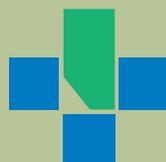


Head and Neck Cancer

Information and Resources for
Patients and Families



Head and Neck Team



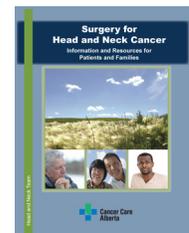
**Cancer Care
Alberta**

Welcome to this general Head and Neck Cancer treatment book.

This book will help you prepare for and go through treatment for head and neck cancer. It has information about common questions and concerns that often come up during this treatment. You will also find suggestions about things you can do to live well during treatment.

The treatment of head and neck cancer is very specific to each person, so you may not find everything you want to know in this booklet. Your surgeon, radiation or medical oncologist and healthcare team can give you more specific details about your cancer.

Treatment for head and neck cancer can be life-changing, both emotionally and physically. This book will introduce you to some of those changes, so that you are better prepared and feel like a partner in your care. If surgery is one of the recommended treatments for you, your cancer care team will also give you the **Surgery for Head and Neck Cancer** book.



You don't have to read the whole booklet at once!

Read the sections you want to know more about, only **when you need them.**

It is important to think about your return to home after surgery or other treatment and make sure you have supports in place. If you have any concerns about your home situation, please let your healthcare team know as soon as possible so they can help you find solutions.

This book will help you, and your family and friends understand basic information about head and neck cancer and treatment.

Read about:

- types of treatment used for head and neck cancer
- how to manage the possible side effects with the help of your cancer care team
- what exercises will help and how to do them



Bring this book to all of your appointments



Write your questions down in the book. If there's any information you do not understand, ask your healthcare team to review it with you.

For more information:



This book, along with other Alberta cancer care resources are available at your cancer centre or online at:



www.cancercarealberta.ca



Find community support resources with **Alberta 211**

<http://www.ab.211.ca/>



Scan for a digital copy and click directly on website links:



Your cancer care team is here to help you and answer your questions.

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My Plan



Contacts

Doctors: _____

Office Number: _____

Urgent Contact Number (given by your surgeon): _____

Nurse(s): _____

Speech Language Pathologist: _____

Rehabilitation Therapist: _____

Dietitian: _____

Psychosocial / Spiritual Care Provider: _____

My Diagnosis

Type of cancer: _____

Treatment Plan

- Surgery (see the **Surgery for Head and Neck Cancer** book)
- Radiation (_____ fractions)
- Systemic (chemotherapy, targeted therapy or checkpoint inhibitor therapy)
_____ (type and cycles)

Other Possible Procedures:

- | | |
|---|-------------|
| <input type="checkbox"/> Hearing test (audiogram) | Date: _____ |
| <input type="checkbox"/> Biopsy | Date: _____ |
| <input type="checkbox"/> Imaging (CT / PET / Panorex) | Date: _____ |
| <input type="checkbox"/> Dental Appointment | Date: _____ |

Notes:

A. Just Diagnosed

There are things that you can do to help navigate through the emotions, treatments, and information that come with a cancer diagnosis.

- Bring someone to your appointments.
- Take notes, or have your support person take notes for you. Use the **My Care Conversations** app.
- Ask questions. It's okay to ask for another explanation and **keep asking questions until you understand.**
- Write down your questions and the answers you get. Use this book as your workbook.
- Know your limits and ask for help.



You can use the free AHS **My Care Conversations** app to prepare for your next appointment and to audio record conversations with your healthcare team. You can listen to your recordings at home and share with family or trusted friends.

Download it from the App Store or Google Play.



A1

Getting Prepared

Having head and neck cancer treatment can bring up many emotions and questions. You may wonder about pain, changes to your body or future treatment. You may wonder how you'll manage responsibilities at home or work. It's common to have many feelings (such as anger, sadness, or hope), sometimes all in one day. Your healthcare team can help you find the support or answers you need.

This first section has some of the most common concerns that patients are worried about. For more on emotional self-care and awareness, go to [Section D4](#).

Finances, insurance and drug coverage

The cost of your head and neck surgery is covered by Alberta Healthcare. But there are other costs that go along with your cancer treatment(s) that you may not have thought of. For example:

- How long you'll need to be off work for treatment and recovery.
- Your insurance coverage for some of the medicines used for treatment.
- Extra costs such as parking, hotels, splints and rehabilitation equipment.

Need a place to stay during treatment?

Calgary - call the **Foothills Medical Centre Hostel** at 403-944-1156

Edmonton - call the **Patient and Family Resource Centre** at 780-432-8456

You may be able to get help to pay for some of these costs. If you have concerns, it's important to speak to your healthcare team right away. They may be able to help you find the supports you need or can refer you to a resource social worker who can help.

Remember:



- **Keep all receipts related to your treatment** (such as parking, travel, and hotels) and write the reason on the receipts. You may be able to claim medical costs when you file your taxes.



- **Ask your healthcare team what is covered.** When your treatment plan is confirmed, and if you have Alberta Healthcare, most of your treatments will be covered, but there could be extra costs.
- **Call your insurance provider** so you know what they cover and ask about the cost of extra coverage if you need it. Sometimes when you add medical coverage there is a waiting period before the coverage starts.
- **Extra coverage may be helpful** to cover the cost of things such as prosthesis, medicines, transportation, and physiotherapy.



- **Make a list of other costs such as childcare, lodging, and travel.** Your healthcare team may be able to suggest services that cost less.



- **Ask to see a resource social worker** to help you find government financial support, including tax credits and caregiver employment insurance.

Time off from work

How much time off from work you will need depends on the type of treatment you have. If you are diagnosed with cancer, you may be offered surgery, radiation treatment or chemotherapy. Our doctors and nurses who specialize in these areas will meet with you to talk about possible treatment options and the length of time you might be off work. This table is only a guideline.

Type of Treatment	Approximate time off needed
Head and Neck biopsy only	1-2 weeks recovery
Head and Neck surgery without other treatment	2 weeks to 3 months
Radiation or chemotherapy (no surgery)	3-6 months
Combination of all 3 treatments (surgery, radiation and chemotherapy)	6 months-1 year

Doctor's Notes

Your doctor can provide a note for the time off you need for treatment and recovery. If you need to have more treatment (chemotherapy or radiation treatment), the oncologist managing your care will provide a note for the rest of the time off you need.

If you need a letter from your doctor for work, we may ask you to fill out some forms first.

Contact the Human Resources department at your workplace if you want to make a claim to either:

- Your work's disability insurance provider
- Service Canada (Canada Pension Plan Disability Benefits)

Forms and Documents

- Ask your employer what documentation they need you to complete.
- Talk directly with your doctor about the forms you need completed and follow the instructions they give you.
- Doctors usually cannot complete these forms during clinic hours, so you will need to pick them up at another time.



Nutrition to support you during and after treatment

Nutrition is important **both before and after** treatment. Good nutrition before treatment can lead to better outcomes. Dietitians recommend you follow a high calorie, high protein diet to get enough nutrition. Your weight is one way to tell if you are eating enough calories.

Ways to Increase Calories and Protein During and After Treatment

- Try eating smaller, more frequent meals and snacks (every 2-3 hours).
- Take snacks that won't spoil, such as: trail mix, a muffin, fruit, energy bites, granola bars, smoothies, or pudding cups.
- Think of food like medicine. Schedule meals and snacks to help you increase your calorie and protein intake. This is a good tip to help you remember to eat, even if you don't feel hungry.
- Choose drinks with higher calories like: fruit juice, milk (or chocolate milk), fortified soy beverages, and smoothies.
- Limit food and drinks that are labeled "light," "low-fat," or "low calorie." For example, choose whole milk in place of skim or 1% milk.
- Add extra fats and oils to foods, such as: cheese, butter, margarine, cream cheese, full fat sour cream, olive oil, and avocado.
- Make homemade milkshakes or smoothies using whole milk, fortified soy beverage, ice cream, or Greek or Icelandic yogurt as your base. Include ingredients such as: nuts, nut or seed butter, protein powder, avocado, or tofu for extra protein and calories. Ask your dietitian for more recipe ideas.

Continued on next page



- Prepare and freeze meals ahead so you have meals ready for days when you have less energy. Aim to have a source of protein with each meal and snack. Good sources of protein include: meat, fish, eggs, tofu, Greek or Icelandic yogurt, milk, beans and legumes, and nuts and seeds.
- Try adding a nutrition supplement drink that is high in calories and protein between meals, to get more nutrition. These are usually available at local grocery stores and pharmacies.

A dietitian can work with you to improve your nutrition if you have difficulty eating or drinking enough or have lost weight without meaning to before surgery.

See **Section D2** for more nutrition information



Fertility and birth control

Fertility is the ability to get someone pregnant or to get pregnant and carry a child to a healthy birth. Systemic cancer treatment, like chemotherapy, can sometimes damage the reproductive organs such as the ovaries and testicles. These changes can have short-term or long-term effects on your fertility.

Cancer treatment can cause changes to the reproductive organs like:

- decreased sperm quality, number and motility
- irregular menstruation, or it may stop menstruation
- premature menopause

Remember to:

- **Use birth control.** It is important that you do not get someone pregnant or become pregnant while having treatment.
- **Think about your options for children in the future.** If you want to preserve your fertility, you may need a referral to a fertility specialist. Talk to your healthcare team. A referral should be made early so it does not delay your cancer treatment.

Make changes at home



- **Re-arrange your cupboards or ask for help to do this.** Store items that you use often in cupboards that are below shoulder level. It is important that you do not have to reach overhead, especially for heavy items.



- **Use long-handled tools for cleaning.** Make cleaning easier by using tools like brooms or mops that have long handles for cleaning floors and dusting to reduce reaching and strain on your shoulders.

A2

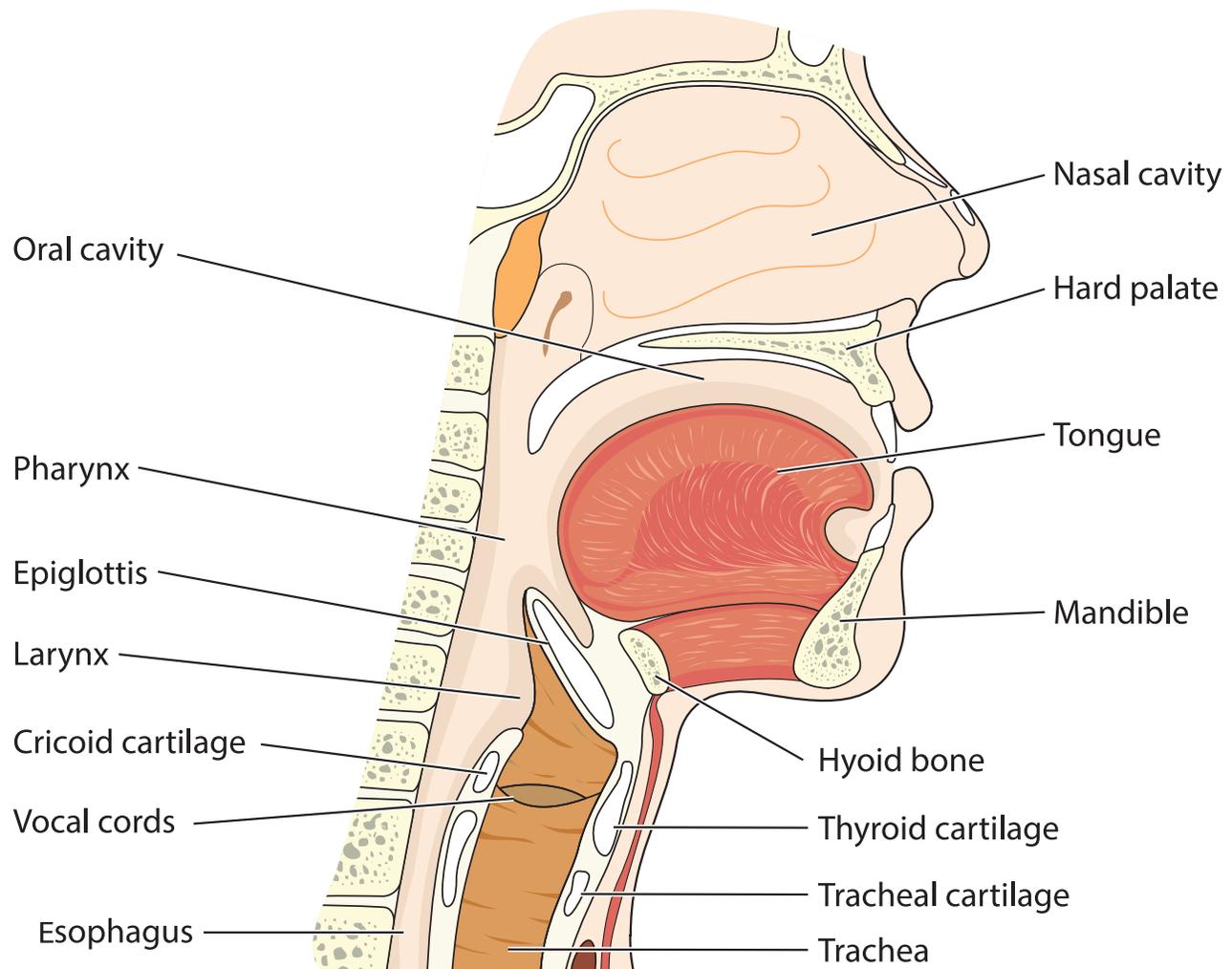
Structures of the Head and Neck

The head and neck has an amazing network of blood vessels, nerves, tissue, and bone which help with some of the most important functions of our body. This network works together to give us so many sensations that the rest of the body can use every day.

