

# UNDERSTANDING OROPHARYNGEAL CANCER





### **CONTENTS**

Oropharyngeal Cancer	1
What is the Oropharynx?	3
What does the Oropharynx do?	4
What is Oropharyngeal cancer	4
What causes Oropharyngeal cancer	4
What are the signs and symptoms of Oropharyngeal cancer?	5
How is Oropharyngeal cancer diagnosed?	6
The cancer care team	7
What is staging?	8
What is grading?	10
Treatment options for Oropharyngeal cancer	10
Radiation Therapy	11
Chemotherapy	14
Surgery	16
Follow-up care	18
Prognosis	18
Supportive care during treatment	19
Diet and nutrition and role of your dietitian	19
Speech, voice and swallowing, and the role of your speech pathologist	20
Teeth and mouth care and role of your dentist	21
Mental health for people with cancer	22
Questions to ask your cancer care team	23



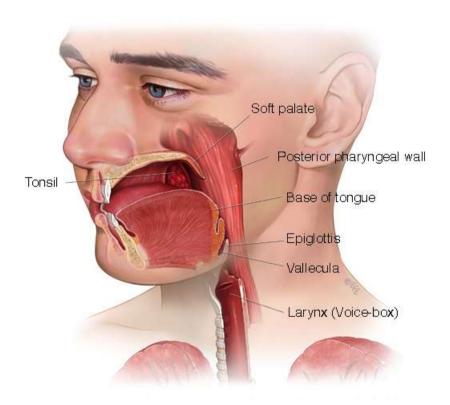
## WHAT IS THE OROPHARYNX?

The oropharynx is the middle part of the throat that is directly behind the mouth.

The oropharynx is made up of four parts (see Diagram below):

- sides of the throat, including the tonsils
- base of the tongue (back third of the tongue), sitting above the voice box
- soft roof of the mouth (or the soft palate) and the fleshy part of skin hanging from the roof (or the uvula)
- back wall of the throat (or the posterior pharyngeal wall)

This diagram shows parts of the oropharynx and the surrounding regions





#### WHAT DOES THE OROPHARYNX DO?

The oropharynx has two main jobs:

- it allows air to pass from the nose and mouth, through the voice box and windpipe, into the lungs
- it pushes foods and drinks from the mouth, down the food passage to the stomach. The base of the tongue helps stop foods and drinks from entering the voice box and lungs.

#### WHAT IS OROPHARYNGFAL 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).

Cancer that starts anywhere in the oropharynx is called oropharyngeal cancer. Your doctor may also call it by the part it has grown in, like tonsil or tongue base cancer. Most oropharyngeal cancers start in the cells that line the surface of the throat (called squamous cell carcinomas).

#### WHAT CAUSES OROPHARYNGEAL CANCER

Doctors often can't explain why a person gets cancer. But we do know what makes some cancers more likely. The main causes of oropharyngeal cancer are:

- human papillomavirus (HPV) infection (especially HPV types 16 and 18). We now know HPV
  causes many oropharyngeal cancers.
- 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 oropharyngeal cancer than someone who does not smoke.
- drinking alcohol. If a person drinks a lot of alcohol over many years, they have a higher risk
  of getting oropharyngeal cancer, especially combined with smoking.



# WHAT ARE THE SIGNS AND SYMPTOMS OF OROPHARYNGEAL CANCER?

The signs and symptoms of oropharyngeal 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 throat that doesn't go away
- a sore (like an ulcer) in the throat
- a lump in the throat
- a lump in the neck (this is common and may be the only sign in many people)
- trouble swallowing food, or moving the tongue
- trouble opening the mouth
- trouble breathing
- noisy breathing
- ear pain
- coughing up blood
- voice change
- unexplained weight loss.

Most often these symptoms are not from oropharyngeal 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 OROPHARYNGEAL 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 scan.

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:

- <u>Nasoendoscopy</u>: Your doctor will look inside your nose and throat using a very thin flexible tube with a tiny light and camera on it (called an endoscope). This can be done in an office or clinic.
- <u>Biopsy</u>: This involves taking a piece of tissue (sample) either from the throat or from a lymph node in the neck, if it appears to be involved by the cancer. A pathologist then looks at the sample under a microscope to check for cancer cells. This is often the only sure way to tell if you have cancer. If the suspicious area can be safely accessed through the mouth, your doctor may take a sample for biopsy in the office. However, this is often not possible because the cancer may be too far back and some patients need to be asleep under a general anaesthetic for the biopsy. This is usually done as a day procedure.

Your doctor may order one of two types of biopsies of the lymph nodes in your neck. Both are usually don using an ultrasound scan to make sure the needle is in the right spot.

- Needle biopsy (Fine Needle Aspiration or FNA) 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. It may feel a bit uncomfortable during the biopsy.
- o **Core biopsy** uses a bigger needle to get more cells for the biopsy. This is more uncomfortable than needle biopsy so doctors only use this if it is really needed.



