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WHAT ARE THE SALIVARY GLANDS?

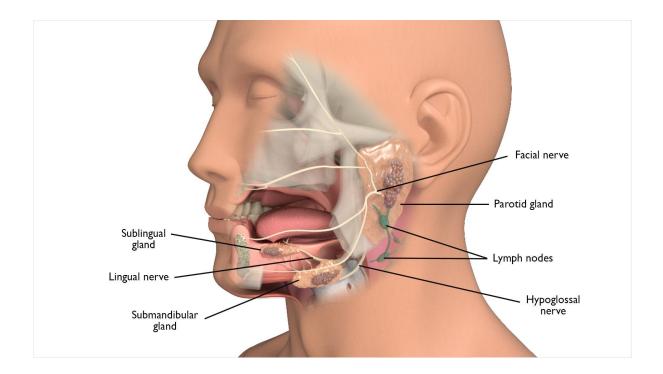
The salivary glands make spit (saliva) and releases it into the mouth to keep the mouth and throat moist and help with swallowing and digesting food.

There are major (large) and minor (small) salivary glands. There are three pairs of major salivary glands called:

- parotid
- submandibular
- sublingual

The minor salivary glands are found inside the mouth, just under the surface including the lips, cheeks and top of the mouth (soft palate).

This diagram shows parts of the salivary glands and the surrounding regions



PAROTID GLAND



The parotid glands are found just in front of the ears and behind the jaw. They move saliva into the mouth through a tube called the **parotid duct**. This tube opens on the inside of the cheek, near the upper molar teeth. The nerve that controls the facial muscles (called the facial nerve), runs through the parotid gland. This nerve makes you smile, frown, close your eyes and raise your eyebrows.

The parotid gland is the largest salivary gland and where most salivary gland cancers occur. The parotid glands also contain lymph nodes (bean shaped glands that are part of the immune system's defence against infections). Sometimes, <u>skin cancers</u> can spread to the lymph nodes inside the parotid glands. Most parotid gland tumours are not cancers and are called benign tumours.

SUBMANDIBULAR AND SUBLINGUAL GLANDS

The submandibular glands lie under the jawbone, one on each side. They release saliva into the mouth through a duct (tube) that opens in the floor of the mouth, under the tip of the tongue. Three important nerves are found next to these glands – the hypoglossal nerve, lingual nerve and marginal branch of the facial nerve. These nerves give movement, feeling and taste to the tongue and move the lower lip. Tumours of the submandibular gland can be benign (not cancer) or malignant (cancer).

The sublingual glands lie under the tongue, one of each side. They release saliva into the submandibular duct and are near the lingual nerves which give feeling and taste to the front of the tongue. The sublingual glands are the smallest of the major salivary glands and rarely develop tumours, but tend to be malignant (cancer) when they do develop.

MINOR SALIVARY GLANDS

There are hundreds of minor salivary glands throughout the mouth and throat. The minor salivary glands can also develop tumours, which can be benign or malignant.



WHAT IS SALIVARY GLAND CANCER?

Cancer occurs when <u>cells</u> 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).

Most salivary gland tumours are not life threatening (malignant) and are called benign tumours. Some benign tumours can become malignant over time. Most salivary gland cancers are found in the parotid glands. The parotid glands contain glands of the immune system (lymph nodes).

Cancer of the parotid glands may either start:

- in the salivary gland tissue (called a primary parotid cancer)
- in the skin and then spread to the lymph nodes in the parotid glands (called a secondary or metastatic cancer).

A small number of salivary gland cancers start in the submandibular, sublingual and minor salivary glands lining the mouth and throat.

There are many different types of primary salivary gland cancer. Each of these cancer types behave differently. Some high-grade salivary tumours spread along nerves or to lymph nodes and to other parts of the body. Low-grade tumours are less likely to spread.

WHAT CAUSES SALIVARY GLAND CANCER?

Doctors often can't explain why a person gets cancer. However, things that may increase the risk of salivary gland cancer include:

- age most salivary gland cancers are in people aged over 50 years
- exposure of the head and neck to radiation therapy
- autoimmune diseases these can lead to a type of cancer in the salivary glands called lymphoma
- skin cancers can spread to lymph nodes in the salivary glands.



Other things, such as using mobile phones and exposure to industrial chemicals, have not been proven to increase the risk of salivary gland cancer.

WHAT ARE THE SIGNS AND SYMPTOMS OF SALIVARY GLAND CANCER?