There are many body parts that make up the head and neck region. Each part has its own function. More information on the function of each part can be found at the back of the book, in the **Words to Know** section.



Ask your doctor to show you where your cancer is.
Circle or mark the areas.



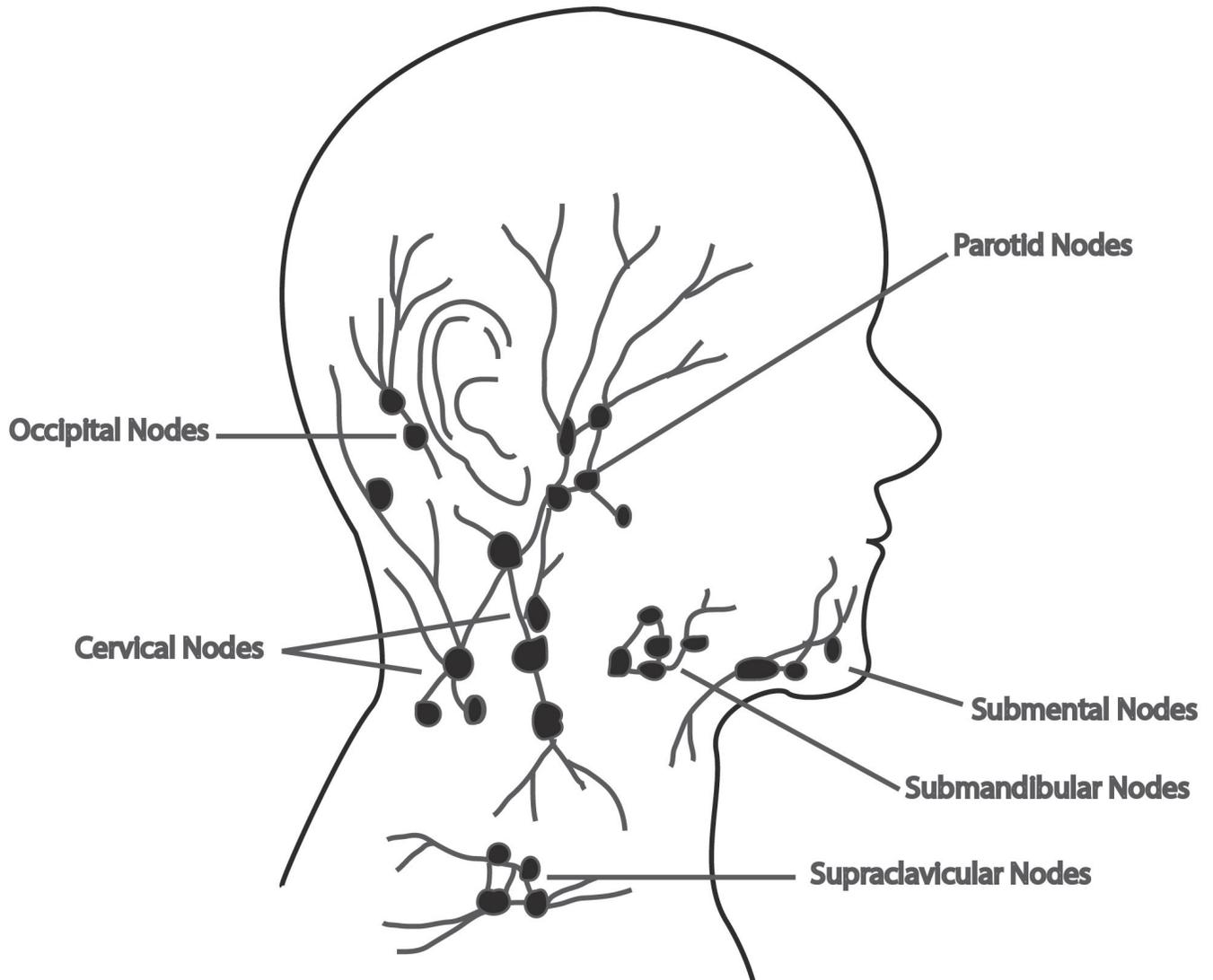


Lymph Nodes of the Head and Neck

The lymphatic system is a network of organs, vessels and lymph nodes located throughout your body. Many of the nodes are located in your head and neck.

This system collects fluid from your tissues, filters it through the lymph nodes and returns it back to your blood (circulatory system). Lymph nodes that are close to the area of your cancer are usually the first place cancer spreads to. If this is the case for you, your lymph nodes will be removed with surgery (neck dissection) or treated with radiation.

If you have radiation treatment for your head and neck cancer, the radiation will treat the lymph nodes along with your tumour. Treating the lymph nodes can cause swelling of your face and neck, also known as lymphedema. If you have a neck dissection surgery, your lymph nodes may be removed which can also contribute to swelling. See [page 29](#) for more information about lymphedema.



What is head and neck cancer?

Most head and neck cancers begin in the cells that line the surfaces of the head and neck, such as the mouth, nose and throat. Cancer is always named for the place that it starts in the body. When cancer spreads to other parts of the body and grows, it's called **metastasis**. When head and neck cancer spreads to another area like the lungs, it is still called head and neck cancer. It would not be called lung cancer unless it started in the lung.

Cancers of the head and neck are identified by type of cell and the area they start in and there are many different structures in each area. You may have cancer in a particular area, but only in 1 part of that area. For example, perhaps you have cancer on the front part of the tongue. Your diagnosis would be "oral cavity cancer" but this does not mean that all of the parts in the oral cavity (lips, gums, hard palate, and so on) are affected by cancer. Your doctor can tell you exactly what parts they are concerned about.

- The **Oral Cavity** includes lips, front part of tongue, gums, lining of cheeks and lips, bottom of mouth under tongue, hard palate, small area of gum behind wisdom teeth. See the picture on [page 8](#).
- The **Nasal cavity** is the area between the nostrils and the hard palate and goes down into the nasopharynx. See the picture on [page 9](#).
- The **Oropharynx** is from the back of the tongue and goes down to the voice box, and in toward the top of the nasopharynx. It includes the base of the tongue, the tonsils and the soft palate. See the picture on [page 9](#).
- The **Nasopharynx** is the upper part of the throat behind the nose and above the oropharynx. See the picture on [page 9](#).
- The **Hypopharynx cancer** starts in the lower part of the throat beside and behind the voice box. See the picture on [page 10](#).
- The **Paranasal sinuses** are the air spaces inside the nose and facial bones (also called the sinuses). See the picture on [page 10](#).
- The **Larynx** is the voice box. See the picture on [page 10](#).
- Primary Unknown** Sometimes the area that the cancer has come from is not known. The cancer may be found in a lymph node or somewhere else, but your doctors are not able to find the original site or location that your cancer started growing from.
- The Salivary Glands include the parotid, sublingual and submandibular glands. See the picture on [page 11](#).



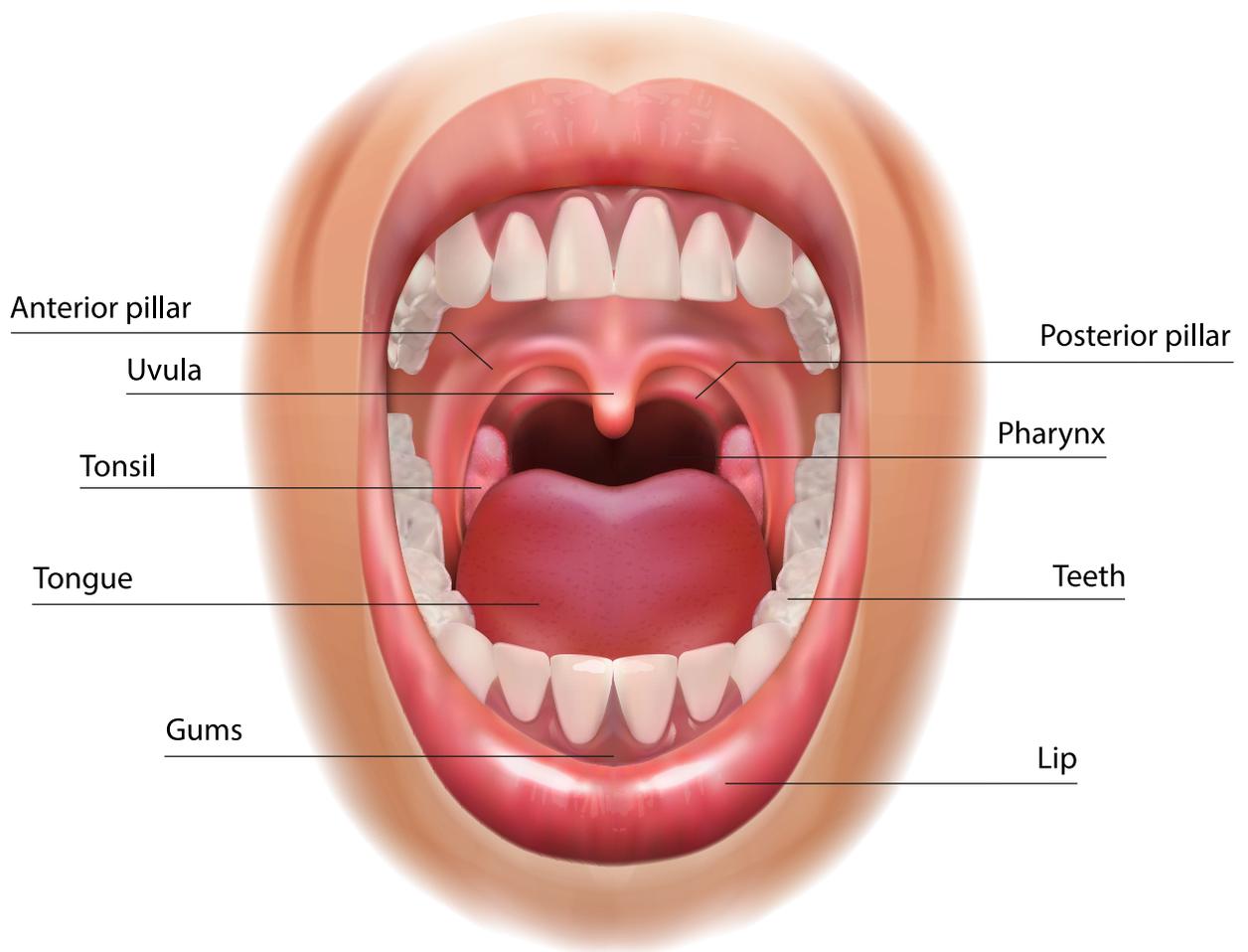


Use the pictures on the following pages to circle the structures affected by cancer. If you are having surgery, ask your doctor to help you mark the area(s) of what will be removed.