- <u>CT (Computed Tomography) scan</u>: 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 your doctor see how far a cancer has grown into the tissue around it.
- <u>PET (Positron Emission Tomography) scan</u>: This is a whole body scan that uses a radioactive form of sugar which can show if oropharyngeal cancer has spread to the lymph nodes or elsewhere in the body.

#### 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.

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	are healthcare professionals who assist people with worries about coping and living with cancer (mental health).
Social workers	are healthcare professionals who provide practical and emotional support to people living with cancer.

Visit the <u>Head and Neck Cancer Australia website</u> for further information on the health professionals who may be part of your <u>cancer care team.</u>

#### 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 complication 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.

Not all oropharyngeal cancers do the same thing. HPV-related oropharyngeal cancers respond more to treatment than similar cancers caused by smoking. So, the chances of cure for people with any TNM stage oropharyngeal cancer can be very different depending on the cause of their cancer (e.g. HPV or smoking).

The chance of cure depends on both the type of cancer and the stage. It is important to know that most patients with advanced oropharyngeal 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 OROPHARYNGEAL CANCER

Following a diagnosis of oropharyngeal cancer, your <u>cancer care team</u> will discuss the treatment options that are suitable for you, including the possibility of participating in a clinical trial that is suitable for you. This is also a good time to consider if you would like a **second opinion**.

The most appropriate treatment for oropharyngeal cancer depends on many factors. These include:

- size and location of the cancer
- whether the cancer has spread
- whether the cancer is caused by smoking or HPV
- personal factors (e.g. age, general health and treatment history)
- treatments available (and whether any clinical trials are available)
- your preferences for treatment.

There are three types of treatment available for oropharyngeal cancer. These include:

- Radiation therapy
- Chemotherapy
- Surgery

For many people there may be more than one treatment option that gives approximately the same chance of curing the cancer. Each treatment option has its advantages and disadvantages. Generally, people with curable oropharyngeal cancer may be offered one of two treatment options. These include:



- **Definitive radiation therapy** either on its own or at the same time as chemotherapy (concurrent chemoradiation)
- Surgery which depending on the pathology results, may need to be followed by a course of radiation therapy (adjuvant radiation therapy); either on its own or at the same time (concurrent) as chemotherapy

#### **RADIATION THERAPY**

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

- **Definitive radiation therapy:** This is the main treatment for oropharyngeal cancer. It is used without surgery to cure oropharyngeal cancer. Typically radiation therapy is delivered daily (but not on weekends) for 7 weeks. Sometimes chemotherapy is added to the radiation therapy (chemoradiation) to make it more effective.
- 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. It usually starts about 4 weeks
  after surgery to allow recovery from surgery. Radiation therapy treatment usually lasts for
  about 6 weeks. Sometimes chemotherapy is added to the adjuvant radiation therapy
  (chemoradiation) to make it more effective.
- Palliative radiation therapy: In cases where a cure is not possible, radiation therapy is used
  to relieve symptoms of advanced oropharyngeal 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: If you are having radiation therapy for advanced stage oropharyngeal
  cancer, dental extraction may be needed to remove any broken or infected teeth before
  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:
  - O 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 and monitor any side effects that you may have. About 12 weeks after your last radiation therapy session, your doctor will usually order a PET scan to make sure the cancer has completely gone. If the cancer has not gone away after radiation therapy, or comes back in the future, you may still be able to have surgery to try to remove the cancer.



Your doctor may recommend some specific supportive care options to help you during your treatment and recovery. Further information about supportive care is available on the website.

#### **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:

- Definitive: Sometimes chemotherapy is added to definitive radiation therapy
   (chemoradiation). It is usually used for advanced stage oropharyngeal cancers. This may be
   given once every 3 weeks or once a week throughout the duration of radiation therapy.
   Although chemotherapy makes the radiation more effective at destroying cancer cells, it may
   also lead to increased side effects for most patients.
- Adjuvant: This is when chemotherapy is given after surgery, usually in combination with
  radiation therapy (called concurrent chemoradiation). This may be given once every 3 weeks
  or once a week throughout the duration of radiation therapy. Although chemotherapy makes
  the radiation more effective at destroying cancer cells, it may also lead to increased side
  effects for most patients.
- 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.
- Palliative chemotherapy: This is used when the cancer is incurable. The cancer may be too
  large or has spread too far 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 medications used and the dose. The most common medicines used are called cisplatin, carboplatin and 5-flurouracil (5-FU).

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.

Once your treatment ends, 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 supportive care to help during your recovery. Further information about <u>supportive care</u> is available on the website.



#### **SURGERY**

There are a number of different operations that can help treat oropharyngeal cancer. If surgery is recommended, the type of operation will depend on the person and their cancer.

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 help 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 in combination with chemotherapy (chemoradiation), which is typically started about 4 weeks after surgery to allow recovery and for planning purposes. The treatment itself usually lasts about 6 weeks.

