



Understanding Head and Neck Cancers

A guide for people with cancer,
their families and friends

Cancer
information

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13 11 20



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Check the publication date above to ensure this copy is up to date.

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This booklet is funded through the generosity of the people of Australia.

Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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About this booklet

This booklet has been prepared to help you understand more about head and neck cancers, a general term for a range of cancers in the mouth, nose, throat and neck areas. Specific head and neck cancers are named after the area where they start – for example, oral cancer, nasal or paranasal sinus cancer, salivary gland cancer, pharyngeal cancer, and laryngeal cancer.

As the experience for every person with a head and neck cancer is different, you need to discuss your treatment options with your doctors. However, the information in this booklet may answer some of your questions and help you think about what to ask your treatment team (see page 78 for a question checklist).

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This information was developed with help from a range of health professionals and people affected by a head and neck cancer. It is based on international and Australian clinical practice guidelines for head and neck cancers.¹⁻³

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council
13 11 20**

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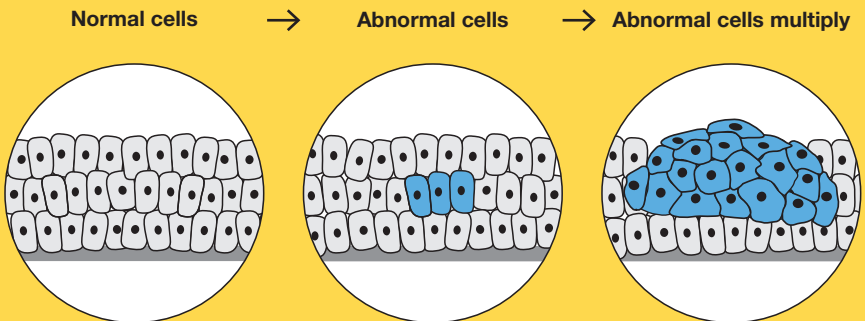
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as head and neck cancers, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

How cancer starts

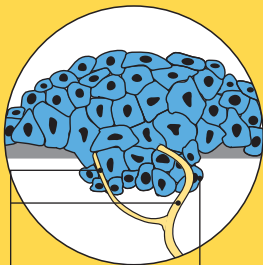


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, oral cancer that has spread to the lungs is called metastatic oral cancer, even though the main symptoms may be coming from the lungs.

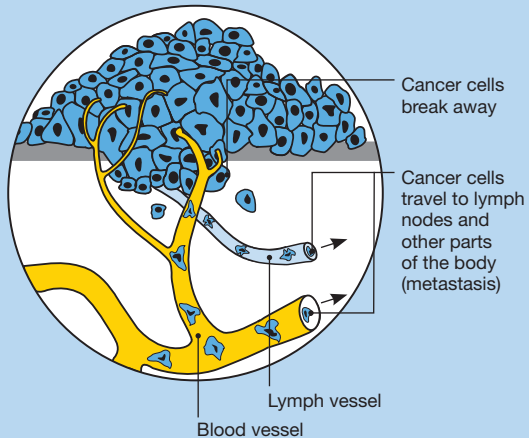
How cancer spreads

→ Malignant cancer



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue





What are head and neck cancers?

Head and neck cancer is a general term for a range of cancers that start in the tissue or lymph nodes in the head and neck area. This region includes the mouth, tongue, palate, gums, salivary glands, tonsils, throat (pharynx), voice box (larynx), nose and sinuses.

Only malignant tumours are cancer. Some tumours in the head and neck are benign (not cancer).

Most head and neck cancers start in the cells that line the moist surfaces of the mouth, nose or throat (squamous cells). These are called squamous cell carcinomas (SCC). Some head and neck cancers start in glandular cells. Many of these are called adenocarcinomas. Squamous cell carcinomas and adenocarcinomas can also occur in other parts of the body.

Other cancers in the head and neck area

Cancer can start in the brain, eye, oesophagus, thyroid gland, skin and scalp. It can also start in the bone or muscle of the head and neck. These cancers are not usually classified as head and neck cancer.

Sometimes a cancer first appears as an enlarged lymph node in the neck. This looks like a lump in the side of the neck. Because this may be the first sign of a head and

neck cancer, the primary tumour must be looked for in the mouth and throat. Cancer from elsewhere in the body (for example, stomach cancer) can also spread and cause an enlarged lymph node in the neck. This is not a head and neck cancer.

