

ORAL CANCER





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WHAT IS THE ORAL CAVITY?

The mouth (or oral cavity) is the area between the lips and top of the throat (or oropharynx):

Cancer can affect different parts of the mouth, including:

- Front of the tongue
- Bottom of the mouth (under the tongue and above the lower jaw)
- Jaw bones
- Upper and lower gums (gingiva)
- Lining of the lips and cheeks (buccal mucosa)
- Front of the top of the mouth (hard palate)
- Behind wisdom teeth (retromolar trigone).

Although the lips are part of the mouth, cancers affecting the lip are more similar to skin cancer.

WHAT DOES THE ORAL CAVITY DO?

The mouth (oral cavity) is important in everyday activities such as tasting, chewing and swallowing food, and talking. The tongue mainly helps with

eating and making foods soft enough to swallow. It also helps talking. If the tongue cannot move properly, either because of loss of muscle from surgery, or getting stuck from scarring and limiting movement, then talking and the ability to eat can be affected greatly. The jaw bones help keep the shape of the face and gives a strong bony frame to allow room for chewing.

WHAT IS ORAL CANCER?

Cancer occurs when cells become abnormal, grow uncontrollably and have the potential to spread to other parts of the body. These cells build up to form a mass (or lump).

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Most oral cancers start in the cells that line the mouth (the mucosa; called squamous cell carcinomas, the same as the common types of skin cancer). Oral cancers can also start to grow in minor salivary glands, bone, blood vessels, nerves, and other structures. These cancers are rare and only make up less than 5% of oral cancers.





WHAT CAUSES ORAL CANCER?

Doctors often can't explain why a person gets cancer. But we do know what makes some cancers more likely.

The two main causes of oral cancer are:

- **Smoking (cigarettes, cigars or pipes)**
or using smokeless tobacco (snuff and chewing tobacco). If a person smokes or has smoked in the past, they have a higher risk of getting oral cancer than someone who has never smoked.
- **Drinking alcohol.**
If a person drinks a lot of alcohol over many years, they have a higher risk of getting oral cancer, especially combined with smoking.

Three out of four people with oral cancer have been a smoker or consumed alcohol regularly for a number of years.

Other factors that may increase the risk of oral cancer are:

- Being male – in Australia, men are about three times more likely than women to get oral cancer
- Age – most (about 90%) of oral cancers are in people aged over 50 years
- Previous diagnosis of oral cancer
- Using mouthwash containing alcohol over a number of years
- Using betel nut (betel quid) – oral cancers are more common in parts of Asia where betel quid is chewed
- Lichen planus – an inflammatory condition that causes white and red patches in the mouth (although less than 1 in 100 people with this condition develop oral cancer)
- A poor diet low in fruit and vegetables
- Broken and sharp teeth rubbing on the tongue and cheek

WHAT ARE THE SIGNS AND SYMPTOMS OF ORAL CANCER?

The signs and symptoms of oral cancer depend on the where the cancer is, its size and how far it has spread in the body.

Common signs and symptoms include:

- A sore (like an ulcer) or lump in the mouth that doesn't go away
- Pain in the mouth or ear
- White or red patches on the gums, tongue or mouth
- Unusual bleeding or numbness in the mouth
- Trouble chewing or swallowing food, or moving the tongue
- Difficulty opening the mouth
- A lump in the neck
- Loose teeth or dentures that no longer fit.

Most often these symptoms are not from oral cancer. However, if you have any of these symptoms for more than a few weeks, talk to your doctor as early as possible. They may be able to help diagnose and treat you.

HOW IS ORAL CANCER DIAGNOSED?

It is important that your doctor establishes the diagnosis of oropharyngeal cancer, assesses the size of the cancer and whether it has spread to the lymph nodes in the neck or elsewhere in the body.



To answer these questions, your doctor will need to do the following things:

- **Talk with you about your medical history.** This includes signs you may have noticed, any other health conditions, medications that you are taking, and whether you smoke or drink alcohol
- **Perform a physical examination** by feeling and looking inside your throat and neck
- **Order diagnostic tests**, which may include scans.

Not everyone will need to have every test for oropharyngeal cancer. Your doctor will recommend the tests that are right for you.

Common tests include:

- **Nasoendoscopy:**
Your doctor will use a very thin flexible tube with a tiny light and camera on it to look inside your nose to see your nasopharynx.
- **Biopsy:**
This involves taking a small piece (sample) from the cancer. The sample is then examined under a microscope to check for cancer cells. This is often the only sure way to tell if you have cancer. Your doctor may recommend one of the three types of biopsies:
 - **Excision biopsy:** This is when the doctor removes the cancer completely. This will usually be done for small cancers in the clinic or the operating room.
 - **Incision biopsy:** This is when the doctor removes a small piece of tissue using a surgical knife. This can be done in the clinic using local or general anaesthesia, so that you don't feel any pain. Depending on the size and location of the biopsy, you may need stitches. There may be some bleeding after the biopsy. If you take blood thinners (e.g. warfarin), you may need to stop these for a few days before the biopsy.