#### **SURGICAL PROCEDURES**

The different surgical options for oropharyngeal cancer include:

- Trans-oral robotic surgery (TORS): Sometimes, oropharyngeal cancers can be removed through the mouth without any external cuts using a robotic system or by using laser surgery
- **Neck dissection:** For most patients, TORS may be combined with an operation to take out lymph nodes from the neck (neck dissection). Even if there are no signs of cancer in the lymph nodes on the scans, there is a risk of microscopic cancer cells in the lymph glands in the neck. Neck dissection is often carried out on one side of the neck but some people may need surgery on both sides.
- Mandibulotomy: surgery for oropharyngeal cancer may need to be more extensive in some
  patients. This can be because the cancer is too far back to remove through the mouth or
  because it is very large. A mandibulotomy involves cutting the jaw bone to allow better
  access to the cancer in the throat. The jaw is put back together at the end of the operation
  with titanium plates.
- Free flap reconstruction: in people, who have had a large area of tissue taken out, they may need reconstructive surgery. This involves taking skin and its blood supply from another part of the body and using that skin to cover the throat. This operation is carried out by a surgeon who specialises in reconstructive surgery, your head and neck surgeon or another surgeon.



- Tracheostomy: most people having major surgery for oropharyngeal cancer with a free flap reconstruction will also need a temporary 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.
- **Gastrostomy:** 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).
- Nasogastric feeding: 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 oropharyngeal 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.



Possible side effects depend on the surgical approach that best suits your individual cancer. This includes whether you need to have lymph nodes removed from the neck and whether you need tissue taken from another part of your body to fix the area where the cancer was taken out. Your treating team will talk about the type of surgery they will do in more detail and the specific risks that apply to you.

Your doctor may recommend that you receive supportive care to help during your recovery. Further information about <u>supportive care</u> is available on the website.

#### **FOLLOW-UP CARE**

You will need regular check-ups with your cancer care team after treatment for oropharyngeal cancer. This may include a physical exam and checking the nose and throat with a thin, flexible tube with a light and camera (nasoendoscopy).

Some people may also need imaging such as <u>CT</u>, <u>MRI or PET</u> scans during follow-up. Ask your doctors if you need any of these scans. It is important to have follow-up to make sure that if the cancer comes back, it is caught and treated as early as possible. If you have any concerns between appointments you should contact your doctor.

People with smoking-related oropharyngeal cancer have a higher risk of getting another cancer in their head and neck such as the throat or voice box. This is another reason to keep up your follow-up visits to your doctor. People who smoke can reduce the risk of their cancer coming back or getting a new cancer if they quit smoking. Ask your cancer team for advice if this applies to you.

#### **PROGNOSIS**

Prognosis means the chance of recovery and cure. In oropharyngeal cancer the prognosis depends on:

- the HPV status of the cancer
- the stage of the cancer
- whether you smoke.



Staging systems for oropharyngeal cancer can help give a guide to prognosis, but are often not very accurate at predicting the chance of cure for a given person. It is best to discuss your prognosis with your doctor. Usually, if the cancer hasn't come back after 5 years, you would be considered to be cured.

#### 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 AND NUTRITION AND 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 <u>here</u>.

#### SPEECH, VOICE AND 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 AND MOUTH CARE AND 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 or 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 (<u>late effects</u>).

#### 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.

#### 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 oropharyngeal 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 CANCER CARE TEAM

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:

- Exactly what type of cancer do I have? Where is it located?
- Why did I get this cancer? Is it related to the HPV virus?
- What stage is the cancer? What are the chances of cure with treatment?
- What are my treatment options? Which treatment do you recommend for me and why?
- Have you discussed my case at a Multidisciplinary Team meeting and what were the recommendations?
- 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?



- What are the possible side effects of treatment in the short- and long-term? How can they be prevented or managed?
- Will the treatment affect my ability to eat, swallow, or speak? Will I need a feeding tube?
- What will happen if I don't have any treatment?
- How much will the treatment and/or operation cost? Will Medicare or my health insurance cover it?
- What follow-up tests will I need? How often will they be?
- Am I suitable for any clinical trials?
- What lifestyle changes (diet, exercise) do you recommend I make?
- Who can I call if I have any problems or questions?
- Where can I find emotional support for me and my family? Is there a support group or psychologist you can recommend?
- If I wanted to get a second opinion, can you provide all my medical details?



You may want to write specific questions here to ask your doctor or cancer care team		

#### **About Head and Neck Cancer Australia**

Head and Neck Cancer Australia (formerly Beyond Five) is Australia's only charity dedicated to providing information and support to people living with head and neck cancer, caregivers, family and healthcare professionals.

Head and Neck Cancer Australia'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.

Head and Neck Cancer Australia supports people through their cancer journey, from diagnosis to treatment and life after cancer by providing comprehensive, easy to understand and easy to access information. We have the only Directory of Head and Neck Cancer services and support groups available in Australia and New Zealand helping people to find the right services and support when they need it most.

Phone: 1300 424 848

Email: <a href="mailto:contact@headandneckcancer.org.au">contact@headandneckcancer.org.au</a>
Web: <a href="mailto:www.headandneckcancer.org.au">www.headandneckcancer.org.au</a>

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First Published: 2016

Last updated: September 2020