For details about other cancers, call Cancer Council **13 11 20**, or see the relevant *Understanding Cancer* booklet.

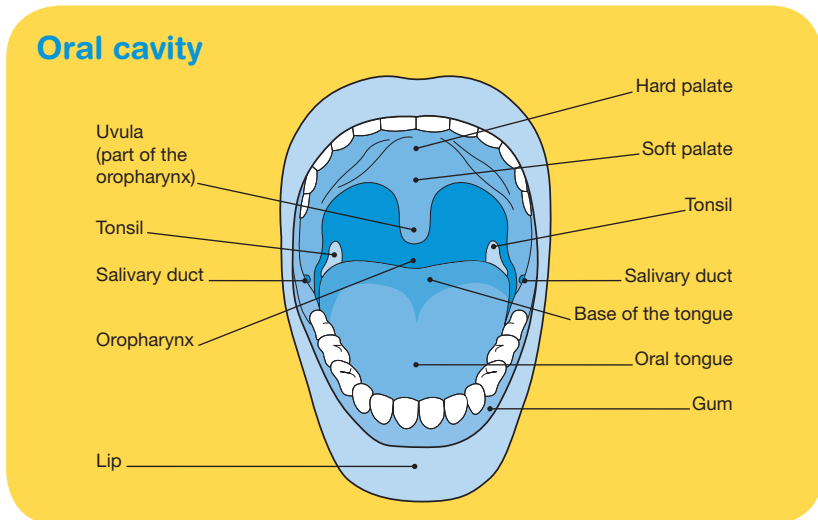
Types of head and neck cancers

Cancers of the head and neck are categorised by the area of the head or neck where they begin.

Mouth (oral cavity)

The mouth, also called the oral cavity, includes the lips, tongue and gums. The muscles of the base of the tongue continue into the upper throat (oropharynx). Cancer that starts in the mouth is called oral cancer.

Cancer can begin in any part of the mouth – the lips, gums, inside lining of the cheeks and lips, front two-thirds of the tongue (oral tongue), floor of the mouth under the tongue, bony roof of the mouth (hard palate), and the small area behind the wisdom teeth. Cancer that starts in the base of the tongue is oropharyngeal cancer (see page 10).

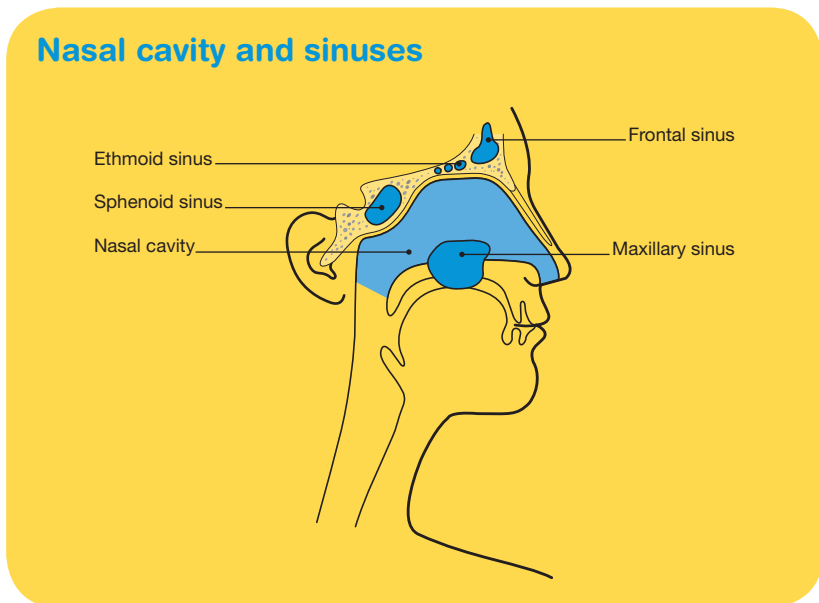


Nasal cavity and paranasal sinuses

The nasal cavity is the large, hollow space inside the nose. This space warms, moistens and filters the air that you breathe. The bones around the nasal cavity have a group of small, air-filled spaces called the paranasal sinuses. These sinuses affect the sound and tone of your voice.

There are four pairs of paranasal sinuses:

- **maxillary sinuses** – under the eyes and in the cheek area
- **frontal sinuses** – behind the forehead
- **ethmoid sinuses** – above the nose and between the eyes
- **sphenoid sinuses** – behind the nose and between the eyes.