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

Common signs and symptoms include:

- a lump in front of the ear or in the neck
- drooping on one side of the face
- numbness in the face
- a lump or sore inside the mouth that does not go away
- trouble swallowing or opening the mouth widely.

Most of these are also signs and symptoms of other conditions. However, if you have any of these signs or symptoms for more than a few weeks, speak with your doctor so that they can be looked at carefully.

How is salivary gland diagnosed?

It is important that your doctor establishes the diagnosis of salivary gland 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 symptoms as well as your other health conditions and medications (called a medical history)
- feel and look at your face, scalp, mouth and neck (called a physical examination)
- order some tests including scans (called diagnostic tests)

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

Your doctor will recommend the tests that are right for you. Common tests include:



- Nasoendoscopy: 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.
- Biopsy: 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 done 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.
- 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.
- 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 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 the cancer has spread to the lymph nodes or
 elsewhere in the body.
- <u>Ultrasound scan:</u> this uses sound waves and helps your doctor to see salivary gland cancer. An ultrasound scan can show if a lump is solid, cystic (full of fluid) or a combination of the two. Ultrasound scans are often used to guide a needle biopsy and to look at lymph nodes.



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 nutrition 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 and 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.

It is important to know that staging of salivary gland cancer may not accurately predict your chance of cure. This is partly because the chance of cure often depends on the type of salivary gland cancer and its grade. One type of salivary gland cancer called adenoid cystic cancer commonly spreads to the lungs, but patients with this cancer may live many years without any problems. Other high-grade salivary cancers are more difficult to treat once they have spread to other parts of the body.

It is important that you discuss the stage and type of your cancer with your doctor to understand what it means for you.

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 SALIVARY GLAND CANCER

Following a diagnosis of salivary gland cancer, your MDT 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 salivary gland cancer depends on many factors. These include:

- Specific type of cancer.
- 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.

Surgery is often the main treatment for salivary gland cancer. This involves cutting the cancer out and, for some patients, taking out the lymph nodes. A week or two after surgery, your pathologist will give a detailed report on the cancer. This will be used by your MDT to decide if you need more treatment to reduce the risk of the cancer coming back. This treatment may be radiation therapy alone or radiation combined with chemotherapy (chemoradiation) and, occasionally, it may be radiation therapy followed by chemotherapy.

Adding another treatment after surgery is called adjuvant therapy. Adjuvant therapy usually starts about 4–6 weeks after surgery so that you have time to recover from your surgery. Adjuvant therapy usually lasts for about 6 weeks.

- Low-grade cancer is usually treated with surgery alone and, usually, the lymph nodes do not need to be removed.
- High-grade cancer usually involves removing the lymph nodes during surgery and
 adjuvant radiation therapy after surgery. Sometimes chemotherapy is added, however,
 this will depend on the features of the cancer, your healthcare team and, sometimes,
 what clinical trials are available.



Salivary gland cancer can cause physical changes while its treatment can cause side effects.

Some of these physical changes and side effects will go away soon after treatment, while others may be long-term or permanent.

SURGERY

There are a number of different types of surgery that can be used to remove salivary gland cancer. The type of surgery used will depend on the size and the location of the cancer.

SURGICAL PROCEDURES:

- Parotidectomy is the removal of the parotid glands (pair of major salivary glands located in front of each ear) and the surrounding tissue.
- Submandibular gland surgery is removal of the submandibular glands (located beneath the floor of your mouth) and some of the surrounding tissue and/or bone.
- **Sublingual gland surgery** is removal of the sublingual glands (located in the mouth) and some of the surrounding tissue.
- Minor salivary gland surgery may be considered when cancer is found on the lips, tongue, mouth, throat, nose or sinuses.
- Facial nerve sacrifice (radical parotidectomy) is removal of facial nerve this nerve controls facial expression. It is performed when a cancer in the parotid glands has spread to surround the facial nerve.
- Lateral temporal bone surgery is the removal of some or all of the bone in the temple and behind the ear. It is used when a cancer in the parotid glands spreads into the ear canal and nearby bone.
- Neck dissection is the removal of lymph nodes from the neck. It is used when cancer of
 the salivary glands has spread to the lymph nodes in the neck or there is a risk of cancer
 in the lymph nodes of the neck. Neck dissection is often carried out on one side of the
 neck only, but some patients require surgery on both sides. There are different types of
 neck dissection. More information on neck dissections can be found here.