Use this picture to mark the location of:

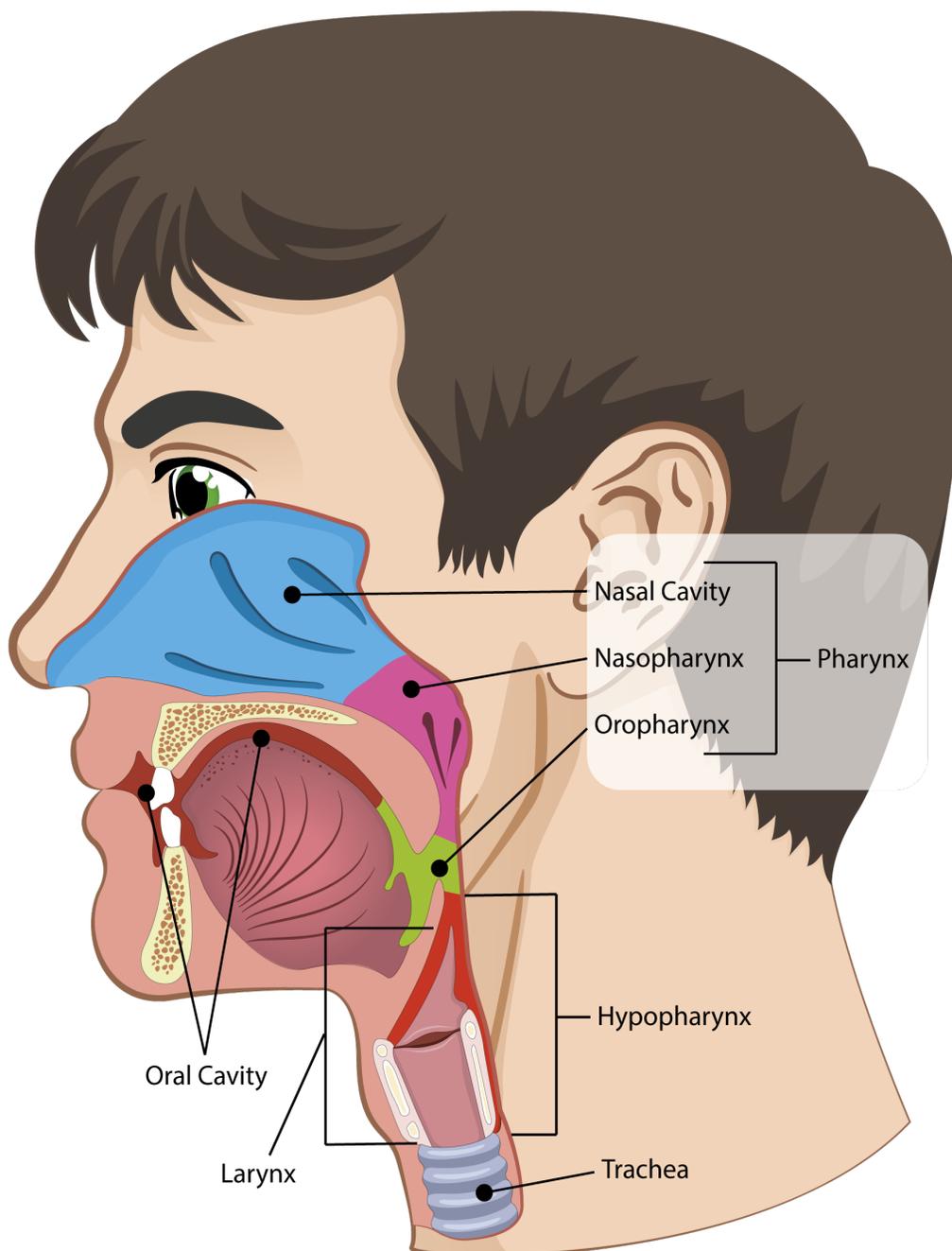
Oral Cavity Cancer





Use this picture to mark the location of:

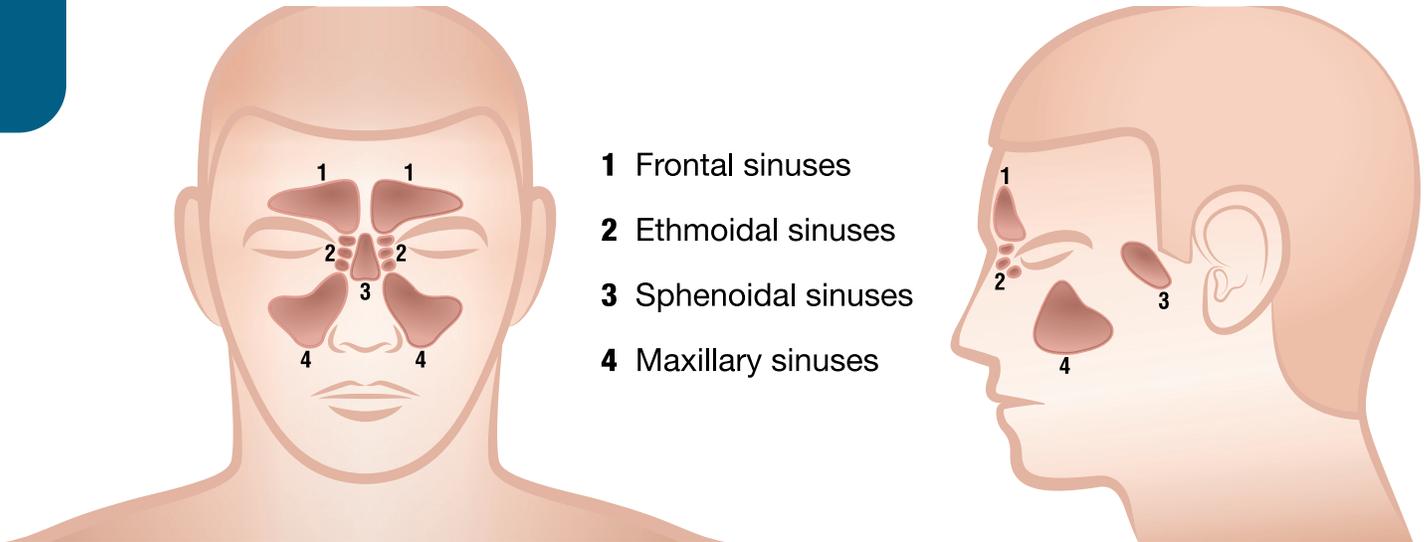
- Nasal Cavity Cancer
- Oral Cavity Cancer
- Oropharyngeal Cancer
- Hypopharyngeal Cancer
- Laryngeal Cancer
- Nasopharyngeal Cancer





Use this picture to mark the location of:

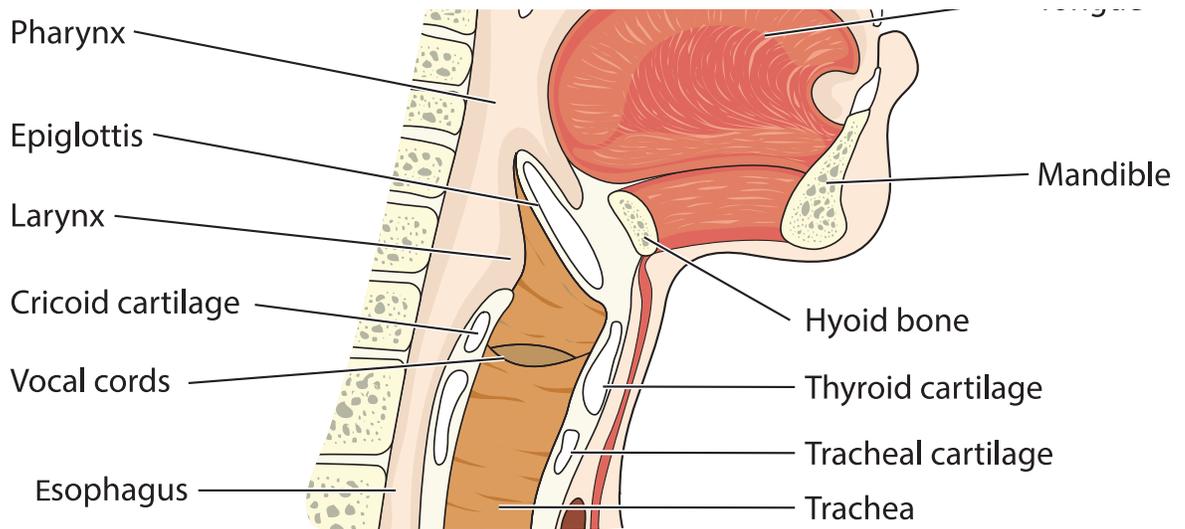
Paranasal Sinus Cancer



Use this picture to mark the location of:

Hypopharyngeal Cancer

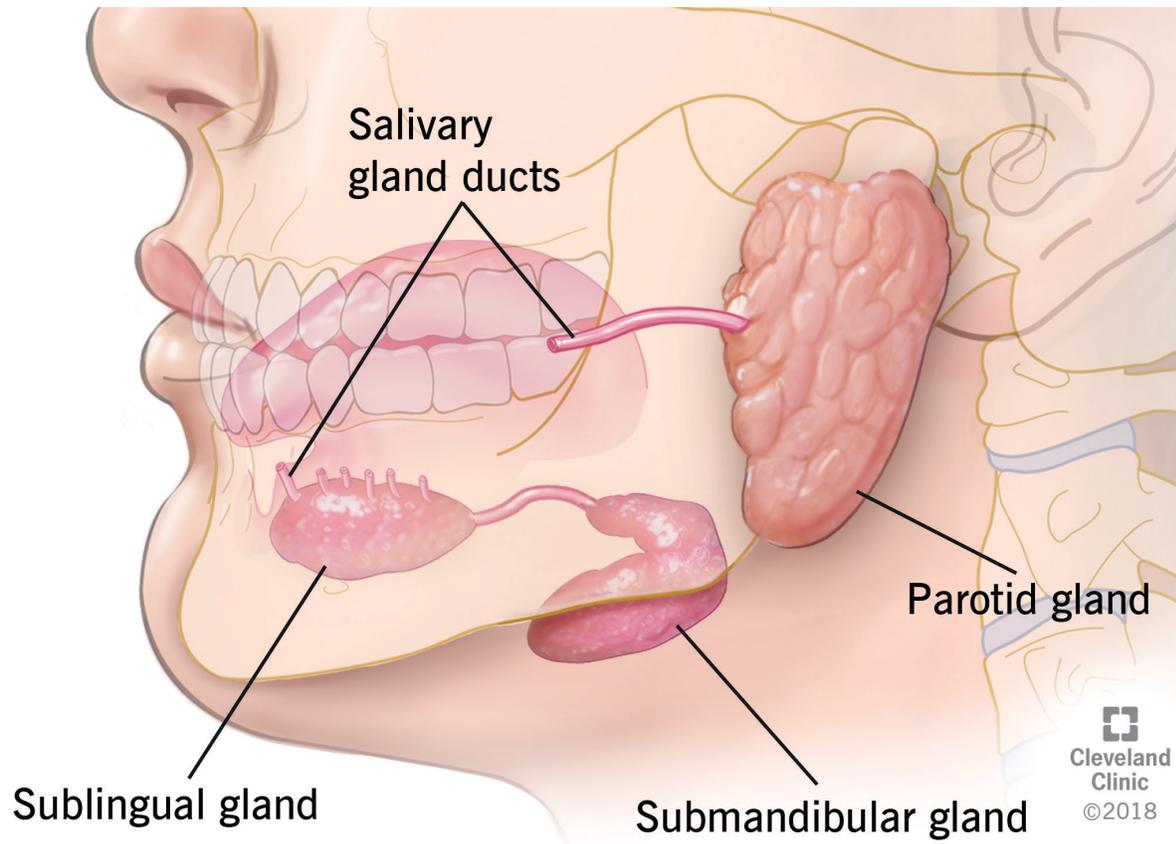
Laryngeal Cancer





Use this picture to mark the location of any salivary glands affected.

- Parotid
- Sublingual
- Submandibular

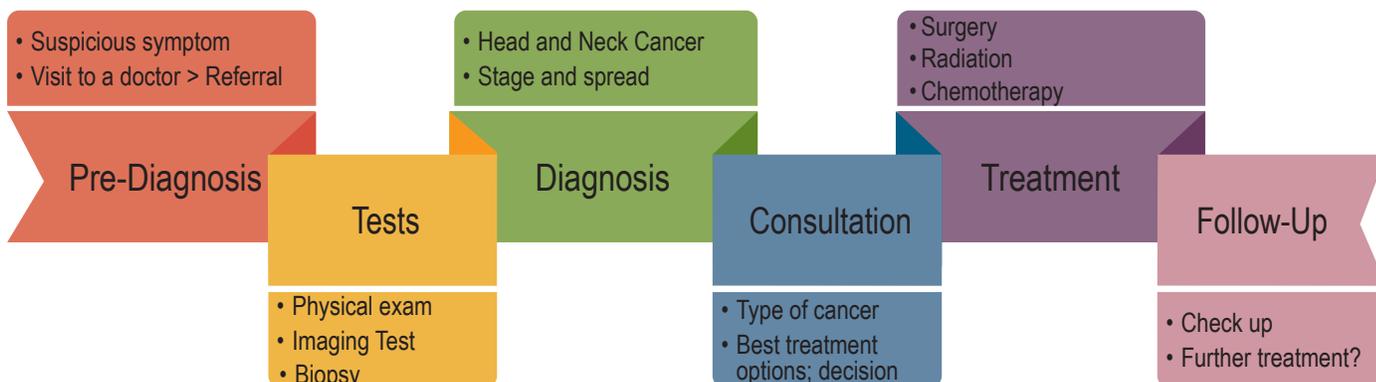


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<https://my.clevelandclinic.org/health/diseases/17965-salivary-gland-cancer#>



How is cancer diagnosed?