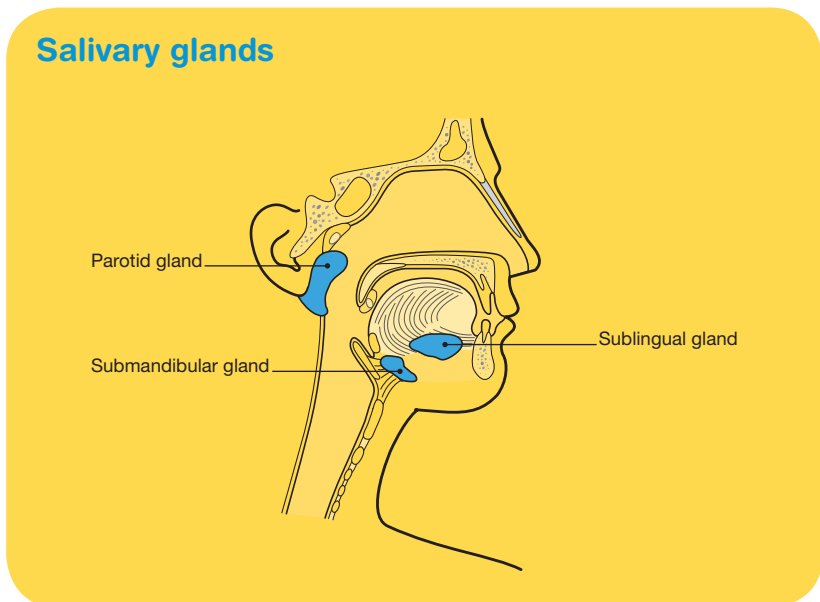


Salivary glands

The salivary glands make saliva. This keeps the mouth moist, helps you swallow food and protects the mouth against infections. There are three pairs of major salivary glands:

- **parotid glands** – in front of the ears
- **sublingual glands** – under the tongue
- **submandibular glands** – under the jawbone.

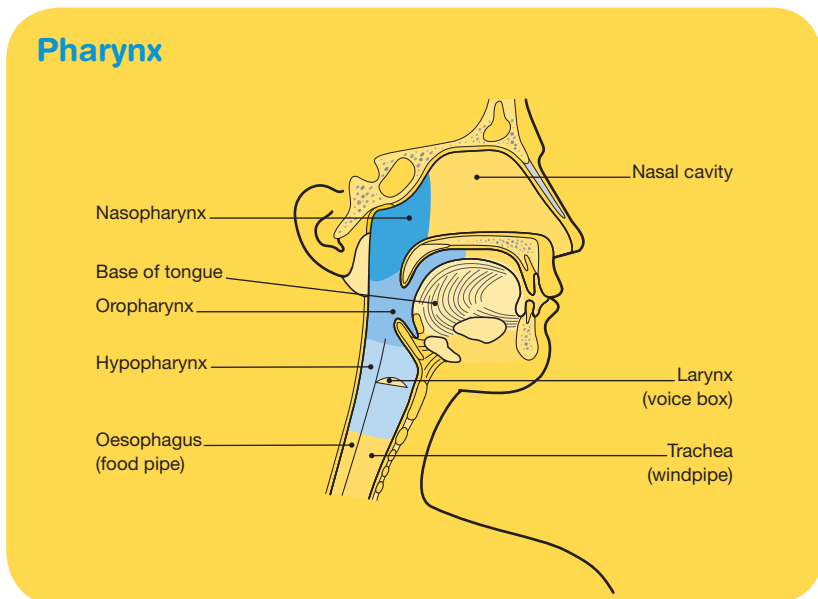
There are hundreds of smaller glands throughout the lining of the mouth and throat. These are known as the minor salivary glands. Most salivary gland cancers affect the parotid glands. Less commonly, the submandibular and sublingual glands are affected.



Throat (pharynx)

The throat, also called the pharynx, is a hollow tube that starts behind the nose and leads to the food pipe (oesophagus) and the windpipe (trachea). Cancer can affect the three parts of the pharynx:

- **nasopharynx** – the upper part, behind the nose and above the soft palate; cancer starting in this area is called nasopharyngeal cancer
- **oropharynx** – the middle part, the area from the soft palate and base of the tongue to the back of the mouth, including the tonsils; cancer starting in this area is called oropharyngeal cancer
- **hypopharynx** – the lower part, around the voice box (larynx); cancer starting in this area is called hypopharyngeal cancer.