- **Needle biopsy (Fine Needle Aspiration or FNA):**
This is used when there is a lump (enlarged lymph node) in the neck that could have cancer cells in it. During the procedure, your doctor will take some cells from the lump using a needle. Usually this is done with guidance from an ultrasound to make sure the needle is in the right spot. You may feel a bit uncomfortable during the biopsy.
- **CT (Computed Tomography) scan:**
This uses X-rays to take pictures of the inside of the body. If a person has cancer, a CT scan can help the doctor to see where it is, measure how big it is, and if it has spread into nearby organs or other parts of the body.
- **MRI (Magnetic Resonance Imaging) scan:**
This uses magnetic fields to take pictures of the inside of the body. This helps the doctor see how far a cancer has grown into the tissue around it. Not all people with oral cancer need a MRI scan.
- **PET (Positron Emission Tomography) scan:**
This is a whole body scan that uses a radioactive form of sugar, which can show if oral cancer has spread to the lymph nodes or elsewhere in the body. Many patients with oral cancer do not need a PET scan.
- **Dental X-Ray:**
This X-ray will help the dental team assess your oral health.
- **Blood tests:**
Although there is no blood test specific for oral cancer, other blood tests are important to check your health and fitness for treatment.



THE CANCER CARE TEAM

After a diagnosis of cancer has been made, your doctor is likely to talk about your diagnosis with the cancer care team they work with. This is known as a head and neck cancer MDT (multidisciplinary team). You may be asked to attend an appointment where the MDT talks about how best to treat your cancer, and coordinate your treatment and care. This team includes experts who will review the diagnosis and tests performed, and considers all parts of your treatment and recovery. The purpose of the MDT is to decide on the best treatment for your cancer and to help you regain the best function possible in the long-term.

[Visit the *Beyond Five* website for further information on the health professionals who may be part of your cancer care team.](#)

HEALTHCARE PROFESSIONALS THAT ARE A PART OF YOUR HEAD AND NECK CANCER MDT

Head And Neck Surgeons	Specialist doctors who remove cancers in the face, mouth, throat and neck. This includes surgeons with a background in otolaryngology (ear nose and throat), general surgery, maxillofacial surgery, and reconstructive surgery. If surgery is required, the head and neck surgeon will carry out the procedure.
Reconstructive (Plastic) Surgeons	Specialist doctors with expertise in reconstructing the head and neck. Some head and neck surgeons also do reconstructive surgery, depending on their training and experience.
Radiation Oncologists	Specialist doctors trained in the use of carefully directed radiation to treat cancer.
Radiation Therapists	Healthcare professionals who deliver the radiation treatment prescribed by the radiation oncologist.
Medical Oncologists	Specialist doctors who are experts in the use of medicines like chemotherapy to treat cancer.
Speech Pathologists	Healthcare professionals who work with people who have difficulties speaking or swallowing.
Dietitians	Healthcare professionals who give food and dietary advice.
Dentist/Oral Medicine Specialists	Healthcare professionals who care for the mouth and teeth. Mouth care is very important in head and neck cancer, especially if radiation therapy is needed.
Pathologists	Specialist doctors who are experts in looking at cells under a microscope and determining if they are cancer.
Radiology And Nuclear Medicine Specialists	Specialist doctors who interpret scans such as CT, MRI and PET scans.
Palliative Care Team	Specialist doctors and nurses who have expertise in managing symptoms and improving quality of life, often in patients where the cancer can't be cured.
Nurses	Healthcare professionals who are experts in the care of people with cancer, and work with all members of the cancer care team. Often, specialist cancer nurses are part of the MDT. They will help to plan and coordinate your care.
Psychologists	Healthcare professionals who assist with worries about coping and living with cancer (mental health).
Social workers	Healthcare professionals who provide practical and emotional support to people living with cancer.



BEYOND FIVE IS AUSTRALIA'S LEADING CHARITY SUPPORTING PEOPLE AFFECTED BY HEAD AND NECK CANCER.

WHAT IS STAGING?

Once your doctor has made a diagnosis of cancer, it is important that they assess the extent (or stage) of the cancer. Staging a cancer is important because it helps doctors to choose the best treatment for you. It also gives information about the chances of cure. The stage is based on the size of the cancer, whether it has invaded into nearby areas of the body and whether it has spread to lymph nodes in the neck (called lymph nodal metastases) or other sites in the body, such as the lungs, liver or bone (called distant metastases).