Cancer in the head or neck can be diagnosed by a biopsy or other medical tests. An appointment will be made for you to see an Oncologist. **Oncologists** are doctors specializing in the treatment of cancer.



During your first appointment, the Oncologist will review test results, look at your medical history, and perform a physical exam. This includes looking inside your mouth and nose and at your neck, throat, and tongue. A small camera will be inserted inside your nostril to look at all the areas inside your nose down to your voice box (or larynx).

Cancer staging and grading

Staging is a way for your healthcare team to find out how much cancer there is and where it is in the body. Sometimes, the cancer is not just in one area. Your doctor will be able to tell you the stage of your cancer after all tests, biopsies, and surgery are complete. Most doctors use the **TNM** way of staging cancer:

Letter	Meaning	Rating
T	how big is the tumour?	0-4
N	has the cancer spread to your lymph nodes?	0-3
M	has the cancer spread to other areas of your body? (metastasized)	0-1
Overall Stage		0-4

An overall stage of 0-4 is assigned based on the combination of the T, N, M.

The more serious the growth, the higher the number assigned. Each cancer type has its own staging (and grading). Your treatment plan options will depend on the stage of your cancer.

What tests do I need to prepare for cancer treatment?

There are many tests that doctors can use to understand someone's cancer including:

- The type of cell your cancer came from (pathology)
- Where the cancer is in your body
- If the cancer has spread
- How your body is coping with treatment

Some tests are only helpful for some types of cancer, or for some parts of the body. Your doctor(s) will decide which tests or procedures are right for you.



Biopsy

A small piece of tissue is taken from the cancer or tumour and looked at under a microscope. This test helps us learn what kind of cells the cancer came from. Knowing the cell type helps us decide the best kind of treatment. The tissue may be taken during an outpatient visit, after your surgeon gives you freezing to numb the area. Sometimes, the surgeon may need to take the biopsy in the operating room instead. In this case, you would be put to sleep with a general anesthetic. At this same time, your surgeon may use a small, flexible camera to look at the tissue in your mouth, throat and neck. This is called a **quadroscopy** or **pandendoscopy**.



Blood Work

You may have several visits to the "lab" to have your blood work done during your treatment, especially if you have chemotherapy. Blood work helps your healthcare providers monitor how you are doing on treatment.



Hearing Test (Audiogram)

This test lets the doctor know how well you can hear. Hearing can be affected by the location of your cancer, radiation treatment to the ear, and from some kinds of chemotherapy.



Imaging Tests

Your doctor may order 1 or more imaging tests. Each kind of imaging (CT scan, MRI, PET scan, X-ray, ultrasound) provides different kinds of information about your cancer. Your doctor will decide which imaging tests are right for you.

What about HPV? (Human Papillomavirus)

Human papillomavirus (HPV) is a viral infection that can be responsible for oropharyngeal cancers (cancers of the tonsil and base of tongue). About 6 out of 10 cases of these types of cancer are related to HPV.

HPV is a common sexually transmitted infection in both men and women. A vaccine has been developed to help prevent cancer from HPV infections. These vaccines are most effective if given before an individual has any sexual contact. The vaccine will **not** clear a human papillomavirus infection that someone already has.

How do I know if I have HPV?

When your cells are tested for cancer, the pathologist will test the sample for evidence of an HPV infection.

HPV and Head and Neck
Cancer Slideshow

bit.ly/hpvandheadandneckcancer



After my treatment, will I be re-tested for HPV?

No. The treatment will not get rid of HPV so there is no need to repeat the test.



A4

Your Care Team

Head and neck cancer is a very complex kind of cancer that requires the help of many kinds of healthcare providers. The kind of treatment you will have depends on many things, including the type of head and neck cancer you have, your general health, and your situation.

You will be cared for by many different kinds of doctors during your cancer treatment. These doctors have different roles in your care, and depending on the kinds of treatment you need, you will have different kinds of doctors involved in your care.

Surgeons

Head and Neck Cancer Surgeon

A doctor who will perform your surgery. Your surgeon will assess your medical condition to help prepare for your surgery, and they will also provide care after the surgery.

Radiation Oncologist

This doctor will make recommendations about radiation treatment, manage your care and help you with any side effects you develop.

Medical Oncologist

This doctor will make recommendations about systemic treatment (chemotherapy, targeted therapy or checkpoint inhibitor therapy), to manage your care and help you with any side effects you develop.

Oromaxillofacial Surgeon or Prosthodontist

This specialist dentist works with an interdisciplinary team to restore teeth and use prosthetics (artificial devices that replace missing body parts) to help with appearance and function.

Respiratory Therapists

These healthcare professionals work with people who are having breathing problems. They specialize in caring for patients who need help keeping their airway open (such as people who have a tracheostomy).

Our hospitals are teaching hospitals. You may have doctors-in-training working with you. They work closely with the doctor responsible for your care (your primary surgeon, radiation oncologist, and medical oncologist).

Fellows - Fully qualified doctors who have finished their residency training and are getting additional training in a specialty area, like head and neck cancer.

Residents - Doctors who have finished medical school and are now in residency training in their area of interest.

Nurses

Advanced Practice Nurses (APN)

An APN is a registered nurse with additional education, training and experience as a Nurse Practitioner or Clinical Nurse Specialist. They work closely with the doctor to provide medical care in the clinic and during your hospital stay. The APN may be involved in your diagnosis, diagnostic evaluation and management of medical problems and treatment symptoms. As a survivor, you may be followed long term by an APN.

Head and Neck Cancer Nurses (RNs/LPNs)

You will meet many nurses during your cancer treatment. These nurses specialize in head and neck cancer and will work with the rest of your healthcare team to support you at every stage of your cancer journey. Some nurses specialize in surgical care, some in the area of chemotherapy and its side effects (Medical Oncology) and others in radiation treatment and its side effects. These nurses can provide you with information and help you manage any side effects, including skin care.



Hospital Dentist

Your cancer treatments can affect the health of your mouth and teeth, which can lead to poor dental health. If you have radiation treatment, you will see a dentist specialized in caring for cancer patients before your radiation treatments start.

Some people need to have dental work before they begin their radiation treatments. You will be given time for your mouth to heal before starting radiation.

Good mouth and dental care is important during head and neck cancer treatments. Ask for the booklet “**Mouth and Dental Care for Cancer Patients**” at your cancer centre, or view online at www.cancercarealberta.ca > In Treatment > Managing Side Effects.

Anaplastologist

A clinician who specializes in making custom prostheses, such as eyes, ears and noses, to rehabilitate an absent, disfigured or malformed part of the body.

Radiation Therapists

Experts in radiation treatment and patient care. Radiation Therapists will help you prepare for each step of your radiation treatment, including:

- Cast and Mould
- CT Simulation
- Treatment Planning (also known as dosimetry)
- Daily radiation treatment





Registered Dietitians

Experts in food and nutrition science. They can help you to improve your food intake, manage side effects, and develop a plan for good nutrition. If you are having surgery, you will likely see a registered dietitian (RD) before and after surgery. If you are having radiation, you will likely see an RD before starting treatment and then regularly throughout your radiation treatment. You can ask to meet with your dietitian any time if you have questions or concerns.

Psychosocial Oncology Specialists

These professionals are from the areas of psychology, social work, spiritual care, or psychiatry, specializing in cancer care. They are available to help you and your family cope with the stress that often comes with cancer. They are a part of your treatment team and offer different types of programs and services to support your wellbeing:

- Individual, couple and family counselling
- Professionally-led support groups
- Practical support for your finances and other basic needs
- Classes and programs

Primary Care Provider

A Family Doctor (also known as a General Practitioner or GP) or a Nurse Practitioner. They help manager your health before, during and after treatment.

If you don't have a family doctor, you can find one at:

 811 (Health Link)

 www.albertahealthservices.ca »  find a doctor

Rehabilitation Oncology Specialists

Rehabilitation (also called “rehab”) aims to help you return to normal activities as soon as possible, and is very important part of treatment for patients with head and neck cancer. The type of rehab you need will depend on the type of cancer and the treatments you have. Rehab can include physical therapy, occupational therapy, and speech language pathology. Rehab specialists are often involved in helping you plan to return home after your hospital stay.



Physiotherapist

Cancer and cancer treatments may cause physical problems that can affect how well your body functions and performs. Physical therapy (PT) can help you improve physical issues that may happen as a result of cancer. Physiotherapists can help with:

- Exercises for range of motion and strengthening (jaw, neck, shoulder)
- Swelling and scar management
- Positioning and wound prevention
- Pain management
- Fatigue management
- General conditioning
- Mobility, balance, and gait aids

Occupational Therapist

Cancer and cancer treatment can disrupt your lifestyle. Occupational Therapy (OT) helps to solve problems that interfere with a person’s ability to do things that are important to them, including self-care, going to work or school and social activities. Occupational therapists can help with:

- Positioning
- Fatigue management
- Equipment and adaptive aids
- Body image and sexual health concerns
- Swelling and scar management
- Memory and brain fog
- Pain management
- Exercises for range of motion and strengthening (jaw, neck shoulder)

Speech Language Pathologist (SLP)

Cancer and cancer treatments can affect your ability to speak and swallow. A Speech Language Pathologist can work with you on improving speech and swallowing function. They can help with:

- Communication challenges
- Changes to your swallowing, speech and voice

Physiatrists

Physiatrists are medical doctors who have completed specialized training in physical medicine and rehabilitation. They assess a person’s readiness for rehabilitation and other therapies and focus their treatment on function by treating the whole person, not just one problem area. They can help with:

- Overall recovery plan
- Interventions for pain, spasms, or fibrosis
- Diagnostic tests
- Pain management
- Fatigue management
- Bowel and bladder problems
- Recommendations for return to work, school, or leisure activities

B. Treatment Options for Head and Neck Cancer

Treatment for head and neck cancer can be given in different ways:

- surgery
- radiation
- chemotherapy
- combination treatment

Some people will have all 3 treatments, while other people may have only 1 or 2 different kinds of treatment.

Many people will have surgery and then may have radiation or combined radiation and chemotherapy. Your treatment options are specific to your kind of cancer, the stage of the cancer, and your overall health.



B1

Surgery

Surgery can be an important part of treatment for head and neck cancer.

When you meet with a surgeon, they may use a camera to look inside your nose, mouth and throat as part of their initial assessment. Your surgeon may take a small sample of cells from the lump or tumour. This is called a **biopsy**. The biopsy tissue is tested to see what kind of cells it is made of. If it is cancer and surgery is recommended for you, your surgeon will try to remove the tumour with a little bit of normal tissue around it. During surgery, your surgeon may remove lymph nodes in your neck to see if the cancer has spread.

If your tumour is large, your surgeon may need to use tissue from another area of the body to rebuild the region (this is called **reconstruction**). They may use tissue that is close to the area of surgery or take some from different parts of your body. This is done to help you with important functions such as speaking and swallowing.

The kind of surgery you have, and the care you will need is specific to you, your health, and the type of surgery and cancer you have. Your surgeon will talk to you about your surgery and recovery.

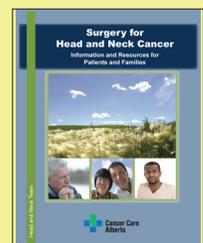
All of the information you need to know about surgery can be found in the Surgery for Head and Neck Cancer book. You will get a copy if this is one of the treatments you will be having.

Read the book at:

www.ahs.ca/cancertreatment
> Surgery



SCAN ME



Cancer removal (resection)

When a cancer is treated surgically, the goal is to remove or **resect** the entire cancer (or tumour). This usually involves removing the cancer with a small amount of normal tissue. Depending on where your cancer is, this can include removing sections of the mouth, throat, sinuses, swallowing tube, or voice box. Often neck surgery is performed at the same time to remove some of the **lymph nodes** in the neck.

Our goal is to remove the cancer by taking as little extra tissue as possible. Your quality of life is important. However, most often one or more structures need to be removed. Sometimes this means taking out part or all of your:

- tongue
- tonsil(s)
- inside of the cheek (buccal mucosa), gums, retromolar trigone, floor of the mouth, roof of the mouth (hard or soft palate), salivary glands
- jaw (mandible) - may include some teeth.