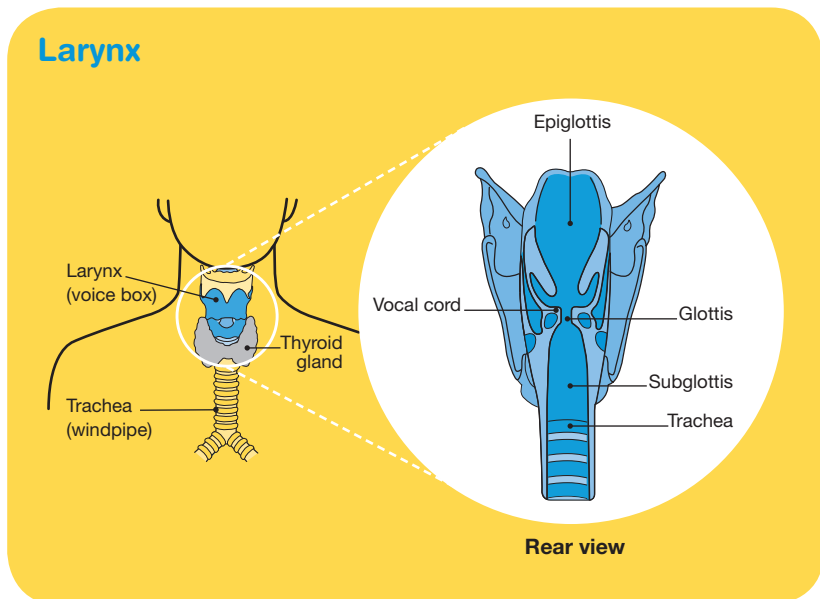


Voice box (larynx)

The voice box, also called the larynx, is a short passageway that connects the lower part of the throat (hypopharynx) with the windpipe (trachea). The thyroid gland is in front of the trachea under the voice box. Cancer that starts in the larynx is called laryngeal cancer.

The larynx includes the:

- **epiglottis** – when you swallow, this small flap of tissue moves to cover the larynx to prevent food going into the trachea and lungs
- **glottis** – the area containing the vocal cords, which vibrate when air passes through them to produce the sound of your voice
- **subglottis** – located below the vocal cords.





Key questions

Q: How common are head and neck cancers?

A: About 4630 people in Australia are diagnosed with a head and neck cancer each year. This includes about 1460 people diagnosed with cancer in the mouth and tongue; 935 with lip cancer; 1055 with pharyngeal cancer; 640 with laryngeal cancer; 330 with salivary gland cancer; and 210 with nasal or paranasal sinus cancer.⁴ Men are about three times more likely than women to develop a head and neck cancer.



For an overview of what to expect during all stages of your cancer care, visit cancerpathways.org.au/optimal-care-pathways/head-and-neck-cancer. This is a short guide to what is recommended, from diagnosis to treatment and beyond.

Q: What are the risk factors?

A: Head and neck cancers are associated with a number of major risk factors. Two of the main risk factors are alcohol and tobacco, and the combined effect of drinking and smoking is significantly greater than the risk of just drinking or just smoking. Known risk factors include:

- drinking alcohol
- smoking tobacco (including cigarettes, cigars and pipes)
- chewing or smoking areca nut, betel nut, pan or gutka
- infection with the human papillomavirus (HPV), especially HPV 16, or the Epstein-Barr virus (EBV)
- being overweight or obese

- older age (being over 40)
- being male
- having a first-degree relative (parent, child or sibling) with some types of head and neck cancer
- being from southern China or South-East Asia (because of cultural practices such as chewing tobacco or eating salty fish)
- breathing in asbestos fibres, wood dust, dry-cleaning solvents or certain types of paint or chemicals
- having a weakened immune system
- sun exposure (for skin cancer of the lip).

Eating adequate amounts of fruit and vegetables may help lower the risk of getting oral and oropharyngeal cancers. Talk to your doctor if you are worried about any of these risk factors.

What is human papillomavirus (HPV)?

HPV is the name for a group of viruses. It is a very common sexually transmitted infection that affects the surface of different areas of the body, including the cervix and skin. Most people will not know they have HPV.

Some types of HPV are linked with the development of cancer. This includes cancers of the mouth and throat (known as oropharyngeal cancers). HPV

in the head and neck area is usually spread through oral sex.

