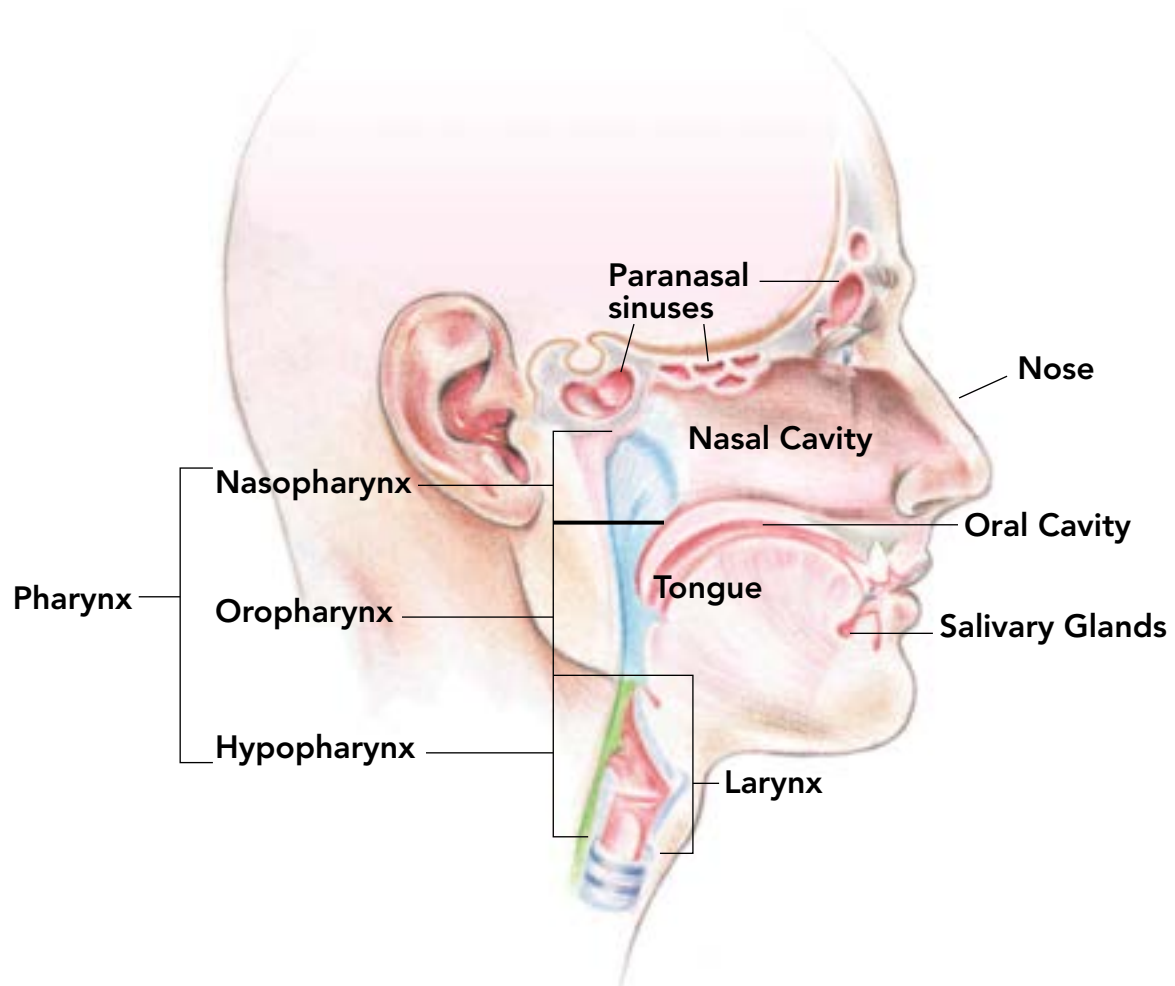
<sup>1</sup> Duvvuri U, Myers JN. *Current Problems in Surgery*. 2009 Feb; 46(2):114-7.

<sup>2</sup> Jemal A, Siegel R, Xu J, Ward E. CA: A Cancer Journal for Clinicians. 2011 Mar-Apr; 61(2): 133-4.

<sup>3</sup> Amer. Cancer Soc., *Cancer Facts and Figures*, 2012.