Surgery side effects or complications

Side effects from surgery depend on:

- The type of surgery you had
- Your age
- Where your surgery was
- Your overall health

Complications of Surgery

All surgeries have some risks. Some complications include:

- Infection in the lung, such as pneumonia.
- Infections in the area you had your surgery (the wound or surgical site).
- Wound breakdown and loss of a portion of, or all of the “flap”. This could mean you may have to have another surgery.
- Sometimes nerves in the head and neck are damaged by the removal of the cancer and can cause weakness. This may affect your face, neck or shoulder muscles. Ask to see a physiotherapist if you experience any weakness.
- Pain and swelling in the head and neck region after surgery, as well as any donor site are common and may last for 2 to 3 months. This is how your body tries to heal. Ask to see a rehabilitation therapist who is trained in lymphedema management if this swelling persists past 3 months or is bothering you. They can teach you ways to resolve or manage it better.

For side effects, go to [page 24](#)



Your surgeon and healthcare team will talk to you about possible side effects from surgery, and what you can do about them.

B2

Radiation Treatment

Radiation treatment is the delivery of radiation to cancer cells. Radiation treatment **only affects the area of the body being treated.**

General information about radiation treatment

Radiation works by damaging the DNA of cells. It's hard for cancer cells to fix DNA damage. The damage helps prevent the cancer cells from growing, and tells the cells to die.

Your treatment will be delivered by a team of **Radiation Therapists**. They are experts in patient care and operating the radiation machines. You will meet several Radiation Therapists during your treatments.

Radiation Treatment Appointments

- Radiation appointments take 15 to 30 minutes. Your first appointment may take longer.
- Treatments are usually scheduled daily, **Monday through Friday**, for 5 to 7 weeks. In some cases your Radiation Oncologist may plan your treatments with a different schedule. There are no radiation treatments on holidays.
- Radiation treatments usually start 2 to 3 weeks **after your CT Simulation** appointment.

What to Expect at Appointments

- Radiation is created by a machine called a Linear Accelerator, or a Linac. This machine rotates around you while you lie on a bed, and will not touch you during treatment.
- Each treatment starts by taking images, using radiation, to **position your body** for treatment.
- You must **lie still** for radiation. Since this is hard to do, **you will have a mask made of your head and neck** area that you will wear during each of your treatments to keep you still.
- You will not feel radiation.

After Your Treatment Appointments

- You will not be radioactive after your treatment.
- It is important to do your neck and jaw exercises to prevent a loss of movement and help reduce swelling during and after radiation.

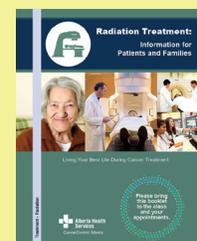
All of the information you need to know about radiation treatment, how to prepare and how to manage side effects can be found in the Radiation Treatment book. You will get a copy if radiation is one of the treatments you will be receiving.

Read the book, watch the videos or take the class.

www.ahs.ca/cancertreatment
> **Radiation Treatment**



SCAN ME



Radiation treatment side effects

Side effects from radiation treatment **develop in the body area where you got your radiation**. This includes areas and structures in your head and neck, such as your mouth, jaw, and throat.

Radiation side effects **build up over time** as you have treatment. Side effects can be their worst 1 – 2 weeks (7 to 14 days) **after your treatment is finished**. Most radiation side effects get better, but how long it takes, and how much you recover can vary.

Radiation Side Effects

Below is a list of some common and uncommon side effects that can develop from radiation treatment **to the head and neck**. This list does not include all of the possible radiation side effects. Tell your healthcare provider as soon as you notice any of these side effects and they will guide you about how to manage them.

	Short Term Side Effects (develop during or right after treatment)	Late Side Effects (develop months to years after treatment)
Common	<ul style="list-style-type: none"> • Fatigue • Dry mouth • Altered or absent taste and smell • Painful or difficult swallowing • Mouth sores • Skin redness, dryness, peeling • Neck and jaw stiffness • Change in posture • Swelling of the face or neck (lymphedema) • Hair loss (beard or back of neck) • Heartburn • Nausea 	<ul style="list-style-type: none"> • Fatigue • Dry mouth • Altered taste • Painful or difficult swallowing • Fibrosis - permanent changes in skin (lighter or darker, or change in texture) and loss of elasticity • Neck and jaw stiffness; difficulty opening mouth • Change in posture • Swelling of the face and neck • Thyroid dysfunction • Cavities (from decreased saliva) and gum disease
Uncommon (less than 10 people in 100)	<ul style="list-style-type: none"> • Hoarseness of voice • Streaks of blood on Kleenex from your nose, or from your throat after coughing • Fungal infection in the mouth • Nerve injury affecting your shoulder or arm movement 	<ul style="list-style-type: none"> • Bone injury in your jaw (osteoradionecrosis) • Hearing loss • Nerve injury affecting your shoulder or arm movement • Difficulty with wearing dentures

For side effects, go to [page 24](#) 



B3

Systemic Treatment

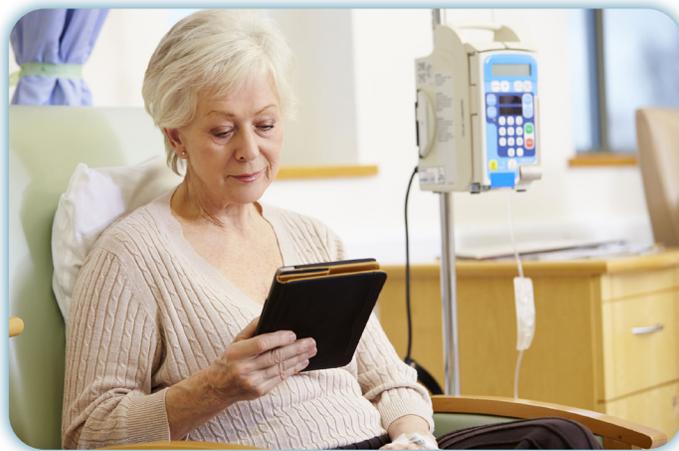
There are many kinds of systemic therapy (like chemotherapy), and your **Medical Oncologist** (chemotherapy doctor) will decide what kind is right for you. Most often systemic treatment for head and neck cancer is given “**intravenously**” (IV) or through the veins.

General information about systemic treatment

What is systemic treatment?

Systemic treatment is any medication that travels through your body in the bloodstream to find, damage or destroy cancer cells. It includes chemotherapy, immunotherapy (checkpoint inhibitor treatment), hormone therapy or targeted therapy. The goals for systemic treatment are different for everyone and they can also change over time.

Using a single drug, or a combination of drugs, medications are used to destroy cancer cells, or to prevent new cancer cells from growing.



Your **Medical Oncologists** is responsible for your systemic treatment plan, and will decide:

- What type of systemic treatment you will have
- How much you will have
- How often you need to have it

All of the information you need to know about chemotherapy treatment, how to prepare and how to manage side effects can be found in the Systemic Treatment book. You will get a copy if you will be having this treatment.

Read the book, watch the videos or take the class.

www.ahs.ca/cancertreatment

> [Systemic Treatment](#)



SCAN ME

Chemotherapy side effects

There are many different kinds of chemotherapy, and each one can have different effects on your body. Because chemotherapy travels through your whole body, it is able to attack cancer cells all over your body. The ability to travel through your body is what causes side effects.

The Systemic Treatment book gives you some ways to manage side effects. Specific side effect resources can be found online at: www.ahs.ca/cancertreatment > Managing Side Effects.

Your oncology care team **will give you a separate information sheet on common side effects** of the chemotherapy drug you will be receiving. They will help you manage any chemotherapy side effects you develop.

What is a clinical trial?

Your doctor may ask you to participate in a clinical trial. Clinical trials are research studies. Clinical trials test new or experimental types of treatment. If this is an option for you, your doctor will talk to you about the clinical trial details. Being a part of a clinical trial **is your decision**. To find out more, visit www.albertacancerclinicaltrials.ca.



C. Managing Side Effects and Concerns at Home

Side effects from surgery, radiation treatment, and chemotherapy can all be different. Some side effects, like **cancer-related fatigue**, can result from all of your treatments.

There are 2 kinds of side effects:

- **Short term** side effects develop while you are on treatment. These side effects should improve and some will go away completely
- **Late side** effects develop weeks, months, or years after treatment. These side effects last longer and can be permanent. There are things you can do to help improve these side effects.

Things That Can Help

There are things that you can do to reduce your side effects. You may have to try more than one thing to see what works for you. The most important thing for you to do is talk to your healthcare team about your side effects, and how they are impacting your life. They can refer you to specialists who will work with you to improve your symptoms.

C1

Dehydration



Dehydration is very common for head and neck cancer patients.

Your body needs lots of fluids to heal. During cancer treatment fluids help to flush out cells, waste products, and chemotherapy drugs. Drink enough fluids to keep your urine pale.

Tell your oncologist, nurse or healthcare provider if you are feeling dehydrated or having difficulty drinking fluids. If you need help to get enough fluids, a tube may be inserted in your arm (by IV, or intravenous line) to give you extra fluids.



C2

Skin care after Radiation Treatment

Be gentle with your skin in the head and neck area while you have radiation treatment. Your skin is fragile after radiation. See the section on **Caring for Your Incisions**.

- Have warm showers, not hot
- Gently pat your skin dry, don't rub
- Cover up your skin from the sun, cold and wind
- Use an electric razor to shave, don't use a blade
- Use skin care products on your skin as directed by your healthcare team

For more information look in the **Radiation Treatment** book.



Applying cream regularly helps to keep skin moist. If you notice the skin is becoming dry despite the regular application of cream, your healthcare provider may recommend putting on dressings. A nurse will teach you how to do this.

Tip!

If you are doing massage to your head and neck area after surgery, stop until after your skin is healed after radiation.

C3

Weakness and Fatigue

Shoulder weakness

Shoulder weakness can be caused by surgery but can also start after radiation treatment. If you don't have a referral already, ask to see your cancer clinic physiotherapist if you notice pain or reduced movement in your shoulder after surgery or radiation. If you were given shoulder exercises to do, it's important to continue doing the exercises as you were instructed. If you had surgery, you can find the shoulder exercises in the **Surgery for Head and Neck Cancer** book, **Section E1**.

Fatigue

Fatigue is one of the **most common** side effects during and after treatment. It can take a long time to regain your energy. It is not the same "normal" tiredness that others experience.

Following treatment, resume usual activities gradually as your body is using lots of energy to heal. Try to do small amounts of activity combined with rest periods through your day.

Tip!

- Be active. Spread your activity out over the week and rest when needed.
- Maintain your nutritional intake (eating small amounts every 2-3 hours can help)
- Watch helpful videos at www.myhealth.alberta.ca/Alberta/cancer-fatigue



C4

Mouth Problems

Dry mouth and phlegm

Dry mouth is a problem that starts during treatment and often continues as a long-term side effect. The liquid (saliva) in your mouth is made in your salivary glands. These glands are found in different spots along your jaw. Saliva helps you chew and swallow food, talk, and keeps your mouth clean.

Sometimes during surgery, the larger salivary glands are removed. Dry mouth is not a big problem because there are smaller glands called accessory salivary glands also found in the mouth (see the picture on [page 11](#)).

But with radiation treatment, dryness may be the first side effect you notice. Salivary glands are sensitive to radiation treatments and can cause the loss of saliva. Instead, a thick, sticky, ropey phlegm develops that is difficult to cough up or swallow.

To help clear this thick phlegm from your throat:

- swish and gargle club soda
- drink warm water or tea
- take sips of carbonated beverages before eating

Tip!

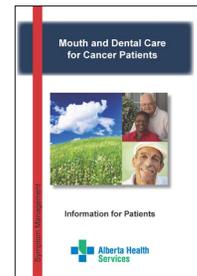
Tips for Managing Dry Mouth

- Keep a water bottle with you and sip throughout the day
- Use a humidifier near the head of the bed at night
- Eat foods that are soft and moist like gravies, pasta with sauce, soups, and yogurt
- Use recommended mouth rinses (see your **Mouth and Dental Care** booklet)
- Suck on sugarless mints or gum that has xylitol (like Pur[®] gum). XyliMelts[®] tablets can be used at night inside your cheek.
- Use water based lip care like Blistex[®], Dermabase[®], or Glaxal Base[®] cream
- Avoid or try to quit smoking and commercial tobacco products (see **Healthier Together** on [page 34](#))
- Avoid or try to quit drinking alcohol
- Acupuncture may be helpful and is available at some cancer rehab centers or in your community



Mouth sores, mouth care and dentures

- Keep rinsing your mouth as instructed, especially after eating. You may have numbness in your lower lip or other parts of your mouth, which causes some drooling. The numbness can last for a long time.
- Dry mouth and sore mouth due to the cancer treatments can make wearing dentures difficult. It's important to clean your dentures well and practice good mouth care to prevent infections.
- Mouth sores can make it very difficult to eat. Follow the instructions in the **Mouth and Dental Care for People with Cancer**. Read about how to manage Painful Swallowing ([Section C6](#) of this book).