HPV often goes away on its own. If it doesn't go away, it can take many years to develop into cancer. Most people with HPV don't develop oropharyngeal or other types of cancer.

HPV vaccination can reduce the risk of developing abnormal cell changes that may lead to cancer.

Q: What are the symptoms?

A: In their early stages, head and neck cancers may have no symptoms. There are many possible symptoms when they do occur (see below). However, these symptoms can also



Mouth (oral) cancer

- mouth pain or pain when swallowing
- a persistent sore or swelling in the mouth
- unusual bleeding or numbness in the mouth
- red or white patches on the gums, tongue or mouth
- bad breath
- changes in speech or difficulty pronouncing words
- difficulty chewing or swallowing food, difficulty moving the tongue, or limited chewing
- weight loss
- a lump in the neck
- loose teeth, or dentures that no longer fit
- earache or ringing in the ears



Nasal or paranasal sinus cancer

- decreased sense of smell
- a persistent blocked nose, particularly in one nostril, or a blocked ear
- frequent nosebleeds
- excess mucus in the throat or back of nose
- frequent headaches or sinus pressure
- difficulty swallowing
- loose or painful upper teeth
- a lump on/in the face, nose or mouth
- numbness of the face, upper lip, or within the mouth or upper teeth
- pressure or pain in ears
- a bulging or watery eye
- double vision
- complete or partial loss of eyesight

occur with other illnesses, so they don't necessarily mean you have cancer – only tests can confirm the diagnosis. If you are concerned about any of these symptoms, make an appointment with your general practitioner (GP) without delay.



Salivary gland cancer

- swelling or a lump near the ear, jaw or lip, or inside the mouth
- different appearance on each side of the face or neck
- difficulty swallowing or widely opening the mouth
- drooping, numbness or muscle weakness on one side of the face (palsy)



Pharyngeal cancer

- throat pain or difficulty swallowing
- a persistent sore throat or cough
- coughing up bloody phlegm
- bad breath
- weight loss
- voice changes or hoarseness
- dull pain around the breastbone
- a lump in the neck
- pain in the ear or frequent ear infections
- feeling that your air supply is blocked
- numbness of the face
- nasal congestion
- hearing loss
- headache



Laryngeal cancer

- swelling or a lump in the neck or throat
- a persistent sore throat
- a persistent change in the sound of your voice, including hoarseness
- difficulty swallowing or pain when swallowing
- constant coughing
- difficulty breathing
- weight loss
- pain in the ear

Q: Which health professionals will I see?

A: Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist, who will arrange further tests. If head and neck cancer is diagnosed, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting.

Health professionals you may see

ENT (ear, nose and throat) specialist*	treats disorders of the ear, nose and throat
head and neck surgeon*	diagnoses and treats cancers of the head and neck; may be an ENT, general, plastic, or oral and maxillofacial surgeon
oral and maxillofacial surgeon*	treats disorders of the mouth, face and jaws
reconstructive (plastic) surgeon*	performs surgery that restores, repairs or reconstructs the body's appearance and function
dentist or oral medicine specialist*	evaluates and treats the mouth and teeth, which can be affected by cancer treatment
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy
medical oncologist*	treats cancer with drug therapies such as chemotherapy, targeted therapy and hormone therapy (systemic treatment)

During and after treatment, you will see a range of health professionals who specialise in different aspects of your care. It is recommended that complex head and neck cancer is treated in a specialist centre. Call Cancer Council 13 11 20 for information about specialist centres for head and neck cancer in your area. You can also ask Cancer Council about assistance that may be available if you have to travel a long way for treatment.

nurse	administers drugs and provides care, information and support throughout treatment
cancer care coordinator	coordinates your care, liaises with MDT members, and supports you throughout treatment; may be a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
speech pathologist	evaluates and treats communication, voice and swallowing difficulties during and after treatment
dietitian	recommends an eating plan to follow while you are in treatment and recovery
social worker	links you to support services and helps you with emotional, practical and financial issues
counsellor, psychologist	help you manage your emotional response to diagnosis and treatment
physiotherapist, occupational therapist	assist with physical and practical problems, including restoring movement and mobility after treatment, helping with breathing and airway clearance, and recommending aids and equipment

**Specialist doctor*



Diagnosis

If you notice any symptoms, make an appointment to see your GP. You can also mention any mouth sores, swelling or change of colour in your mouth to your dentist.