# Anatomy of the Throat and Sinus Cavities

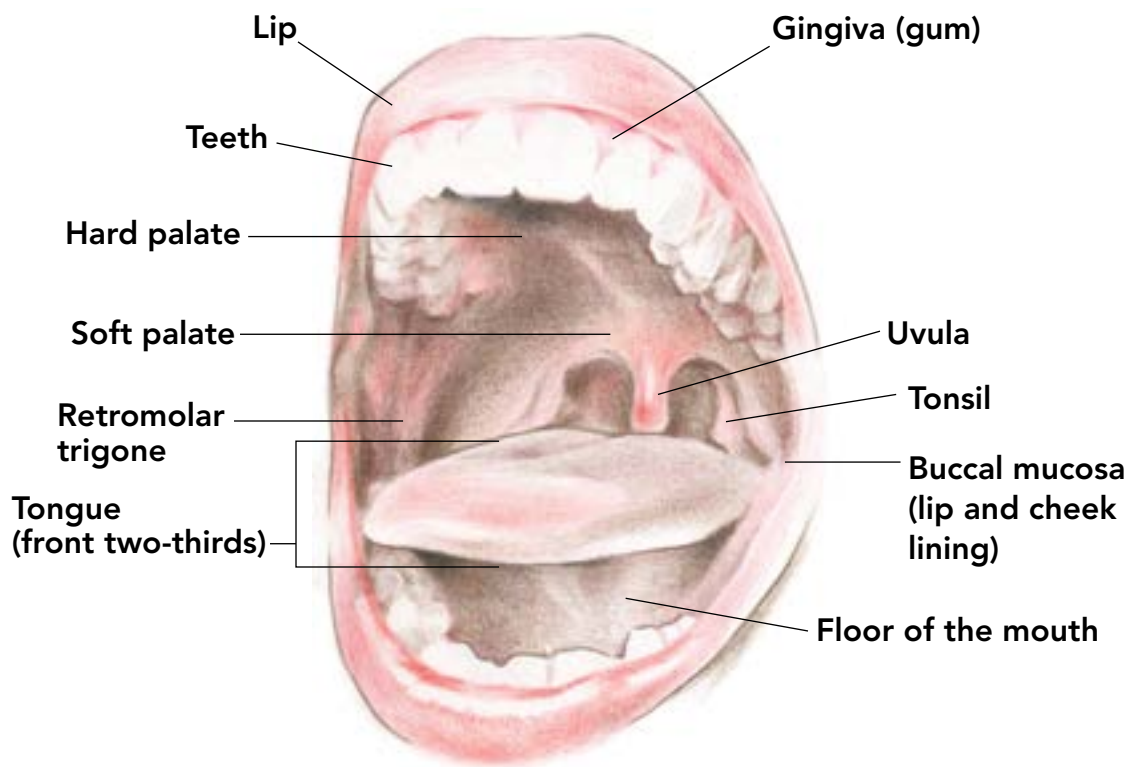
**Figure 1. Anatomy of the Throat and Sinus Cavities**





# Anatomy of the Oral Cavity

**Figure 2. 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)
- Lips
- Teeth

# What Is Cancer?

When abnormal cells divide rapidly and are able to invade other parts of the body through the blood and lymph systems, you have cancer.

When this happens, cells may grow and divide out of control and form a mass of tissue or tumor. If the tumor grows and spreads, it is often cancerous.

But 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.

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 3 ways that cancers spread in the body:

1. **Through tissue:** Cancer invades the surrounding normal tissue.
2. **Through the lymph system:** Cancer travels in the lymph fluid to other body parts.
3. **Through the blood stream:** Cancer travels in the blood to other body parts.

**Most cancers are named for the organ or type of cell where 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.** 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.

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

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*Ken N.* — oropharynx cancer survivor

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# Head and Neck Cancer

There is a greater risk of developing cancer when risk factors exist in a person's life. **The most common risk factors for developing head and neck cancer are:**

- 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 can also cause head and neck cancer: The Epstein-Barr Virus (EBV) and the Human Papilloma Virus (HPV). Epstein-Barr Virus is linked to nasopharyngeal carcinoma.

Recently, research has shown that HPV can cause 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. HPV can lead to oropharyngeal cancer in both men and women.

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.

Wellness coaching provides personalized support to help you quit. Get guidance and encouragement, develop a quit plan, and consider stop smoking medications, all by phone. To learn more or schedule an appointment, call **1-866-862-4295**.

# Head and Neck Cancer *(continued)*

## **Other known risk factors for head and neck cancer include:**

- Eating preserved fish or vegetables, especially salted fish products from East Asia.
- Exposure to inhaled substances 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 jawbone.
- Loss of muscle function or feeling in the face.
- Ear pain or hearing loss.
- Trouble breathing.



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

*Ken N. — oropharynx cancer survivor*

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# Diagnosing Head and Neck Cancer

Cancer screening is the most effective tool in the fight against head and neck cancer. When cancer is found early, there is a better chance of successful treatment.