Tooth decay and gum disease

Tooth decay can happen as a result of radiation treatment. It can reduce the amount and increase the thickness of your saliva, which increases your risk of tooth decay and of gum disease. It's important to follow the advice in the **Mouth and Dental Care for People with Cancer** booklet and practice good mouth care. Your dentist may also recommend special fluoride treatments to help protect your teeth, along with other things to improve gum health.

Sometimes, radiation treatment can cause tooth decay. If you have severe tooth decay, you may need to have your teeth removed. This should be done by a specialist called an **oromaxillofacial surgeon**. Another specialist (**oromaxillofacial prosthodontist**) can help you restore the missing teeth or work with a team to create a prosthetic.

Yeast infection of the mouth

Yeast Infection (Thrush)

Sometimes, even if you practice good mouth care, you may develop an infection. A yeast or thrush (fungal) infection can affect the whole mouth, including the tongue and roof of the mouth.

The usual treatment for thrush is a prescription mouthwash called Nystatin. Follow these instructions, unless you were given different instructions by your doctor or nurse:

1. Brush teeth with toothbrush and/or toothettes.
2. Be sure to attempt to brush tongue.
3. Use toothettes to clean remainder of mouth cavity especially in pockets of cheek and lips.
4. Rinse mouth with water or mouthwash thoroughly.
5. Apply medication to affected area/mouth, using the dropper or toothette method (see next page):

Call your healthcare team if you have a:

- Yellow/white coating on the top of the tongue or mouth that does not brush away
- Bright red mouth cavity that is sore and makes it difficult to eat
- Foul smell coming from your mouth



Dropper	Toothette (if you can't swish or control liquid in your mouth)
<ul style="list-style-type: none"> • “drop” prescribed Nystatin medication into mouth • Swish liquid throughout mouth for at least 2 minutes, then spit/swallow medication as is ordered by your doctor • Do not eat or drink for 30 minutes 	<ul style="list-style-type: none"> • Drop the proper dose of Nystatin in a small, clean cup • Use toothette to “paint” the medication throughout mouth • Do not rinse, eat or drink for 30 minutes

Taste changes

Taste changes can happen from chemotherapy, radiation treatment or surgery.

- Chemotherapy can change the taste receptors and sometimes change your sense of smell, which will make food taste different.
- Radiation treatment can damage the taste buds and salivary glands, and cause changes to the sense of smell. This results in changes in the way food tastes to you. Taste changes from radiation treatment start to improve 3 weeks to 2 months after treatment ends.
- If you have had salivary glands removed during surgery, your sense of taste may not return fully the way it was before treatment.



C5

Stiffness and Swelling

Jaw and neck stiffness

The exercises included in this book ([Section D3](#)) are **very important** in preventing and improving jaw and neck stiffness from treatment. Jaw stiffness can make it very difficult to open your mouth, which can affect your ability to eat and talk. Neck stiffness can affect your ability to move, sleep, and do daily activities. There are things you can do to help:

- During treatment, do the exercises in this book. Use pain medication if you need to so you can keep doing the exercises. Tell your healthcare provider if the exercises become too painful.
- 3–5 months after treatment, the neck and jaw stiffness can increase. It is very important to do the stretching exercises daily for **at least 1 year** or longer to prevent permanent loss of range of motion. Ask to see a physiotherapist if you start to develop pain and/or stiffness in the jaw or neck.

Swelling of the face and neck (lymphedema)

Swelling (also known as lymphedema) of the face and neck is common during and after treatment. If you have surgery you will most likely have swelling right away. If you have radiation treatment, lymphedema usually starts to develop about 6 weeks after your treatment finishes.

Keep doing the jaw and neck exercises every day (see [Section D3](#)). If your swelling is causing you symptoms or is not improving, ask for a referral to your rehabilitation team. They can help you manage this using different treatments to help move the fluid out of the tissue. Depending on your situation, your therapist may recommend compression (such as a chin strap) to help manage your swelling.

Lymphedema is more common after a neck dissection (see [Section A1](#) in the **Head and Neck Cancer Surgery book**) because more lymph nodes are taken. It may be temporary or permanent and needs treatment to be managed. Treatment works best when it starts early.

Review the signs of lymphedema so you can get treatment right away.

If you have any type of swelling in your neck, jaw, or face, talk to your doctor and ask for a referral to Rehabilitation Oncology.

Lymphedema is easier to manage if you get help early.

Signs of lymphedema

The affected area may:

- become thick, with firm swelling of the neck, jaw or face that may indent with pressure to it. Swelling often gets worse at night, when laying flat
- feel heavy, numb, or tingle
- be more difficult to move
- have pain or discomfort or both
- have an increased risk of infection



Image © AHS

Tip!

Keeping your head a bit elevated while you sleep can help with swelling and comfort. Sleeping with a foam wedge pillow or 2 to 3 pillows under your head and shoulders may help reduce swelling and discomfort. Sleeping in a recliner may also help.

C6

Swallowing Problems

Swallowing changes

Head and Neck cancer and the treatment for this cancer can cause problems with swallowing. These problems can develop because of a change in the way the swallowing muscles work.

Treatment side effects can also cause swallowing problems. Common side effects are:

- dry mouth
- thick saliva
- sore throat
- swelling and tightness of the swallowing muscles

A combination of these issues can cause problems swallowing solid food, drinks, or your own saliva.



If you are coughing or choking, tell your healthcare team immediately. It can be dangerous for food or fluid to go into your lungs.

How do I know if I have a swallowing problem?

While eating or drinking you:

- have problems finishing a meal
- cough, choke or clear your throat more, especially right after swallowing
- have a wet voice
- need extra liquid to wash down solid foods
- need extra swallows and effort needed to clear a mouthful



Your medical team will assess your symptoms and give you ways to manage them.

Swallowing changes can make certain foods or fluids difficult to swallow. You may need to eat softer solids or a mostly liquid diet. Diet changes may be temporary or permanent.

If your swallowing difficulties cause a lot of weight loss you may need a feeding tube. You may also need a feeding tube if food or fluids are going into your lungs (your swallow is unsafe). The feeding tube can be temporary or permanent, although permanent feeding tubes are less common. This is usually assessed by a **Speech Language Pathologist (SLP)**.

The SLP will:

- assess the safety of your swallow
- work with you and your team to make changes to your diet to make your swallow easier and safer
- teach you swallowing exercises and strategies to maintain or improve swallowing, if you need it. Swallowing exercises are important to support your ability to eat solid food and drink liquids in order to keep nourished and hydrated.

What can I do to reduce my risk of having swallowing problems?

Reducing the risk of swallowing problems means taking a proactive approach to keep the swallow muscles active through treatment. If the SLP gave you swallowing exercises, keep doing them—even if you have a feeding tube. They will help you maintain your swallowing muscles.

Painful swallowing

Radiation side effects such as changes to saliva, painful swallowing, and taste changes can all make eating and drinking more difficult or unpleasant through treatment.

What can I do to relieve the pain when I swallow?

Tell your Oncologist or Nurse Practitioner you are experiencing pain with swallowing. They will assess your symptoms and may prescribe mouthwash or pain medication to help relieve your symptoms.



Tip!

- If you have a prescription for pain medication, take it 20-30 minutes before you eat or drink.
- If you have a prescription mouthwash, follow the instructions on when to use the mouthwash.



C7

Speech, Voice and Resonance Changes

Speech changes

People who have surgery on the lips, tongue, or jaw may have speech changes. Very large tongue cancers can change speech as well, even without surgery. Usually, other people will still be able to understand you. Sometimes, quality and precision of certain speech sounds may change.

Voice changes

Voice changes are most common in people with laryngeal cancer (cancer of the vocal folds). Such cancer and its treatment will often cause hoarseness, and sometimes the entire loss of voice.

If a laryngeal cancer required removal of the voice box (a total laryngectomy), voice sounds can be made in other ways. An SLP will work closely with you if this is the case.

If you are getting radiation treatment for laryngeal cancer, your voice quality may change. It is common to have very hoarse voice before and during treatment. In most cases, hoarseness will improve, although this can take a while. Some voice changes can be permanent. For example,



voice can fatigue throughout the day. Tension can develop in and around the voice box, making the voice sound tense and rough. You may need to be checked by a speech pathologist or an “ear, nose and throat” doctor.

People with other types of head and neck cancer can also experience hoarseness and sometimes temporary loss of voice during radiation treatment. This is due to swelling in and around the vocal folds and usually improves after treatment ends.

Resonance changes

Cancer and its treatment can change another aspect of speech called **resonance**. Resonance is the balance of air moving out of mouth and nose while you are speaking. Cancer of the soft palate and its treatment can change this balance, making you sound “nasal.” Surgical or prosthetic treatment may be available if the nasal voice quality does not improve on its own. Large cancer on the base of the tongue can also change your resonance by making your voice quality “stuffy and full.” This improves as the tumour shrinks with treatment.



If you have concerns about changes in speech, voice or resonance, ask to see a Speech-Language Pathologist.



D. Living Your Best During Treatment and Beyond

D1 Personal Care, Activity and Finding Information

Driving



Make sure you have a ride arranged when you are ready to come home from the hospital. Then, **do not drive for at least 24 hours** after you come home from the hospital. Your doctor will tell you if you need to stop driving for longer than 24 hours.

Do not drive until you:

- are no longer taking pain medications that make you feel sleepy
- can move your arms normally
- can shoulder check without pain
- can hit the brake pedal for an emergency stop without pain
- feel stronger and comfortable

Activity and exercise



Regular exercise before treatment and after your incisions have healed has many benefits. It can help:

- reduce fatigue and improve energy levels
- reduce your risk for blood clots
- reduce nausea
- boost your immune system
- lower your risk for falling by keeping you stronger
- improve your mood and help you feel better as treatment progresses



Studies show that exercise helps patients feel better — even something as short as a 10-15 minute walk.

It's important to check with your cancer doctor first before you start any exercise program or go back to doing sports. Light activity, such as walking is a good way to increase your strength. Gradually increase your activity level, but make sure you still get enough rest and are getting enough calories to match the extra activity. **Avoid activities that can strain your neck and shoulder muscles.**



Exercises

Treatment of head and neck cancer often causes stiffness in your neck, shoulders, and jaw. Your rehabilitation therapist will tell you when you can begin the exercises to help prevent stiffness (see [Section D3](#)). You may need to continue rehabilitation services when you go home from the hospital.

A rehabilitation therapist at a cancer centre (Rehabilitation Oncology) may be the best person to meet your rehabilitation needs. If you do not live near a cancer centre, then virtual visits by video call can be arranged or your local, community physiotherapist can work with the cancer centre therapists so you get the specialized care you need.

Tobacco products

We know stopping the use of tobacco can be difficult and often takes several tries. By stopping your tobacco use after a cancer diagnosis, you can improve your health and body's response to treatment, whether it's surgery, radiation treatment or systemic treatment.

Studies show many important benefits of quitting the use of tobacco after a cancer diagnosis, including:

- A better chance of successful treatment
- Fewer serious side effects
- Faster recovery from treatment
- Decreased risk of the cancer coming back, or getting another cancer diagnosis
- Lower risk of infection
- Easier breathing
- More energy
- Better quality of life

Cancer patients who quit tobacco say they **feel better physically, emotionally, and have a better quality of life!** Now is the BEST time to be tobacco free.



For support quitting commercial tobacco or for more information:

Visit www.AlbertaQuits.ca or call 1-866-710-QUIT(7848)

or www.healthiertogether.ca/living-healthy/live-tobacco-free

Find Information and access resources

Cancer Care Alberta



Visit www.cancercarealberta.ca for resources, support and information from prevention to treatment and beyond.

Head and Neck Dental Specialists

Foothills Medical Centre Dental Clinic (Calgary)



403-944-2401

bit.ly/foothillsdentalclinic

University of Alberta Hospital Dental Clinic (Edmonton)



780-407-6854

bit.ly/uofadentalclinic

Reconstructive Specialists

Alberta Prosthodontists



www.dentalhealthalberta.ca

> Find a Dentist > Prosthodontist

Institute for Reconstructive Sciences in Medicine (iRSM)



irmsmyeg.ca

Head and Neck Specific Resources

Head and Neck Cancer Resources (a full listing of reliable websites)



bit.ly/headandneckresources

Web Whispers



webwhispers.org/

Head and Neck Cancer Survivor Videos



www.headandneck.org/survivor-stories/



MyHealth.Alberta.ca

Visit MyHealth.Alberta.ca for health information on many topics.