The TNM (Tumour, Node, Metastases) system is used to stage cancer. This system is used to summarise information about the size of the cancer and whether it has spread to lymph nodes at other parts of the body.

The TNM system

- T stands for the size of the cancer. A T value can range from 1 (small cancer) to 4 (large cancer).
- N indicates whether the cancer has spread to the lymph nodes. Where there is no cancer in the lymph nodes, the N value is 0. An N value can range from 1 to 3, depending on the size and number of cancerous lymph nodes.
- M stands for distant metastases, or whether the cancer has spread to other parts of the body outside the head and neck. An M value can be either 0 (cancer has not spread to other parts of the body) or 1 (cancer has spread to other parts of the body).

Once the values for T, N and M have been worked out, they are combined to give an overall score between 1 and 4. Your doctor may write this in Roman numerals: I, II, III and IV.



Staging is complicated but in broad terms cancers may be described as:

- **Early stage cancer (Stage I or II cancers)** which are small (less than 4 cm in size) and have not spread to the lymph glands or other parts of the body.
- **Advanced stage cancer (Stage III or IV cancers)** which are more advanced due to their size (more than 4 cm) have spread to other nearby parts of the body or the lymph nodes.

The staging system for oral cancers is very different to other cancers and sometimes not very accurate in predicting the chance of cure. This is partly because Stage III and IV cancers each combine a number of cancers together with different chances of cure. For example, TNM Stage IV cancer includes some cancers where the chances of cure are very good and others where the cancer may be incurable. It is important that you discuss the stage of your cancer with your doctor to understand what it means for you.

The chance of cure depends on both the type of cancer and the stage. It is important to know that most patients with advanced oral cancer (even stage IV) can be cured.

WHAT IS GRADING?

Staging and grading are not the same. Your doctor may also be interested in the grade of the cancer. Grading refers to the growth pattern of the cancer. The grade of the cancer is determined by a pathologist who examines a biopsy sample under a microscope. The pathologist determines the grade of the cancer by how the cells look. The grade can be used to estimate how quickly the cancer is likely to grow and spread.

TREATMENT OPTIONS FOR ORAL CANCER

Following a diagnosis of oral cancer, your cancer care team will discuss the treatment options that are suitable for you. This is also a good time to consider if you would like a second opinion.

The most suitable treatment for oral cancer depends on many factors. These include:

- Size and location of the cancer
- Whether the cancer has spread
- Personal factors (e.g.. Age, general health and treatment history)
- Treatments available (and whether any clinical trials are available)
- Your preferences for treatment.

Whilst some people can be treated with surgery alone, others may need extra treatment after surgery to reduce the risk of the cancer returning. Your cancer care team will decide whether it is necessary for you based on a detailed report on the cancer from the pathologist 1–2 weeks after surgery.

Adding another type of treatment after surgery is called adjuvant therapy. This can be either radiation therapy alone or combined with chemotherapy (called chemoradiation), which is typically started about 6 weeks after surgery to allow recovery and for planning purposes. The treatment itself usually lasts about 6 weeks.



SURGERY

There are a number of different operations that can be used to remove oral cancer. The type of operation used will depend on the size of the cancer and where it is.

SURGICAL PROCEDURES

The different surgical options for oral cancer include:

- **Glossectomy:**
This involves removing part of, or all of the tongue. It is used if the cancer is growing in the tissue of the tongue.
- **Mandibulectomy:**
This involves removing part of the lower jaw (mandible). It is used if the cancer has spread into the bone of the jaw or is next to the jaw.
- **Maxillectomy:**
This involves removing part of the upper jaw (maxilla), in the roof of the mouth. It is used when the cancer is affecting the roof of the mouth or upper gums.
- **Mandibulotomy:**
This involves cutting the jaw bone to allow better access to the cancer in the mouth. This may be needed if the cancer is further back and difficult to reach through the mouth. The jaw is put back together at the end of the operation with titanium plates.
- **Neck dissection:**
This involves removing lymph nodes from the neck. It is used when oral cancer has spread to the lymph nodes in the neck or there is a risk of cancer in the lymph nodes of the neck.
- **Reconstructive surgery (soft tissue free flap and bone free flap):**
This may be considered if a large area of tissue is removed. This may involve taking tissue from another part of the body called a free flap repair. If your jaw has been removed, bone from another part of the body may be used to replace your jaw bone. This operation is carried out by a surgeon who specialises in reconstructive surgery, your head and neck surgeon or another surgeon.
- **Tracheostomy:**
A tracheostomy is used to create an opening in the trachea (windpipe) in the lower neck, where a tube is inserted to allow air to flow in and out, when you breathe. This is used as swelling after major head and neck surgery may affect your ability to breathe. The tracheostomy tube is usually removed within a week of surgery once normal breathing is possible.
- **Feeding tubes:**
 - A gastrostomy tube (called a PEG tube) goes through the skin and the muscles of your abdominal wall into the stomach. Gastrostomy is recommended if feeding is needed for a medium to longer time (months or years).
 - A nasogastric tube goes through the nose down into the stomach. Nasogastric feeding is used for short time (days or weeks).