Most commonly, a head and neck surgeon will diagnose head and neck cancer. This process may include:

- **Endoscopy:** The endoscope is a lighted tube with a small camera that is moved 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.
- **Magnetic resonance imaging (MRI):** This scan creates detailed pictures of soft tissues in the head and neck.
- **Positron emission tomography (PET):** This whole-body scan helps find the extent of cancer in the head and neck, as well as possible spread of the cancer to other parts of the body. Often, the PET scan is combined with a CT scan. It may still be called a PET scan or a PET/CT.
- **Fine-needle aspiration (FNA):** This procedure uses a small needle to remove a tissue sample or part of a lymph node. 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 lab for analysis to see if cancer cells are present in the sample. A biopsy can be done either in the doctor's office or in the operating room with an anesthetic.



# Cancer Staging

When cancer is found, it is important to learn the stage (or extent) of the disease. Staging is a careful attempt to find out whether the cancer has spread, and if so to which parts of the body (see Table 2). Tests are done to

learn the size of the tumor. Staging will help guide your treatment and give an estimate of expected treatment results. In general, the earlier the cancer is detected, the lower the stage.

**Table 2. How we stage head and neck cancer.**

Precancerous stage	<b>Stage 0</b>	Abnormal cells have been found but have not yet become cancerous. This stage is often called carcinoma in situ.
Early stage	<b>Stage I and II</b>	Tumors are generally small and have not spread to any nearby lymph nodes.
Advanced stage	<b>Stages III</b>	Tumors are larger than Stage II cancers and may involve lymph nodes.
	<b>Stages IVa and IVb</b>	Tumors are more advanced and involve more lymph nodes than Stage III cancers.
	<b>Stage IVc</b>	Cancer has spread to other organs outside of the head and neck region. This is the most advanced stage of head and neck cancer.

## **My Doctor Online • The Permanente Medical Group • [kp.org/mydoctor](http://kp.org/mydoctor)**

Kaiser Permanente's My Doctor Online website provides programs and health information that is reviewed or written by our own clinicians and staff. You can find information about our services, doctors, and facilities. You can email your doctor, make appointments, and order medications. You can participate in online educational programs or simply research health topics.

To view your personal health information, you will need to set up your own secure account. You can do this online at your physician's home page. If you have any questions about registration, please call Member Website Support at **1-800-556-7677**.

# Multidisciplinary Cancer Treatment Team

At Kaiser Permanente, we understand the complexity of cancer and how it may affect you and those close to you. To give you the best possible care, we have brought together a multidisciplinary cancer treatment team.

Creating a treatment plan that's best for you requires specialists from many different fields. Our specialists work together to recommend a treatment plan that best suits your needs. This team will follow you throughout your cancer treatment and afterwards to ensure you remain cancer free.

Your cancer treatment team will meet with you as a group to explain treatment recommendations. They will discuss the treatment plan, describe the therapies that will be used, and explain the side effects that can occur.

We hope you will feel comfortable with all members of our team. Please talk with any member of the team about questions or concerns. Your treatment team may include:

Head and Neck Surgeon	Oncology Nurse	Radiologist
Licensed Clinical Social Worker	Pathologist	Radiation Oncologist
Maxillofacial Surgeon	Physical Therapist	Registered Dietitian
Medical Oncologist	Plastic Surgeon	Speech Therapist
Medical Assistant		



# Treatments for Head and Neck Cancer

People with head and neck cancer often want to take an active part in making decisions about their care. It's natural to want to learn everything about your cancer and treatment options. However, the shock and stress after a diagnosis of cancer can make it hard to remember what you want to ask the doctor.

## Here are some ideas that might help you in discussions with your doctor:

- Make a list of questions.
- Take notes at the appointment.
- Ask the doctor if you may use a tape recorder during your appointment.
- Ask a family member or friend to come to the appointment with you.

Your cancer care team can describe your treatment choices and what to expect for each treatment option. You will want to consider how treatment may change the way you look, breathe, and talk. You and your cancer care team can work together to develop a treatment plan that meets your specific situation, needs, values, and preferences.

## The most common treatments used to fight head and neck cancer are:

- **Surgery:** An operation to cut out and remove the cancer, which 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.



## Before treatment

Good self-care before treatment can help ensure the best outcome. Try to improve your general health habits before your treatment begins. Taking good care of yourself can help lessen possible side effects, encourage more rapid healing, and increase the likelihood of successful outcomes.

Before treatment begins, please look at the section in this booklet called **Self-Care: Before, During, and After Treatment**.