Wellspring Calgary and Edmonton

Wellspring is a warm and welcoming place that offers a variety of supportive programs, at no cost, for cancer patients, their families and caregivers. They are part of a network of Wellspring centres in Canada that provide emotional, restorative and educational support programs and services to anyone affected by cancer.

Calgary



wellspringcalgary.ca



403-521-5292 (North) / 587-747-0260 (South)



404 Home Road NW / 3910 Seton Drive SE

Edmonton



wellspring.ca/edmonton



780-758-4433



11306 65 Ave

Support Groups and Other Connections

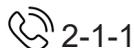
Your nurse might have suggestions or information for Head and Neck support groups or other resources. Support groups can be a great way to connect with others who share your experience. See Wellspring (above) or try:

Head and Neck Cancer Support Society (HNCSS) - head-way.org



Alberta 211

Alberta 211 is a local resource and information service. It provides information in several ways: by phone, online or by web chat (phone service is available in many, but not all, areas). We encourage local and community organizations to list their services here. This is a great place to check on what is available near you!



www.ab.211.ca to search or chat online

Search for information on things like:

- Financial and social assistance
- Food assistance and meal programs
- Parenting and family programs
- Newcomer services
- Mental health support
- Government program assistance
- Seniors' services and home care
- Housing and utility help
- Disability support services

Canadian Cancer Society (CCS) and Community Services Locator

The CCS community services locator (CSL) is a directory that helps cancer patients, caregivers and healthcare providers find the services they need across Canada. There are over 4000 cancer-related services listed. You can search for:

- emotional support programs
- homecare
- how to get to your cancer treatment

cancer.ca

<https://csl.cancer.ca/en> (locator)

Can't find what you need? 1 888 939-3333 (Monday to Friday)

Books

- Carper, Elise. 2008. **100 Questions & Answers about Head and Neck Cancer.** Jones and Bartlett. ISBN-10: 0763743070
- Lydiatt, William. MD, and Perry Johnson MD. 2001. **Cancers of the Mouth and Throat: A Patient's Guide to Treatment.** Addicus Books. ISBN-10: 1886039445
- Rann, Patti E. 2002. **Dinner Through a Straw.** Self-published.
- Leupold, N. and James J. Sciubba eds. 2008. **Meeting the Challenges of Oral and Head and Neck Cancer: A Survivor's Guide.** Plural Publishing. ISBN-10: 9781597562393
- Beaudette, Susan. 2003. **The Healing Jaw.** (A liquid diet resource and recipe guidebook for maxillary trauma and reconstructive jaw surgery.)
- Support for People with Oral and Head and Neck Cancer (SPOHNC) 2006. **We Have Walked in Your Shoes - A Guide to Living with Oral, Head, and Neck Cancer.** www.spohnc.org/online-store/we-have-walked-in-your-shoes/



Integrative and complementary therapies

What are integrative and complementary therapies?

These include different healing approaches and therapies not considered to be standard medical treatments.

- **Standard medical treatments** are scientifically tested and researched and include treatments such as radiation, surgery, and systemic treatment (such as chemotherapy or hormone therapy). These treatments are used by doctors to treat people with cancer.
- **Complementary medicine** is used along with standard medical treatments. It is meant to help relieve symptoms or side effects, or boost emotional or physical health.

Talk to your surgeon, oncologist or family doctor if you are thinking about using complementary therapies or if you have any questions or problems. Check with your pharmacist or registered dietitian to see if there are possible interactions with medications or supplements.



Does my healthcare team need to know if I am using integrative or complementary therapies?

Yes. Tell your doctor or nurse about anything you are taking or using.

Some complementary medicine or natural health products may make your treatment less effective or interact in unexpected ways. It's always best to talk to your healthcare team before you start any additional treatments or therapies.

These include things like:

- pills
- vitamins
- massage
- hyperbaric oxygen treatment
- injections
- herbal remedies
- acupuncture
- cannabis

Are there natural health products I can take during treatment?

- You can take a regular strength multiple vitamin and mineral supplement. Choose a brand that is made for your age group. The supplement should have small doses of a wide variety of nutrients (high doses are not recommended).
- We recommend that you do not use other natural health products for 1 month after you finish your treatments, and when possible, for 1 month before you start treatment. Always talk with your cancer doctor first.

To find out more, visit:

CAMEO website: cameoprogram.org

Canadian Cancer Society's website:

bit.ly/CCS-complementary-and-alternative-therapies



D2

Nutrition During Head and Neck Cancer

Importance of nutrition



Good nutrition is very important to maintain your overall body weight and muscle mass, which will keep you strong during your treatment and recovery.

During treatment it is common to have trouble getting enough nutrition. Some side effects of cancer or cancer treatment can make it difficult to eat and drink well, such as:

- Poor appetite
- Dry mouth
- Thick saliva
- Taste changes
- Having a sore mouth or throat
- Constipation and dehydration
- Dehydration
- Swallowing difficulties

Poor nutrition, even over a short time period, can lead to weight and muscle loss and can affect your health. Eating enough will help you go through treatment and recover from side effects faster. If you are not eating or drinking much, are eating less than normal for you, or have lost weight, **speak to your dietitian**.

Tip!

- Follow a high protein, high calorie diet
- To make chewing and swallowing easier, try soft, moist foods. Mincing or pureeing foods may also make them easier to eat.
- If drinking is easier than eating, try a temporary liquid diet. Focus on liquids higher in calories and protein, such as milkshakes or soups with beans or lentils.
- Rinse your mouth and take small, frequent sips of fluid throughout the day to maintain hydration, and better manage thick saliva/phlegm.
- Increase your protein and calories by making homemade smoothies and adding protein powder or using store-bought nutrition supplement drinks. Ask your dietitian for more recommendations.
- Talk to your healthcare team about a feeding tube.

Nutrition resources

There are many kinds of nutrition resources that can help you with your nutrition needs during cancer. Visit www.ahs.ca/nutritionresources for more information. Look under:

- **“Dysphagia (difficulty swallowing)”** for ideas for **soft foods that are easy to chew and swallow**
- **“Cancer”** for ideas on how to **add calories and protein** to your diet.





Seeing a Dietitian is Important!

The Registered Dietitian is a member of your healthcare team. They can help you with your nutrition during and after your cancer treatments by providing information to:

- Increase your nutrition by providing suggestions for you
- Ease any other diet restrictions during your treatment (such as diabetic or heart healthy diets)
- Manage side effects that affect how much you are able to eat and drink.
- Provide meal and snack ideas.

A dietitian will be available to you during and after your treatment for head and neck cancer.

Types of diets

You may need to change to soft and moist foods as side effects progress. If symptoms get worse, a pureed or full liquid diet will help make eating and drinking easier. These changes will also help you meet your nutrition needs better. Starting on a new diet texture or using a feeding tube to meet your nutrient needs does not mean you are doing something wrong. Everyone is unique and will have their own journey through treatment.

Soft Diet

This diet includes foods that are easily chewed and are soft in texture. It may also include pureed foods and full liquids. Examples of a soft diet may include:

- Tender meats with sauce or gravy, baked or broiled fish, egg or tuna salad
- Well-cooked vegetables, canned fruits, ripe bananas, melons, peeled apples or pears
- Cooked noodles, pancakes, casseroles, cooked cereals
- Soups (do not need to be blended), cottage cheese, soft cheese, yogurt



Pureed Diet

The pureed diet includes foods that are ground, processed, or blended to a soft, smooth consistency (texture). Pureed foods are about as thick as pudding. This includes full liquids, as well as the following:

- Pureed meat, fish or poultry (the puree does not need to be thinned)
- Scrambled eggs, cottage cheese, mashed potatoes
- Pureed fruits and vegetables, applesauce, smooth pie filling
- Pureed bread products (such as pancakes, casseroles, and pastas)

Full Liquids (Fluid) Diet

The full liquid diet is sometimes called a **blenderized** diet. Foods are cooked until tender, then combined in a blender or food processor until they reach a consistency that can be easily sucked through a straw or syringe. These foods should not require any chewing. Here are some examples:

- Easiest meals include milkshakes, smoothies, and blended soups
- Nutrition supplement drinks can help you get calories, protein and some vitamins and minerals
- Protein sources like yogurt, milk, protein shakes, protein powders, blended meats and cheese
- Pureed meats thinned with gravy, creams, sauces in a blender
- **For your safety:** use a strainer to remove any seeds or skins left over after blending nuts, seeds, fruits or vegetables

Low protein and low calorie liquids such as juices, broths, coffee, and teas, are forms of hydration, **not meals**.

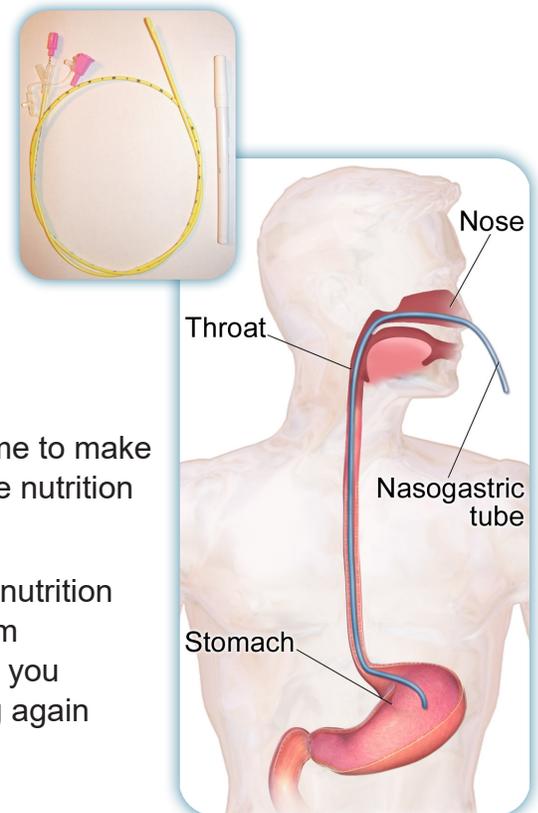
Feeding Tubes

Some people may need a feeding tube to help provide nutrition support if it becomes too difficult to get enough nutrition by mouth. Temporary feeding tubes called **nasogastric (NG)** tubes are used.

A dietitian will choose a formula and amount to provide enough calories and protein during treatment and recovery.

Your healthcare team will monitor you closely during this time to make sure you are managing well with the formula and getting the nutrition you need.

Your healthcare team will decide how long you need to get nutrition by tube feeding. This will depend on how your recovery from treatment is going. Your dietitian can answer any questions you have and will coach you on how to start eating and drinking again when your body is ready.



Nasogastric Intubation
By BruceBlaus - Own work,
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File:Nasogastric_Intubation.png](https://commons.wikimedia.org/wiki/File:Nasogastric_Intubation.png)

Picture of Tube above.
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ASYS_CORFLO_NG_TUBE_FR8.JPG](https://en.wikipedia.org/wiki/Nasogastric_Intubation#/media/File:VI-ASYS_CORFLO_NG_TUBE_FR8.JPG)



D3

Stretching Exercises

Stretching your jaw

Normally you should be able to put **3 stacked fingers sideways** in your mouth. If you cannot do this, you may have jaw stiffness. You need to be able to open your mouth for eating, speaking, and dental care. The exercises below will help you prevent and improve jaw stiffness. Your surgeon may have special instructions depending on the type of surgery you had.

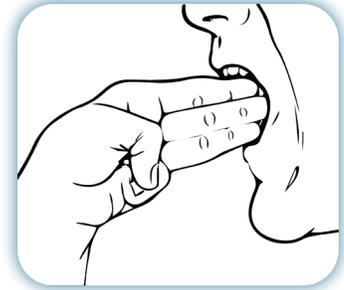


Image © AHS

For each of the exercises, practice with good posture (see [page 42](#) for good posture tips). Doing these exercises in front of a mirror can help. Do these exercises for at least 1 year after your surgery or treatment.

Follow these instructions **without causing pain**:

- **Hold for 5 seconds** before slowly returning to your normal position.
- Do these exercise 5 times each, 3 different times of the day.

Jaw Stretches Side to Side

- Keep your teeth slightly apart.
- Slide your bottom teeth sideways to the right.
- Slide your bottom teeth sideways to the left.



Jaw Opening

- Lower your jaw as far as possible to feel a big stretch.



Jaw Protrusion (move forward)

- Keep your jaw slightly open.
- Slide your bottom jaw forward as far as it is comfortable.



Images © Physiotec

Stretching your neck

Neck stiffness is common after surgery, but is even more of a problem after radiation treatment. You may notice that it is more difficult to turn or tip your head, or look up at the ceiling. The exercises below will help you to keep your neck from getting stiff. A rehab therapist can show you how to do them properly. Always practice good posture. Do these exercises for at least 1 year after your surgery or treatment.