HOW CAN I PREPARE FOR SURGERY?

Your doctor will explain details of the surgery, general risks and side effects of surgery. Ask your doctor if you have questions.

They may recommend:

- Stopping blood thinners (e.g.. Aspirin) before surgery to reduce the risk of bleeding
- Special stockings to reduce the risk of blood clots
- Early mobilisation to reduce the risk of blood clots and chest infection
- Antibiotics to reduce to risk of wound infection.

If you smoke, it is important that you consider stopping smoking before starting treatment to help reduce the risk of infection and help you recover after your treatment.

SIDE EFFECTS OF SURGERY

Treatment for oral cancer may lead to a number of side effects. You may not experience all of the side effects. Speak with your doctor if you have any questions or concerns about treatment side effects.

RADIATION THERAPY

The most common radiation therapy treatment for oral cancer is called external beam radiation. This type of radiation therapy applies radiation from outside the body.

Radiation therapy can be used in the following ways:

- **Definitive radiation therapy:**
This is when radiation therapy is used without surgery to cure oral cancer, often in combination with chemotherapy. This approach has a very limited role in oral cancer, as most patients are best treated with surgery as first-line therapy. It may however be used if a patient is not a candidate for surgery.
- **Adjuvant radiation therapy:**
This is when radiation therapy is given after surgery, to kill cancer cells that may not have been taken out during surgery. Adjuvant radiation therapy can also be given in combination with chemotherapy (this is called concurrent chemoradiation). The decision to give radiation therapy, either alone or in combination with chemotherapy, is based on the pathology results after surgery. The aim is to lower the risk of the cancer returning in the mouth or neck, but not all patients may need this.
- **Palliative radiation therapy:**
In cases where a cure is not possible, radiation therapy is used to relieve symptoms of advanced oral cancer. Symptoms that may require palliative radiation therapy include pain, bleeding, breathing and trouble swallowing.



HOW DO I PREPARE FOR RADIATION THERAPY?

You will meet with many members of the cancer care team, who will help you learn how to look after yourself through radiation therapy, recovery and long term follow-up. They will also talk to you about side effects and how to manage them. It may be helpful to write down questions as they come up, so you can ask anyone in your cancer care team when you see them.

- **Mask-making and simulation:**

Radiation therapy is a precise treatment. In order to make sure, that the cancer is covered by the treatment, you will need to very still during the treatment, usually for about five minutes. A radiation therapy mask that is made to fit perfectly to your shape, will be put on you during each treatment to help the machine target where the cancer is.

You will have a planning CT scan (and sometimes other scans) with the mask on. Your radiation oncologist and radiation therapist will use these scans with all your other clinical information to develop a radiation therapy plan just for you (a personalised plan). Your plan will be checked by the radiation therapy and radiation oncology physics team, before it is ready to be used for your treatment. This whole process can take approximately 2-3 weeks.

- **Teeth and mouth care:**

You might need to have some of your teeth taken out; this will depend on the area being treated and the dose of radiation therapy. It is important to take out any broken or infected teeth before radiation therapy. Taking out unhealthy teeth after radiation therapy can cause problems with the jaw bone.

- **Diet, nutrition and the role of your dietitian:**

Your cancer and its treatment can make it hard to eat and drink. Your doctor will recommend you see a dietitian to maximise your nutrition during treatment as well as while you are recovering. Sometime feeding tubes may be recommended depending on the area being treated and the dose of radiation therapy. There are two common types of feeding tubes:

- **Gastrostomy tube (sometimes called a PEG tube):**

This type of tube is inserted through your abdominal wall into your stomach, with part of the tube staying outside the stomach. A syringe can be attached to the tube to give you food this way if needed. The tube is inserted using a camera through the mouth into the stomach (gastroscopy) or using a CT scanner to guide insertion directly through the skin. If a PEG tube is needed, your doctor will organise this before starting your radiation therapy.

- **Nasogastric tube:**

This type of tube goes through the nose down into the stomach and is usually used for short periods (days or weeks). A nasogastric tube can be inserted at any time (before, during or after treatment).

- **Speech, voice and swallowing:**

Your cancer and its treatment can make swallowing and speech difficult. Your doctor will recommend you see a speech pathologist, who can help you with ways to manage swallowing and communication difficulties, during and after treatment. Your speech pathologist will also help with your voice rehabilitation during and after treatment.