## After treatment

Every effective cancer treatment has benefits and side effects. You will probably begin feeling better about 2 weeks after finishing radiation treatment. Side effects from chemotherapy are often gone within a few days after treatment stops.

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.

You will meet with your oncologist one month after treatment has stopped. After radiation treatment, you will be seen every 3 months during the first 2 years. 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.

# Head and Neck Surgery

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 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 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.
- Possible cosmetic and functional changes that could result from surgery.

Sometimes more than one surgery is needed as part of the surgical treatment plan.

## Prepare for surgery online video:

Please go to [kp.org/mydoctor](https://kp.org/mydoctor) and search for "anesthesia for an adult Emmi."

## Questions for your doctor before surgery

Below are some questions you may want to ask your doctor before having your surgery:

- Why do I need this treatment?
- What are the risks and side effects of this treatment?
- Are there any long-term side effects?
- Where will the incisions be and what is being removed?
- What will my speech and voice be like?
- What will my swallowing be like?
- What home care will I need after leaving the hospital?
- When can I return to my normal activities?
- How will my neck look afterward?
- What is the chance that the tumor will come back?
- How often will I need checkups?

## During your surgery

Your cancer surgery will be performed under general anesthesia, so 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.



In rare cases 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 air to flow freely. 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).

### Maxillofacial surgery

If your cancer involves the bones of your face, maxillofacial surgeons, who specialize in surgeries of the jawbones 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 help you chew and speak.

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:** A layer of skin 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 biocompatible synthetic devices.

# Head and Neck Surgery *(continued)*

## Side effects of surgery

Your doctor will talk with you about possible side effects. 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 longer. 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.

## After surgery

Your head and neck surgeon will often be your primary doctor. He or she will follow you throughout your treatment and after. The pathology report from your surgery will help your surgeon determine if further surgery, chemotherapy, or radiation therapy are needed. After you have completed treatment, your surgeon will arrange for regular follow-up visits.

# Chemotherapy

If chemotherapy is part of your treatment, you will meet with a medical oncologist to discuss chemotherapy options.

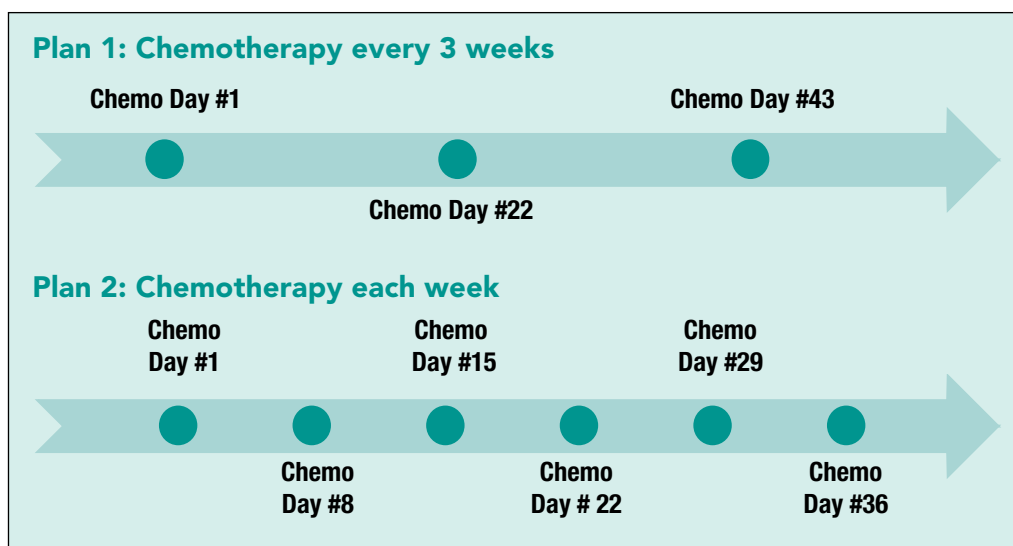
Chemotherapy medications are designed to kill cancer cells. Each cancer has its own prescribed treatment regimen. The type of cancer, the location of the cancer, the size of the tumor, and the spread of cancer cells all determine which drugs or combination of drugs we will use. Chemotherapy may be given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

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 (see Figure 3).

## 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.

### Figure 3: Chemotherapy Treatment Plan Examples



# Chemotherapy *(continued)*

## Questions for your doctor before chemotherapy

Below are some questions you may want to ask your doctor before having chemotherapy treatment:

- Why do I need this treatment?
- What are the risks of this treatment?
- Are there any long-term side effects?
- When will the treatments begin? When will they end?
- How will I feel during therapy?
- What can I do to take care of myself during therapy?
- Can I continue my normal activities?
- How will my neck look afterward?
- What is the chance the tumor will come back?
- How often will I need checkups?