For Good Posture: Neck, jaw and shoulder muscles work better when they are in proper alignment. For good posture during all your exercises, keep the shoulders back and down, chin slightly tucked in, and neck and back straight.

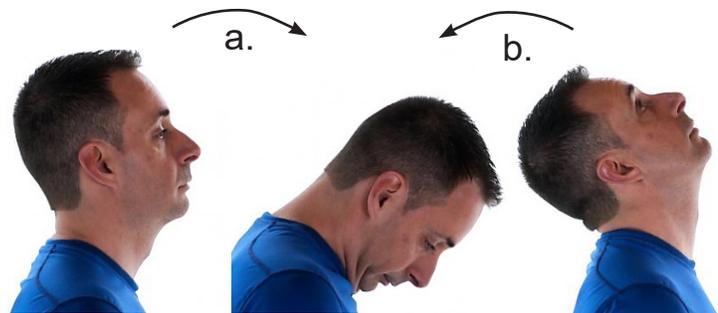
For each of the exercises, do the following without causing pain:

- **Hold for 5 seconds** before slowly returning to your normal position.
- Do these exercise 5 times each, 3 different times of the day.

Tipping Your Head Back and Forth

- Bend your head forward until you feel a stretch behind your neck.
- Tip your head back to look up to the ceiling.

Stop if you feel dizzy or nauseous.



Tilting Your Head to the Side

- Tip your ear towards your shoulder until you feel a stretch at the side of your neck without pain.
- Tip your ear to the other side.



Head Turn

- Turn your head to one side until you feel a stretch.
- You should be able to see behind you.
- Turn your head to the other side.



Images © Physiotec



Posture exercise

Shoulder Blade Squeeze

This exercise helps to improve your posture and movement in your shoulders.

- Standing or sitting, tuck your chin slightly and keep your back and spine tall.
- With your arms relaxed on your sides, gently squeeze your shoulder blades together. Make sure you do not lift or shrug your shoulders.
- Hold for 5 seconds.
- Gently relax the position.
- Repeat throughout the day.



⚠ Move as far as you can go without pain or pinching

Images © Physiotec



If you had surgery, see the **Head and Neck Cancer Surgery** book for important shoulder exercises.



D4

Emotional Self Care and Awareness

It can be hard to talk about having head and neck cancer. Some people find it helpful to talk to friends and family. Speaking with others might help you:

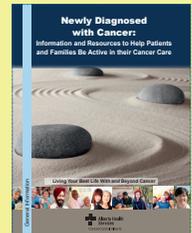
- Understand the information better.
- Get the support you need.
- Create a support network. You may want to have 1 person keep others updated for you.
- Feel in control of your own treatment plan so you're comfortable asking questions.

Difficult emotions often arise during cancer and its treatments. Psychologists and social workers offer counselling to patients and family members to help reduce emotional distress and explore coping techniques.

They help with things such as communication, stress, coping with treatment side effects, mood changes, quality of life, body image or loneliness.

Once you have a confirmed cancer diagnosis, you or your support persons can ask for a referral to the cancer counselling professionals (Psychosocial Oncology).

For more information look in the **Newly Diagnosed with Cancer Book**



or

For contact information visit www.ahs.ca/cancersupportivecare > Psychosocial Oncology

Body image



It's normal to have questions and concerns about body image. You may have unexpected feelings from the changes to your body from surgery or treatment. This is different for everyone. If you can talk about these feelings with your partner, family, and friends, you'll feel less alone when dealing with these changes.

If you'd like more help, talk to:

- Someone in your community who you trust.
- Any member of your healthcare team.

Read more in the **Sexual Health booklet series at:**

-  www.ahs.ca/cancertreatment
- > Managing Side Effects
 - > Sexual Health

Anxiety

What is anxiety?

Anxiety is a feeling of worry, fear, or being nervous and is a normal feeling for patients and families to have when going through a cancer diagnosis.

Tip!

People who learn about their cancer and treatment options may feel more in control and have less anxiety.

Be ready for your appointments with a written list of questions, and bring a support person if you can.

What are signs and symptoms of anxiety?

- Feeling restless, worried, or not able to relax
- Feeling moody or stressed
- Tense muscles
- Trouble sleeping

Some people have strong anxiety which can cause anxiety attacks. You may feel:

- Feelings of doom
- Shortness of breath
- Heart palpitations (your heart feels like it is fluttering or pounding)
- Dizziness and nausea
- Chest pains

What can I do to help my anxiety or depression?

Find support:



- Talk to someone you trust and who is a good listener — friends, family or co-workers.
- Talk to a social worker about support programs at your cancer centre and in your community.
- Get professional help. Professional counsellors can help you learn new ways to manage your anxiety and worry.



- Focus on things that make you feel better.
- Think about the positive parts of your life and the things you can control.
- Spend time with people who make you laugh and avoid those who are negative.



- Get a good sleep — this can give you more energy and help you feel better emotionally.



- Exercise and take care of your body. It's a good way to help you feel better and improve your mood.



- Some people find writing in a journal or expressing their feelings through art can help.



- Try to limit or avoid alcohol because it can lower your mood.



- Try relaxation activities like listening to music, yoga, or deep breathing.



E. Words to Know

Alveolar ridge is the gums and the base of the teeth (can be affected with oral cavity cancer).

Anterior tongue is the front two-thirds of the tongue (can be affected with oral cavity cancer).

Arytenoid cartilages are attached to the vocal folds and connected to Hyoid bone by muscle. There are 2 of these.

Base of Tongue. Back part of the tongue near the back of the throat. Lifts up to the roof of the mouth to prevent food from the front of the mouth to travel to throat before the food can be properly chewed. Once food has moved to the back of the mouth, acts to push the food down the throat.

Buccal mucosa is the lining of the inside the cheeks (can be affected with oral cavity cancer).

Carotid Arteries are the two large blood vessels that carry blood to your head from your heart.

Cricoid cartilage protects the larynx.

Epiglottis is a paddle-like elastic cartilage that lies behind the tongue. It acts like a lid to protect the trachea during swallowing. It can be affected with laryngeal cancer.

Esophagus is known as the “eating tube” or “food tube” It is about 10-12 inches long and runs along the back side of the trachea. The esophagus connects the pharynx to the opening of the stomach and works to move food down from the mouth to the stomach using rhythmic contractions called peristalsis.

Floor of the mouth is under the tongue and between the teeth. It is formed by muscles that support the base of the tongue like a sling. It connects the tongue to the jaw bone (mandible) and covers the submandibular and sublingual glands. It can be affected with oral cavity cancer.

Hard palate is the roof of the mouth, made of bone It can be affected with oral cavity cancer. It forms the floor of the nasal cavity.

Jugular Veins are the largest veins in the neck that carry blood away from your head.

Larynx (throat). This is the part of the body which is affected when you are diagnosed with laryngeal cancer. The larynx has 3 separate areas which can become cancerous – the glottis, the supraglottis, subglottis. The glottis is the voice box and the supra and sub parts mean above and below. The most common form of cancer is of the glottis. The larynx has 3 functions:

- Opens a valve for breathing
- Partially closes valve for speech and voice
- Closes valve securely for swallowing

Lymph Nodes are the small gland-like structures throughout the body that filter fluid and remove bacteria and other foreign materials. When you have surgery, some lymph nodes may be removed. These nodes will be checked to see if the cancer has spread. There are many lymph nodes in this area. Removing some of these nodes will not affect how well your body fights infection or other diseases but can cause swelling in the area.



Nasal cavity is the passageway just behind the nose through which air passes on the way to the throat during breathing. It warms, moistens and cleans the air as it enters the body.

Nasopharynx is the part of the throat (the pharynx) and lives just behind the nose (behind the nasal passages and above the soft palate). Contains the tonsils or adenoids and the Eustachian tube (the tube that causes the plugged ear sensation when flying). It is a box-like chamber and its job is to allow air to pass either direction through the nose. Cancer that develops in this part of the head it is called **nasopharyngeal cancer**.

Oropharynx is the part of the throat behind the tongue. It is what people generally refer to when they talk about their “throat.” Areas included in the oropharynx are: the back 1/3 of the tongue, the soft palate (roof of the mouth), and the tonsils. If cancer develops in this part of the body is called **oropharyngeal cancer**.

Mandible (jawbone) is the horseshoe-shaped bone that forms your lower jaw.

Palate is the roof of the mouth. The bony portion at the front of the mouth is known as the hard palate and the fleshy portion at the back is known as the soft palate.

Paranasal Sinuses are the small, hollow spaces surrounding the nasal cavity. There are 4 paranasal sinuses, named after the bones that contain them (frontal, maxillary, ethmoid, sphenoid). They help with breathing and smell and contribute to the taste of food.

Parotid Glands are the largest pair of salivary glands. They are located in the cheeks just below and in front of the ears. The ducts from these glands open into the mouth on the inside of the cheeks.

Pharynx is a muscle-like tube from the base of skull to the beginning of esophagus. The passage starts behind the nose and goes down to the larynx and esophagus. Commonly known as the throat and is the shared entrance for food and air. The top section of the pharynx is known as the **nasopharynx**, the middle section as the **oropharynx** and the lower section as the **hypopharynx**. It has muscles to help with swallowing.

Salivary Glands are the glands that produce saliva. Saliva is needed to keep your mouth moist, to begin the digestion of food, and to help prevent tooth decay. The major salivary glands are parotid, sublingual and submandibular.

Soft Palate is made of muscle. It attaches to the hard palate, closer to the back of the throat. When swallowing food, it blocks off the nasal cavity so food does not go into the nasal cavity. Your uvula is connected to the soft palate.

Spinal Accessory Nerve carries messages from your brain to your sternocleidomastoid and trapezius muscles. If this nerve needs to be cut as part of the surgery, it may cause your shoulder to droop on the surgical side. Even if it is not cut, stretching this nerve can cause shoulder weakness or tension.

Sternocleidomastoid Muscle attaches to your breastbone, collarbone, and the back of your head behind your ear, allowing you to turn and lower your head.

Sublingual Glands are found under the tongue, they are the smallest of the major salivary glands.



Submandibular Glands lie below and in front of the angle of the lower jaw. Their ducts open under the tongue.

Thyroid is a gland located in the front part of the neck, just beneath the “Adam’s Apple.” It is a gland that produces hormones for how the body uses energy and it controls the body’s sensitivity to other hormones. The thyroid can be affected by cancer and radiation treatment for cancer.

Thyroid Cartilage is what forms the “Adam’s Apple.”

Tongue is made of muscle. It is attached to the hyoid bone and to the floor of the mouth. It is used for speech, taste, chewing, and swallowing. Taste buds are found on the tongue.

Tonsils (also called palatine tonsils) are a pair of soft tissue masses located at the rear of the throat (oropharynx). They help with an immune response to viral and bacterial infections.

Trachea (windpipe) is the tube through which air passes from your nose and mouth to your lungs.

Uvula is the small fleshy piece of tissue that hangs from the soft palate at the back of the mouth.

Vocal Folds are made of mucus membrane and contain the vocal ligament. They are easily stimulated and irritated by particles such as gas, smoke, or food substances resulting in protective cough reflex. They help in producing sound.



F. Urgent Concerns & When to Get Help



If you are having chest pain, chest tightness or difficulty breathing at any time, call 911.

If you have any of the following urgent concerns, call the number your surgeon gave you at any time or go to Emergency if you cannot reach your surgeon right away.

Urgent Concerns:

- Changes to your skin incision:
 - increasing redness, swelling, yellow or green discharge, or a bad smell.
 - bleeding (bright red) and the bleeding does not stop after you put pressure using a clean cloth or gauze. **!** If the bleeding is in your mouth or throat go to Emergency right away or call 911.
 - you have a large or complete separation of your incision (your incision has come open).
- Chills or a fever (temperature above 38.5°C/101.3 °F).
- Severe difficulty eating and drinking.
- Trouble passing urine.
- No bowel movement in 3 days.
- Nausea that is not getting better with your medication or throwing up longer than 24 hours.
- You have pain, swelling, or redness in your leg that is greater on one side compared to the other.
- If you have a drain:
 - ongoing bright red bloody discharge from your drain.
 - drainage from your drain that smells bad or is creamy in color.

Non-urgent Concerns

These concerns are **not** urgent. Call your surgeon **during business hours** to set up an appointment if you notice:

- More redness or swelling around your incision(s) or drain site.
- Any new drainage from your incision(s).
- Your incision has opened a little bit.
- You are having trouble eating or drinking (you are losing weight).
- You have new lumps or bumps in your neck.



Parts of this resource were adapted from the Head & Neck Oncology Patient Guide: Department of Oral & Maxillofacial Surgery, [University of Michigan](#).
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