SIDE EFFECTS OF RADIATION THERAPY

The side effects of radiation therapy start around two weeks into treatment and progress through treatment to peak in the last week or just after treatment ends. The side effects start to improve 2–3 weeks after the end of treatment.

Side effects of radiation therapy depend on:

- The dose of radiation therapy
- The area being treated
- Whether or not chemotherapy is added to the radiation therapy.

Each individual responds to radiation therapy differently. Some people may experience a few side effects while others may not experience any at all.

The following are some common side effects of radiation therapy.

Common side effects of radiation therapy include:

- Tiredness
- Skin irritation in the treated area (e.g.. Redness, dryness and itching, weeping skin, scaling or sometimes skin breakdown [sores])

- Dry mouth and throat due to loss of saliva (called xerostomia)
- Changed taste (usually a loss of taste or sometimes an unpleasant taste in the mouth)
- Pain on swallowing or difficulty with swallowing
- Losing weight.

Most side effects are short lived and may go away within 4–6 weeks of finishing radiation therapy. Some side effects may last for months after you finish radiation therapy and some may be permanent.

Once your radiation therapy ends, you will have regular follow-up appointments so your cancer care team can check your recovery, make sure the cancer has not returned, and monitor and treat any side effects that you may have.

Your doctor may recommend that you receive some specific supportive care to help during your recovery such as help with changes in speech, voice or swallowing, diet and nutrition and teeth and mouth care. Further information about supportive care is available on the website.

“THIS IS ONE JOURNEY WHERE YOU ARE GOING TO BE THE PASSENGER, NOT THE DRIVER... CHOOSING YOUR SUPPORT PEOPLE IS AN IMPORTANT PART OF THE JOURNEY.”

- AMANDA, FORMER HEAD AND NECK PATIENT



CHEMOTHERAPY

Chemotherapy works by destroying or damaging cancer cells. For oropharyngeal cancer, chemotherapy is usually given into a vein through a needle with a cannula (tube) attached.

There are a number of ways that chemotherapy may be used to treat oropharyngeal cancer including:

- **Adjuvant:**
This is when chemotherapy is given after surgery in combination with radiation therapy (called concurrent chemoradiation). It may be given once every 3 weeks or once a week throughout the duration of radiation therapy. This makes the radiation more effective at killing cancer cells but also leads to more side effects in most people. Unlike chemotherapy for many other cancers, most people do not lose their hair or have severe nausea and vomiting.
- **Neoadjuvant:**
This is when chemotherapy is given before surgery or radiation therapy to help shrink large cancers, making them easier to remove during surgery, or target with radiation therapy. This is very rarely used for oral cancer but may be used for sarcomas.
- **Palliative chemotherapy:**
This is used when the cancer is incurable. The cancer may be too large or has spread too much to be removed by surgery. Palliative chemotherapy helps to slow the growth of cancer and reduce symptoms. It is important to remember that palliative chemotherapy is not as intense as other types and is much less likely to have significant side effects.

Before you start treatment, your medical oncologist will choose one or more chemotherapy medications that will be best to treat the type of cancer you have.

The chemotherapy medications your doctor chooses may depend on:

- Whether the treatment is curative or palliative
- When it is used
- Your medical history.

SIDE EFFECTS OF CHEMOTHERAPY

The side effects of chemotherapy depend on the medication used and how much you are given by your doctor (the dose). The most common medications used are called cisplatin, carboplatin and cetuximab.

Each individual responds to chemotherapy differently. Some people may experience a few side effects while others may not experience any at all.

The following are some common side effects of chemotherapy:

- A feeling of wanting to vomit (nausea) or vomiting
- More side effects of radiation, if you have chemotherapy at the same time as radiation
- Loss of feeling in the fingers and toes
- Kidney damage (caused by some medications)
- Hearing loss/thinning
- Ringing in the ears
- Rash
- Higher risk of infection (if the chemotherapy reduces the number of white cells in the blood).

Most side effects are short term and will go away once you finish chemotherapy. Some side effects may be long term and some, such as hearing loss, may be permanent.



“THERE ARE MANY LONG-TERM CHALLENGES FOR HEAD AND NECK CANCER SURVIVORS. THAT IS WHY BEYOND FIVE IS SO IMPORTANT. IT OFFERS INFORMATION FOR THE LONG TERM, AS WELL AS FOR THE ACUTE, INITIAL PERIOD.”

- JULIE MCCROSSIN, BEYOND FIVE AMBASSADOR

Once your treatments end, you will have regular follow-up appointments so that your doctor can check your recovery, make sure the cancer has not returned and monitor and treat any side effects that you may have.

Your doctor may recommend that you receive some specific supportive care to help during your recovery.