## Instructions for chemotherapy patients

- Before each chemotherapy session, you will need to have blood tests done at the laboratory. The tests should be done 2 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 noncaffeinated, nonalcoholic beverages the day before treatment, the day of treatment, and during the 3 days following treatment.
- 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.

### Prepare for chemotherapy online video:

Please go to [kp.org/mydoctor](https://kp.org/mydoctor) and search for "chemotherapy Emmi."



## Side effects can be lessened or prevented

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, they do not become worse with future treatments, with the exception of fatigue.

- 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:
  - Fever (101°F or higher) or signs of infection.
  - Feeling ill.
  - Redness, blistering, or pain where the IV was inserted into the skin.
  - Severe mouth or throat tenderness that prevents drinking.
  - Diarrhea that you cannot control with Imodium.



*Credit: National Cancer Institute*

- Constipation that does not improve with use of laxatives or stool softeners.
- Bleeding that does not stop easily.
- Jaw tightness.
- Loss of balance, dizziness, or passing out.
- Any other concerning symptoms.
- Changes in hearing.
- 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 the 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.

# Chemotherapy *(continued)*



## 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.

It's common to feel anxious before your first treatment. Our goal is to keep your treatment sessions safe and comfortable. 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 Infusion Center has Wi-Fi access, 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 come with you to keep you company.

You will need to stay mostly quiet and still during your infusion 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

Side effects may not be the same for each person, and they may even change from one treatment session to the next. It is difficult to predict how your body will respond. We hope you do not suffer any side effects from chemotherapy. However, we want you to be aware of the most common side effects, to help you cope with them quickly. Most side effects can be helped with medications.

### Side effects of chemotherapy include:

- **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 gets better over time.
- **Sterility:** If you plan to have children, talk with your doctor before you start your treatment.
- **Hair loss:** This usually happens 2 to 6 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.
- **Potential hearing loss:** You will have a hearing test before treatment to monitor any changes during or after treatment.

## Alternative medicine and treatments

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

Many herbal supplements may not work well or even interfere 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 antioxidant 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.

# Radiation Therapy

Kaiser Permanente provides highly specialized external beam radiation treatments. Radiation therapy uses invisible, high-energy rays to destroy cancer cells. A radiation oncologist will oversee your therapy, and a radiation therapist will deliver your treatment.

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, radiation will be delivered to the affected area to kill cancer cells. Some nearby healthy cells will be damaged by the radiation. You will recover after treatment has ended. 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 an 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.

## BEFORE TREATMENT CAN BEGIN

You **MUST** have a complete dental exam performed by your dentist to prevent complications after radiation. This must be done as soon as possible. Your dentist will order prescription fluoride or gel trays that you will use every day.

Dental work or tooth extractions must be done so that they can heal fully before treatment can begin. If you have had surgery to remove a tumor, planning your radiation therapy may be delayed a few weeks to allow for healing.

### Prepare for radiation therapy online video:

Please go to [kp.org/mydoctor](https://kp.org/mydoctor) and search for "radiation therapy Emmi."

## Questions for your doctor before radiation

Below are some questions you may want to ask your doctor before having radiation treatment:

- Why do I need this treatment?
- What are the risks of this treatment?
- Are there any long-term side effects?
- Should I see my dentist before I start treatment?
- When will the treatments begin? When will they end?
- How will I feel during therapy?
- What can I do to take care of myself during therapy?
- Can I continue my normal activities?
- How will my neck look afterward?
- What is the chance the tumor will come back?
- How often will I need checkups?

## Preparing for your radiation treatments

Before beginning radiation treatment, you will meet members of your cancer treatment team, including your radiation oncologist, oncology nurse, and registered dietitian. We will talk about the team's assessment of your cancer and recommendations.

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 your radiation treatments. We will map your anatomy with the 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 during treatment. If you think you may feel uncomfortable lying still on the treatment table during your visits, please discuss this with us. The clinical staff has experience working with many patients who have experienced this. We will do everything possible to assure that you are comfortable.



# Radiation Therapy *(continued)*

## Radiation treatment visits

The usual course of treatment lasts about 6 to 7 weeks and is given once each day, Monday through Friday. Generally, your treatment will last for the same amount of time at 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 placed over your face and fastened to the table. Your mask will be used during each of your radiation treatments.

You will be alone in the treatment room. The radiation therapist will be outside the room watching you on a video screen. He or she can talk with you using an intercom. During radiation treatment you will not notice the beam. The radiation beam does not hurt.