Your GP or dentist may do some general tests and then refer you to a specialist. Depending on your symptoms, tests will include examinations, tissue sampling (biopsy) and imaging tests. Further tests may be needed to work out whether the cancer has spread. The tests you have will depend on your specific situation.

► Listen to our “Tests and Cancer” podcast episode.

Physical examination

Depending on your symptoms, the doctor will examine your mouth, throat, nose, neck, ears and/or eyes. They may use a thin wooden tongue depressor to see inside the mouth more clearly. The doctor may also insert a gloved finger into your mouth to feel areas that are difficult to see, and gently feel both sides of your neck to check your lymph nodes.

The doctor may use equipment to see some areas of the head and neck, such as the nasopharynx, tongue base and pharynx.

Nasendoscopy

In this procedure, your doctor examines the nose and throat area using a thin flexible tube with a light and camera on the end. This device is called a nasendoscope. Before the nasendoscope is inserted, a local anaesthetic is sprayed into the nostril to numb the nose and throat.

You may find that the spray tastes bitter. The doctor will gently pass the nasendoscope into one of your nostrils and down your throat to look at your nasal cavity, nasopharynx, oropharynx, hypopharynx and larynx. Images from the nasendoscope may be projected onto a screen. This test may feel uncomfortable, but should not hurt.

You will be asked to breathe lightly through your nose and mouth, and to swallow and make sounds. The doctor may also take tissue samples (biopsy, see next page). A nasendoscopy usually takes a few minutes. If you need a biopsy, the test may take longer. You will be advised to not have any hot drinks for about 30 minutes after the procedure, but you can go home straightaway.

Laryngoscopy

This procedure allows the doctor to look at your throat and voice box, and take a tissue sample (biopsy). The doctor inserts a tube with a light and camera on the end (laryngoscope) into your mouth and throat. The camera projects images onto a screen. The procedure is done under a general anaesthetic and takes 10–40 minutes. You can go home when you've recovered from the anaesthetic. You may have a sore throat for a couple of days.



A bronchoscope is similar to a laryngoscope, but it allows doctors to examine the airways to see if cancer is present in the lungs. The tube (bronchoscope) is inserted into the lungs via the mouth and throat. This may be done under a local or general anaesthetic.

Biopsy

A biopsy is when doctors remove a sample of cells or tissue from the affected area, and a pathologist examines the sample under a microscope to see if it contains cancer cells.

The sample may be taken during a nasendoscopy or laryngoscopy. A biopsy can also be taken from hard-to-reach areas using a fine needle to collect the sample. This is often done using an ultrasound or CT scan to guide the needle to the correct place (see pages 22–23). Biopsy results are usually available in about a week. If the cancer can't be diagnosed from the tissue sample, you may have surgery to remove the mass so it can be checked for signs of cancer.

Testing lymph nodes

The lymph nodes in the neck are often the first place cancer cells spread to outside the primary site. If you have a lump in the neck or an imaging scan has shown a suspicious-looking lymph node, your doctor may recommend you have a biopsy.

Under the guidance of an ultrasound or CT, the doctor will insert a fine needle to remove a sample of tissue or fluid from the lymph node. If cancer is found in a lymph node, you may need a neck dissection (see page 32) or other additional treatment. Each case is different and your doctor will explain your treatment options.

👤👤 I had a biopsy done under a general anaesthetic. This showed that it was a squamous cell carcinoma. 👤👤 *Brien (laryngeal cancer)*

Overview of lymph nodes

Lymph nodes, also known as lymph glands, are small, bean-shaped structures that are part of the lymphatic system. They are also a key part of the immune system, which helps protect the body against disease and infection. Lymph nodes are found throughout the body, including in the head and neck area. Most of the lymph nodes in the head and neck region run down the sides of the neck and under the jaw.



● Lymph nodes

Imaging tests

You will usually have at least one of the tests described in this section to provide more details about the location of the tumour and to see if the cancer has spread to other parts of your body.

X-rays – You may need x-rays to check for tumours or damage to the bones. X-rays are quick and painless, and include:

- orthopantomogram (OPG)– used to examine the jaw and teeth of people with mouth cancer
- chest x-ray – sometimes used to check the general health of people with mouth, pharyngeal or laryngeal cancer, or to see whether the cancer has spread to the lungs. However, most people have a CT or PET–CT scan to look at these areas (see pages 22–23).