- Reconstructive surgery may be considered if you have a large area of tissue removed.
 For salivary gland cancer, reconstructive surgery may involve taking tissue from another part of the body this is called a free flap repair. This procedure may be carried out by a surgeon who specialises in reconstructive surgery, your head and neck surgeon or another surgeon.
- Tracheotomy is used to create an opening (tracheostomy) in the windpipe (trachea), just below your voice box. A tube is then inserted into the opening to allow air to flow in and out when you breathe. It is used in following surgery because swelling may affect your ability to breathe normally. The tube is usually removed within a week of surgery once normal breathing is possible, but it may take longer in some cases.
- **Gastrostomy:** A gastrostomy tube (also called a PEG tube) goes through the skin and the muscles of your abdominal wall into the stomach. A gastrostomy tube 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).
- Dental extraction: tooth extractions may be recommended to remove any broken or infected teeth before radiation therapy. This is important because removal of unhealthy teeth after radiation therapy can cause problems with the jaw bones.

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 salivary gland cancer may lead to a number of side effects, and you may not experience all of the side effects. Possible side effects depend on the surgical approach that best suits your individual cancer and weather you need to have lymph nodes removed from the neck. Speak with your doctor if you have any questions or concerns about treatment side effects.

RADIATION THERAPY

The most common radiation therapy for salivary gland cancer is called <u>external beam radiation</u>. This type of radiation therapy applies radiation from outside the body.

- **Definitive radiation therapy:** This is when radiation therapy is used on its own without surgery to cure salivary gland cancer. It is used in salivary gland cancer when surgery is not a treatment option.
- 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 can be used either on its own or at the same time as chemotherapy (chemoradiation), to make it more effective.
 The decision to give radiation therapy, either alone or with chemotherapy is based on the pathology results after surgery. The aim of adjuvant radiation therapy is to reduce the risk of salivary gland cancer coming back. Not everyone will require adjuvant radiation therapy.
- Palliative radiation therapy: In cases where a cure is not possible, radiation therapy is
 used to relieve symptoms of advanced salivary gland 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.
 - o 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 salivary gland 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.
 - o 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) as an in-patient or outpatient.



• 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
- weight loss

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 <u>supportive care</u> is available on the website.

CHEMOTHERAPY

Chemotherapy works by destroying or damaging cancer cells. For salivary gland 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 salivary gland cancer including:

- Adjuvant chemo-radiation: This is when chemotherapy is given after surgery and is
 usually combined with radiation therapy (chemoradiation). It is usually given once a
 week during radiation therapy. Adding chemotherapy makes the radiation more
 effective at destroying cancer cells, but also leads to increased side effects for most
 patients.
- Neoadjuvant chemotherapy: This is when radiation therapy is given before surgery or radiation therapy. It is used to shrink large cancers so they are easier to remove during surgery or target with radiation therapy. Neoadjuvant chemotherapy is rarely used for salivary gland cancer.
- Palliative chemotherapy: This is given when the cancer is incurable, because the cancer is too big or has spread too far to be removed by surgery. Even if a cancer is incurable, some patients feel better from palliative chemotherapy as it slows the growth of the cancer, and can relieve or prevent symptoms.

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 medicines 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.

- ulcers on the lining of the mouth and throat
- a feeling of wanting to vomit (nausea) and vomiting
- loss of feeling in the fingers and toes
- ringing in the ears (tinnitus), or hearing loss
- rash
- change in taste
- hair loss or thinning
- higher risk of infection (if the chemotherapy reduces the number of white cells in the blood)
- low levels of red blood cells, sometimes requiring a blood transfusion.

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.

Your oncologist is able to provide you with detailed information about the side effects you might expect for the exact type of chemotherapy that is prescribed for you.

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.

FOLLOW-UP CARE

You will need regular check-ups of your face, mouth, throat and neck after treatment for salivary gland cancer.

Some patients may need imaging using <u>CT. MRI and PET</u> scans; however, most patients with salivary gland cancer won't need this. It is important to see your cancer care team for regular follow-up visits 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. Ask your doctor whether this is needed for you.

People with smoking-related salivary gland 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 salivary gland cancer the prognosis depends on:

- the type of cancer
- the stage of the cancer
- whether you smoke.

Staging systems for salivary gland 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.

Having a good diet can help you:

- get through treatment
- reduce the chance you will get an infection and be admitted to hospital.
- recover more quickly after treatment.
- 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 or smoothies. 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 or try to eat soft foods.

WHERE CAN I FIND SUPPORT?

Your dietitian is an expert in food and nutrition who will help you with your diet and maintaining weight. 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 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 (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.

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 salivary gland 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 <u>beyondblue</u>.

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: contact@headandneckcancer.org.au
Web: www.headandneckcancer.org.au

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First Published: 2016

Last updated: September 2020