FOLLOW-UP CARE

You will need regular check-up of your mouth, throat and neck after treatment for oral cancer. This will include a physical exam. Some people may also need imaging such as CT, MRI and PET scans, during follow-up. It is important to keep up with follow-up appointments to make sure that if the cancer comes back, it is caught early and can be treated. If you have any concerns between appointments you should contact your doctor.

People who smoke and/or drink alcohol can reduce the risk of their cancer coming back or getting a new cancer if they quit smoking and reduce the amount of alcohol they drink. Ask your cancer care team for advice if this applies to you.

SUPPORTIVE CARE DURING TREATMENT

It is important to have appropriate supportive care before, during and after treatment for head and neck cancer. Here are some things you should consider before/during treatment.

- In the first week or two after surgery, you may need to be fed by a tube while your body is healing and the swelling is reducing.
- You may find it difficult to swallow after radiation therapy because it may make your mouth dry and your throat sore. You may notice changes in your taste or you may enjoy your food less. Radiation therapy may also affect your teeth (e.g. cause tooth decay).
- Chemotherapy may cause changes in how you taste food, give you a feeling of wanting to vomit (nauseous) or vomit. These side effects may also reduce your appetite.



DIET & NUTRITION, AND THE ROLE OF YOUR DIETITIAN

It is important for people with head and neck cancer to stay well-nourished and to avoid unplanned weight loss. If you can't eat or drink enough, you may become malnourished or begin to lose weight. To help you get enough nutrition, you may need a feeding tube for a short period of time.

Having a good diet can help you:

- Get through treatment
- Reduce the chance you will get an infection
- Recover more quickly
- Keep your strength and energy levels up.

What can I do to keep my food intake up?

- Eat a diet high in protein and calories (energy)
- Eat small meals or snacks more often if you have trouble eating a full meal
- Drink calorie-rich fluids such as milk, milkshakes, smoothies or juice. Your dietitian may recommend supplement drinks that are high in protein and calories
- If you have a sore throat, avoid foods that scratch or burn it such as citrus, vinegar, chips or toast.

Where can I find support?

Your dietitian is an expert in food and nutrition who will help you with your diet. Your dietitian will help you work out a plan to get all the energy you need. They may give you some tips to help make eating and drinking easier and to help you enjoy your food to help you keep weight on.

You may have trouble eating and drinking because of your treatment, but you may find that this gets better over time. Some people need a feeding tube

to make sure they are eating enough and getting enough energy. If this is the case for you, your doctor, dietitian and nurse will talk with you about what this involves. Feeding tubes are usually only needed for a short time, until you recover enough and can eat more. Some people may need feeding tubes for a longer period of time.

More information about diet and nutrition is available [here](#).

SPEECH, VOICE & SWALLOWING, AND THE ROLE OF YOUR SPEECH PATHOLOGIST

Treatment for head and neck cancer may cause changes to parts of your mouth (lips, teeth, tongue, palate) and/or throat (pharynx, larynx), which can affect your ability to speak and/or swallow. These changes may only last for a short time or they may be permanent.

Speech and voice problems can affect your daily life. This may leave you feeling frustrated, distressed or embarrassed, particularly if people have trouble understanding your speech.

If you find it difficult to swallow (known as dysphagia), you may notice:

- You need to swallow many times to clear food from your mouth or throat
- You need to clear your throat or cough while eating
- It hurts to swallow
- Your voice sounds gurgly after swallowing.

Make sure to drink plenty of water when eating, and include gravy or sauces with foods to help you swallow them more easily.



If your treatment has caused changes to your speech, voice or swallowing, you can get help from a speech pathologist. A speech pathologist is an expert in difficulties with communication and swallowing. Your doctor may recommend that you see a speech pathologist before, during and after your treatment.

Your speech pathologist can:

- Give you exercises or tips to help your speech and voice
- Help you plan other ways of communicating such as writing or using a computerised voice to speak for you
- Show you how to use devices or aids if you need them
- Show you safe swallowing tricks such as changing your head position, or changing the thickness of food/liquids to make it easier to swallow them.

You may also get help from a doctor or a dietitian and, in some cases, they may recommend a feeding tube.

TEETH & MOUTH CARE, AND THE ROLE OF YOUR DENTIST

Treatments for head and neck cancer, especially radiation therapy, can cause side effects that affect your teeth and mouth such as:

- Dry mouth
- An increase in ulcers or inflammation in your mouth (mucositis)
- Altered taste
- Being unable to fully open your mouth (trismus)
- Tooth decay
- Infected or bleeding gums
- Breakdown of tissue/ bone in some areas of the mouth.

These side effects may be painful and may make it difficult to eat, talk or swallow. It is important to take care of your teeth and mouth during treatment because infections can be harmful and slow down your treatment.