## Side effects of radiation therapy

While the radiation beam is painless, radiation to the head and neck does have side effects. Your doctor will discuss side effects and care with you. Please note that the consent form you are signing includes a list of possible side effects.



After 2 to 3 weeks of treatment, you will start to notice side effects. These side effects will gradually worsen throughout treatment and peak 1 to 2 weeks after treatment ends. Side effects will slowly improve over the following months.

Drinking alcohol and smoking will 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 help you.



## Common side effects include:

**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 or 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 throughout 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 occur.

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

**Changes in taste and smell:** Your sense of taste and smell will change during treatment. This can make eating more challenging. Taste sensation 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.

*(continued)*

## Radiation Therapy *(continued)*



**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 regrow 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 research studies that involve cancer patients. The studies test new ways to prevent, detect, diagnose, or treat cancer. People who take part in 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 believe that you should understand all of your treatment options, including participation in a cancer clinical trial. Feel free to talk about this option with your care team.

# Self-Care: Before, During, and After Treatment

We encourage you to take good care of yourself, before, during, and after treatment. 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 yourself can result in:

- Reduced treatment side effects.
- More rapid healing.
- Increased likelihood of successful outcomes.

Below are strategies for effective self-care, including support groups, good nutrition, oral care, and stress and pain management.

## 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 as well as a patient's ability to eat enough. Overcoming these challenges and getting good nutrition throughout your treatment is vital.

You will meet with a registered dietitian to discuss your nutritional needs before starting treatment, throughout your therapy, and beyond.

### Basic guidelines:

- Eat regular meals and include healthy snacks between meals to ensure you get enough calories.
- 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 with your care team as soon as you notice them. There are many ways to manage them.

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"Encouragement is so very important." *Ken N.* — oropharynx cancer survivor



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 percent of the recommended daily intake. Large doses of antioxidants can interfere with your treatment. They are not recommended while undergoing chemotherapy and radiation therapy. Antioxidants protect cells from damage or 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 supplemental 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

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 daily guidelines for 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 mouthwash, baking soda, or salt water rinses.
- Use prescription fluoride treatment daily. Your dentist will order dental trays or prescription fluoride.
- Over-the-counter products are available to manage chronic dry mouth.
- Use lip care products to prevent dry and cracked lips.

# Self-Care: Before, During, and After Treatment

## Jaw exercises

A condition called trismus, if it occurs, means you have trouble opening the mouth. Trismus can affect your ability to eat, talk, or take care of your oral health. To strengthen your jaw muscles before surgery, 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 and physical 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, tongue, and jaw may also be affected. Physical therapists and speech therapists work with you so that you can regain your ability to chew, swallow, speak, and move the head and neck. This service is available before, during, and after treatment.

## Skin care

Radiation treatment dries out the skin. To help keep your skin moisturized, apply aloe vera or calendula 3 times a day followed by the moisturizers we recommend to your skin that was treated. Begin moisturizing on the first day of radiation and then daily afterwards. Do not apply any lotion 2 hours

before your treatment time. You may apply moisturizers immediately after treatment. Continue moisturizing every day for 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.

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*“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

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## Stress reduction

Stress can be reduced through activities like meditation, massage, journal writing, and exercise. Local Health Education Departments offer several free and low-cost classes to help reduce stress. 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.

## Pain management

Having cancer does not mean living with pain. There are many ways to manage pain both with and without medicine. 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.

## Health education resources

Kaiser Permanente's Health Education Department addresses total health. Our resources are both affordable and accessible. They include classes, online and audiovisual 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 and stress reduction
- Nutrition and diet consultation
- Behavioral health
- Tobacco cessation

# Care: Before, During, and After Treatment

## 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.

Although 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, both 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 can become overwhelming and 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, or feeling you don't care about things, over an extended period of time.
- Wide mood swings between elation and despair.
- Feelings of isolation or loneliness that happen often or last a long time.
- Unusual difficulty in sexual relationships.
- Thoughts of hurting yourself.

## Psychosocial support

Cancer can affect your mental, emotional, and physical health. Psychosocial support can be included in all stages of your treatment and follow-up care to help you manage the emotional and behavioral effects of cancer. 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.

# Survivorship



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 learn 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. Other survivors can offer encouragement. Feeling disappointed, alone, and anxious is normal. But you don't need to stay that way. People get through this even though it can be tough. 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.

We want you to have as much control of your life as possible. We encourage you to communicate what you feel and ask for what you 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 joy and something to look forward to.

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.

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*"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*

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# Family and Caregivers



No one can survive cancer 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 ways 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 everyone's lives. Providing emotional support and taking over duties and managing family schedules add complexities and stress to caregivers' lives. They need support too.