Before having scans, tell the doctor if you have any allergies or have had a reaction to dyes during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant.

CT scan – A CT (computerised tomography) scan uses x-ray beams to create detailed cross-sectional pictures of the inside of your body. Before the scan, you may have an injection of dye (called contrast) into one of your veins, which makes the pictures clearer. The dye may make you feel hot all over and leave a strange taste in your mouth for a few minutes.

For the scan, you will need to lie still on a table that moves in and out of the CT scanner, which is large and round like a doughnut. The scan itself takes about 10 minutes.

MRI scan – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to create detailed cross-sectional pictures of the inside of your body. A dye may be injected into a vein before the scan to help make the pictures clearer. During the scan, you will lie on a treatment table that slides into a large metal tube that is open at both ends.

The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention this beforehand to your doctor or nurse. You may be given medicine to help you relax, and you will usually be offered headphones or earplugs. MRI scans usually take between 30 and 90 minutes.

PET-CT scan – A positron emission tomography (PET) scan combined with a CT scan is a specialised imaging test. The CT helps pinpoint the location of any abnormalities revealed by the PET scan. A PET-CT scan is usually recommended to help diagnose oral, pharyngeal or laryngeal cancer, or to see if the cancer has spread.

Before the scan, you will be injected with a glucose solution containing some radioactive material. Cancer cells show up brighter on the scan because they take up more glucose solution than the normal cells do. You will be asked to sit quietly for 30–90 minutes as the glucose spreads through your body, then you will be scanned. The scan itself takes about 30 minutes.

Ultrasound – An ultrasound is sometimes used, particularly to look at the thyroid, salivary glands and lymph glands in the neck.

For this scan, you will lie down and a gel will be spread over your neck. A small device called a transducer is moved over the area. The transducer sends out soundwaves that echo when they encounter something dense, like an organ or tumour. The ultrasound images are then projected onto a computer screen. An ultrasound is painless and takes about 15–20 minutes.

🗨️ I was diagnosed with cancer after I felt recurring pain in my front left jaw. I had intrusive surgery, which meant my facial nerve was cut, causing paralysis in my face, but I am currently free of the cancer. 🗨️

Geoff (salivary gland cancer)

Staging head and neck cancers

The tests described on pages 18–23 help show whether you have a head and neck cancer and whether it has spread. Working out how far the cancer has spread is called staging. It helps your health care team recommend the best treatment for you.

In Australia, the TNM system is the method most often used for staging head and neck cancers. TNM stands for tumour–nodes–metastasis. In this system, each letter is assigned a number to describe the cancer.

TNM staging system

T (tumour) 1–4	Indicates the size of the primary tumour. The higher the number, the larger the cancer.
N (nodes) 0–3	Shows if the cancer has spread to nearby lymph nodes. N0 means the cancer has not spread to the lymph nodes; the more nodes affected, the higher the number.
M (metastasis) 0–1	Shows if the cancer has spread (metastasised) to other parts of the body. M0 means the cancer has not spread; M1 means the cancer has spread.

Based on the TNM numbers, the doctor then works out the cancer's overall stage (I–IV). Each head and neck cancer is staged slightly differently. In general, in stages I–II the cancer is small and hasn't

spread from the primary site (early head and neck cancer). In stages III–IV the cancer is larger and has spread to other parts of the body or the lymph nodes (advanced head and neck cancer). If you are finding it hard to understand staging, ask someone in your health care team to explain it in a way that makes sense to you.

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease. Instead, your doctor can give you an idea about the general prognosis for people with the same type and stage of cancer.

To work out your prognosis, your doctor will consider:

- your test results
- the type of head and neck cancer
- the tumour's HPV status
- the rate and depth of tumour growth
- the likelihood of response to treatment
- other factors such as your age, level of fitness and overall health.

These factors will also help your doctor advise you on the best treatment options.

Usually the earlier head and neck cancer is diagnosed, the better the outcome, but people with more advanced head and neck cancer may also respond well to treatment. Oropharyngeal cancers associated with HPV also tend to have better outcomes.



Key points about diagnosis

Main tests

- Your doctor will do a physical examination of your mouth, throat, nose, neck, ears and eyes.
- A nasendoscopy looks for abnormal tissue in the nose and throat area (including the nasal cavity, larynx and pharynx).
- Sometimes people need an examination under general anaesthetic. This is called a laryngoscopy. It allows the doctor to fully examine the throat and voice box for abnormal tissue.
- A tissue sample (biopsy) is removed and a pathologist examines the sample under a microscope to see whether cancer is present and, if so, what type of cancer it is.