Some side effects can last for a long time after treatment (late effects).

What can I do to keep my teeth and mouth healthy?

There are a number of things that you can do to keep your teeth and mouth healthy.

- Drink plenty of water and chew sugar-free chewing gum to keep your mouth moist
- Gently brush your teeth, gums and tongue with a soft toothbrush after every meal and at bed time
- Gently floss your teeth every day
- Use high-strength fluoride toothpaste
- Use an alcohol-free mouthwash.

Your dentist is an important member of your healthcare team before, during and after treatment because side effects that affect the teeth and mouth can often be prevented or reduced through regular dental check-ups.

- It is a good idea to have a dental check-up before you start treatment. Your dentist will check the health of your teeth and mouth and will give you a plan to keep your mouth healthy. Sometimes teeth that are decayed and unhealthy need to be removed before radiation therapy to reduce the risk of problems after treatment.
- During your treatment, your dentist will look out for any teeth or mouth side effects.
- After your treatment, you should visit your dentist every 6 months for a check-up because the side effects of radiation therapy on your teeth can be long lasting.



“PARTICULARLY IN THE EARLY DAYS AFTER
A DIAGNOSIS, INFORMATION IS KEY,”

- DR BRUCE ASHFORD, HEAD AND NECK CANCER SURGEON



MENTAL HEALTH FOR PEOPLE WITH CANCER

Sometimes this is referred to as psychosocial aspects or survivorship.

Being diagnosed with cancer and having treatment can lead to extra worries or concerns for you and the people caring for you. Depending on the treatment, you may experience any of the following:

- Low mood or depression
- Anxiety
- Disfigurement
- Difficulties with eating
- Difficulties with speaking
- Changes in sexual activity.

You may have got through the diagnosis and treatment for oral cancer, but you may be finding it difficult to deal with some of the side effects of treatment. Speak with your doctor about any difficulties you may be experiencing. Your doctor may give you a referral to a psychologist or another healthcare professional who can help you. Speak with your family and friends too about any concerns you may have.

You may find it helps to join a patient support group and speak with others who are having treatment for head and neck cancer. You can also find help and advice in online self-help resources such as [beyondblue](#).



QUESTIONS TO ASK YOUR DOCTOR

Being diagnosed with cancer can be overwhelming and confusing. There are a lot of information and treatment decisions to make at a distressing time for you and your family. To help you understand everything and get the information you need to make decisions about your health, consider asking the following questions to your cancer care team. We encourage you to print this and take it to your appointment to take notes.

Exactly what type of cancer do I have?
Where is it located?

What will happen if I don't have any treatment?

Why did I get this cancer? Is it related to the HPV virus?

How much will the treatment and/or operation cost?
Will Medicare or my health insurance cover it?

What stage is the cancer? What are the chances of cure with treatment?

What follow-up tests will I need? How often will they be?

What are my treatment options? Which treatment do you recommend for me and why?

Am I suitable for any clinical trials?

Have you discussed my case at a Multidisciplinary Team meeting and what were the recommendations?

What lifestyle changes (diet, exercise) do you recommend I make?

Who will be part of the cancer care team, and what does each person do? Should I see another specialist before treatment, such as a radiation oncologist, medical oncologist, plastic surgeon, dentist, dietician or speech pathologist?

Where can I find emotional support for me and my family? Is there a support group or psychologist you can recommend?