We can help you to offer support to your 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.

It is therapeutic for both you and your caregivers to stay focused on getting on with your life. 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.

## If you are a 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.

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

*Ron E* — tonsil cancer survivor

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# 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 discoloration 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.







## Long-Term Side Effects *(continued)*

**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.

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“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

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# Palliative Care and Oncology Supportive Care Clinic

## Palliative Care

Palliative care is specialized medical care for people with serious illness. Palliative care is appropriate for patients of any age and at any stage in a serious illness and can be provided together with curative treatments such as chemotherapy, radiation, and surgery. This type of care is focused on providing patients relief from the symptoms, pain, and stress of cancer and to help them live as well as possible while facing a serious illness. The goal of palliative care is to improve quality of life for patients and their families.

## Oncology Supportive Care Clinic

### What is provided?

- An added layer of support for patients living with cancer, at any stage of their illness.
- A patient- and family-centered approach to addressing pain and other symptoms to help you achieve the best quality of life during your cancer treatments.
- Support from an interdisciplinary team, including a physician, nurse, social worker, and chaplain, to address emotional, psychological, and spiritual concerns.
- Guidance in medical decision making based on knowing your values, beliefs, and goals.

### What are the benefits?

- Extra support for you and your family during your cancer treatments.
- Expert management of pain and symptoms caused by cancer or its treatment.
- Enhanced well-being through discussions of what is important to you, such as your values, beliefs, and goals.
- Improved communications and coordination of care with all members of your health team.



# Life Care Planning

Another resource available to patients is Life Care Planning. Life Care Planning is a service that assists you and your family in planning for future health care decisions.

When you are able to communicate for yourself, your health care team will always ask you directly about health care decisions. Life Care Planning involves considering a situation that leaves you unable to speak for yourself.

When considering such situations, two of the most important choices you can make are who you would like to speak for you if you could not communicate, and what would you want that person to say? This person is called your health care agent. Life Care Planning helps prepare your agent by allowing you to share your wishes with them.

All adults, including those with early stage cancer, are encouraged to start with **My Values: First Steps**, in which you can begin the planning process by choosing a well-informed health care agent and sharing your wishes with him or her. To begin the first steps of your Life Care Plan, please visit [kp.org/lifecareplan](http://kp.org/lifecareplan).

If cancer is metastatic or recurs, we recommend you have an additional conversation called **My Choices: Next Steps**. This involves exploring the type of treatment you would or would not want if you experienced a severe complication from cancer or its treatment. The best time to think about your treatment options is before

a serious complication happens. During a Life Care Planning conversation, you, your chosen agent, and a specially trained Kaiser Permanente provider (facilitator) discuss your wishes.

The third step in Life Care Planning is for people with a serious illness who are nearing the end of life. As we age or become ill, the decisions we make for our health care become particularly important. In these conversations you will make informed, specific, and timely decisions about life-sustaining treatment options. **My Care: Advanced Steps** is a service for people who are frail, elderly, or those nearing the end of life due to a serious illness.

Your written plan guides your medical care. It includes treatment decisions that match your personal goals.

# Hospice



Facing a life-limiting illness is difficult. If you have been told that your condition is life limiting, this news may bring up a lot of emotions and questions for you and your loved ones. We are here to help you.

Hospice services provide support and care to people who are approaching the end of life. When your prognosis for survival is 6 months or less, you become eligible for hospice. Hospice is a visiting service of providers whose primary goal is your comfort. Providers who may visit you at home during hospice include a nurse, social worker, physician, home health aide, chaplain, and volunteers.

Hospice provides support to your family as they take care of you. Services can be provided in your home or a skilled nursing facility. If provided in a home, you must live with someone or have someone caring for you 24 hours a day. Assistance is provided for pain management, palliative care, bathing, counseling, as well as support for spiritual and emotional needs. Your physician can refer you to this program.

# Insurance and Employment

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 can work together so that your treatment does not disrupt your normal schedule.

If your treatment does affect your job schedule, we will work with you so that this occurs as little as possible. You may need to change your regular work schedule or take time away 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 and federal regulations and programs, such as:

- State Disability Insurance (SDI)
- California Paid Family Leave Program
- 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 your Kaiser medical record, you complete 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 your medical file, you request that information from the non-Kaiser provider be sent to your Kaiser Permanente primary doctor (not to ROMI). The Kaiser Permanente primary doctor reviews outside medical records before approval to send the information to your 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. If you are seeking medically related time off from work or applying for Family Medical Leave (FMLA), you may request "Work Status Activity Forms" from your 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.

This 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 or to help locate resources and assist during and following a hospital stay.