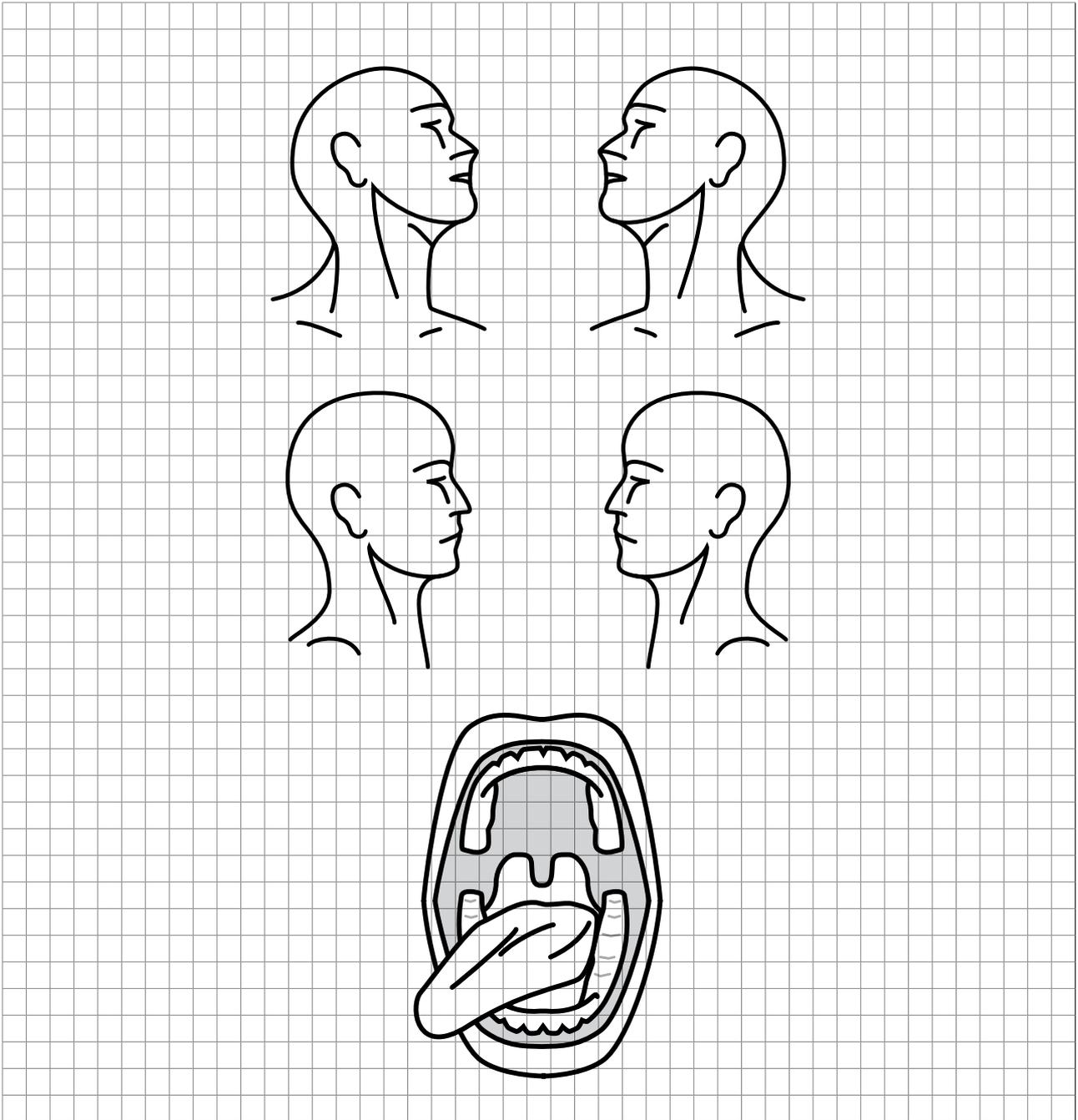
What are the possible side effects of treatment in the short- and long-term? How can they be prevented or managed?

Who can I call if I have any problems or questions?

Will the treatment affect my ability to eat, swallow, or speak? Will I need a feeding tube?

If I wanted to get a second opinion, can you provide all my medical details?

ADDITIONAL NOTES





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NOTE TO READER

Because what is known about head and neck cancer and treatment is constantly changing and being updated, your treating cancer care team will give you information that is specific to your unique needs and situation. This leaflet may help answer some of your questions and help you think of other questions that you may want to ask, however, it is not intended to replace advice or discussion between you and your cancer care team.

This leaflet is written so it can be read as a stand-alone resource. If you would like further information please contact **Beyond Five on 02 8594 8514 or visit our website www.beyondfive.org.au.**

DISCLAIMER

The information contained in this leaflet is for general information purposes only. Beyond Five develops materials based on the best available evidence and takes advice from recognised experts in the field in developing such resources; however, it cannot guarantee and assumes no legal responsibility for the currency or completeness of the information.

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BEYOND FIVE'S MISSION IS TO IMPROVE THE QUALITY OF LIFE OF EVERYONE AFFECTED BY HEAD AND NECK CANCER THROUGH EDUCATION AND ACCESS TO SUPPORT, AND TO RAISE AWARENESS OF HEAD AND NECK CANCER NATIONALLY.

FIND SUPPORT

To find a head and neck cancer service or patient support group near you please visit our Find Support Page <https://goo.gl/C4qFJ6>

DONATE TODAY!

There are more than 17,000 people living in Australia with head and neck cancer and nearly 5,000 people are newly diagnosed with head and neck cancer each year.

Beyond Five currently receives no government funding and relies on public donations and corporate support to fund our activities.

Head and neck cancer affects a person's identity unlike any other cancer. While many people survive the disease, the cancer can strip away a person's voice, distort the face and rob the basic abilities to eat, drink and swallow.

Your donation helps us provide education and support to everyone affected by head and neck cancer in communities right across Australia, making life for families experiencing head and neck cancer that little bit easier.

To donate please call us or visit our website. All donations above \$2 are tax deductible.

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