# Resources

## Online Resources

**Kaiser Permanente My Doctor Online**  
[kp.org/mydoctor](http://kp.org/mydoctor)

**Kaiser Permanente Cancer Care**  
[kp.org/mydoctor/cancer](http://kp.org/mydoctor/cancer)

**National Cancer Institute**  
[cancer.gov](http://cancer.gov)

**National Institutes of Health**  
[nih.gov](http://nih.gov)

**American Cancer Society**  
[cancer.org](http://cancer.org)

**Cancer Care**  
[cancercare.org](http://cancercare.org)

**American Head and Neck Society**  
[headandneckcancer.org](http://headandneckcancer.org)

**Head and Neck Cancer Alliance**  
[headandneck.org](http://headandneck.org)

**National Comprehensive Cancer Network**  
[nccn.com](http://nccn.com)

**Support for People with Oral  
and Head and Neck Cancer**  
[spohnc.org](http://spohnc.org)

## Suggested Reading

*Autobiography of a Face*, by Lucy Grealy

*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

*Meeting the Challenges of Oral and Head and Neck Cancer: A Guide for Survivors and Caregivers* (2nd ed.), by Nancy Leupold and James Sciubba

*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 adrenal 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 in situ.** Precancerous stage 0 in which abnormal cells have been found, but have not yet become cancerous.

**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.** Trouble with swallowing

**edema.** Swelling that is caused by extra fluid in tissues.

**ENT.** A shortened term for ear, nose, and throat.

**epiglottis.** Tissue that is located in the throat that covers the glottis when swallowing.

**external beam radiation.** 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 skin or other 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.

## Glossary *(continued)*

**image-guided radiation therapy (IGRT).**

A process of using imaging to help direct radiation treatment.

**omaging.** 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.

**metastasis.** The spread of cancer from one part of the body to another.

**mucositis.** The 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.** The damage to the nerves that may be caused by cancer treatment.

**neutropenia.** A side effect of chemotherapy in which the white blood cell count is lowered, reducing the body's ability to fight infection.

**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.

**occupational therapy (OT).** The therapy used to help improve the daily functional skills of a patient.

**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.

**palate.** The roof of the mouth.

**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.

**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.

**positron emission test (PET).** A test that uses radioactive substances to obtain images of 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.** The 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.

## Glossary *(continued)*

**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 noninvasive 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.

**regression.** When the cancer site shrinks in response to treatment.

**relapse.** The return of cancer or signs of cancer after a period of improvement.

**remission.** When signs of cancer have disappeared.

**response rate.** The percentage of patients whose cancer shrinks after treatment.

**salivary glands.** The glands in the mouth that produce saliva.

**sarcoma.** Cancer beginning in bone, muscle, fat, blood vessels, cartilage, soft tissue, or other connective tissue in the body.

**screening.** Testing or checking for a disease when there are no symptoms.

**second primary.** The presence of a new unrelated cancer.

**side effects.** An adverse or negative effect that was caused by the use of a drug or other therapy.

**simulation.** Used in radiation therapy to determine the exact location and size of the area to be treated.

**social worker.** A person who works with patients and families with psychosocial and support needs.

**speech therapist.** A therapist trained to help with speech and swallowing disorders.

**standard treatment.** A care plan that is widely accepted and used by medical experts and providers.

**stereotactic radiosurgery (SRS).** A radiation treatment that allows precise doses of radiation to a tumor.

**systemic.** Affecting the whole body.

**targeted therapy.** A treatment using drugs or other substances to identify and attack cancer cells.

**tattoos.** Permanent ink markings placed on a patient as coordinates for radiation therapy treatment.

**thrombocytopenia.** Having lower than normal platelets that are necessary for clotting.

**thrush.** A yeast infection in the mouth or throat usually caused by a lowered immune system.

**thyroid.** A butterfly shaped gland in the front of the neck that produces thyroid hormone.

**tissue.** A group or layers of cells that come together to form a function.

**tonsils.** Lymphoid tissues in the back of the throat that help to fight infections.

**total laryngectomy.** Surgery to remove the voice box.

**toxicity.** Measurement of how much a substance is harmful to the body.

**tracheostomy.** A surgically placed hole in the windpipe to allow for breathing.

**X-rays.** Pictures of the inside of the body using radiation.

# Notes

This information is not intended to diagnose health problems or to take the place of medical advice or care you receive from your physician or other health care professional. If you have persistent health problems, or if you have additional questions, please consult your doctor. Kaiser Permanente does not endorse the medications or products mentioned. Any trade names listed are for easy identification only. Some photos may include models and not actual patients.

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