Other tests

You may have further tests or scans (including x-rays, CT, MRI and PET–CT scans) to show where the cancer is located and whether it has spread to other parts of the body.

Staging and prognosis

- The cancer will be given a stage to describe how far it has spread in the body. This allows your doctor to recommend the best treatment for you.
- Prognosis is the expected outcome of a disease. In general, earlier stages have better outcomes.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 16) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Should I join a clinical trial?

Your doctor or nurse may suggest you take part in a clinical trial.

Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments

and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

► See our *Understanding Clinical Trials and Research* booklet.

Record the details – When your doctor first tells you that you have cancer, you may not remember everything you are told. Taking notes or recording the discussion can help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 78 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist’s recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

It’s your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

➤ See our *Cancer Care and Your Rights* booklet and listen to our “Making Treatment Decisions” podcast episode.



Julie's story

My cancer was caused by the HPV virus. I hadn't drunk alcohol or smoked for over 30 years.

The treatment from my multidisciplinary team sent the stage IV cancer in my tonsils, throat and tongue into remission.

For a month I had chemotherapy once a week and radiation therapy every day. I had to wear a special mask to keep me totally still while the radiation treatment took place. It is called an "immobilisation mask". The mask keeps you safe by ensuring the radiation is delivered to the precise locations necessary.

I found this aspect of the treatment challenging. I had never seen a mask like this and I had never heard about their purpose. A combination of listening to music, light sedation and support from a psychologist helped a great deal.

I have to be honest, the side effects of treatment were tough. My capacity to swallow

was limited to liquid food for some time, so I lost 20 kg in 6–8 weeks. I lost the capacity to talk for quite a few weeks, and used an iPad to communicate.

But the result made the rigours of treatment absolutely worth the effort. I can talk and swallow, and I am back to work and the joy of daily life.

I really recommend asking for help from speech pathologists, nutritionists, psychologists and senior nurses, as well as the medical team.

Find a dentist who understands the effects of treatment and get advice for the health of your teeth long-term.

Tell your trusted family members and friends what you need and ask directly for help.



Treatment

The main treatments for head and neck cancers are surgery, radiation therapy and chemotherapy. You may have one of these treatments, or a combination. Treatment will be tailored to your specific situation.

Preparing for treatment

Treatment for head and neck cancers can affect your mouth, gums and teeth. Before treatment starts:






See a general dentist or special needs dentist – Have a thorough check-up and ask for an oral health care plan. The plan outlines any dental work you need before treatment starts, and also provides advice on how to care for your mouth before, during and after treatment.

Improve diet and nutrition – People with a head and neck cancer often lose a lot of weight and may become malnourished. A dietitian can suggest ways to maintain your weight by changing your diet or taking special drinks (liquid supplements). This will help improve your strength and lead to better treatment outcomes.

Begin an exercise program – This will help build up the strength needed for recovery. Talk to your doctor about this.

Stop smoking – If you are a smoker, it is important to stop smoking before starting treatment. If you continue to smoke, you may not respond to treatment as well as people who don't smoke. Also, smoking may make side effects worse and increase the chance of a second primary cancer. See your doctor, call the Quitline on 13 7848 or type "Quitline" into your search engine.

Treatment options by type of head and neck cancer

 Mouth (oral) cancer	<ul style="list-style-type: none">• Commonly treated with surgery.• Surgery may be followed by radiation therapy alone or combined with chemotherapy (chemoradiation).
 Nasal or paranasal sinus cancer	<ul style="list-style-type: none">• Commonly treated with surgery.• Surgery may be followed with radiation therapy with or without chemotherapy.
 Salivary gland cancer	<ul style="list-style-type: none">• Surgery is the main treatment. This may include removing some lymph nodes.• Radiation therapy may be given after surgery.
 Pharyngeal cancer	<ul style="list-style-type: none">• Treatment depends on the type of pharyngeal cancer you have.• Options include surgery and radiation therapy (with or without chemotherapy), alone or in combination. Radiation therapy with or without chemotherapy is the most common treatment.
 Laryngeal cancer	<ul style="list-style-type: none">• Early laryngeal cancer is treated with surgery or radiation therapy.• Advanced laryngeal cancer is treated with surgery or radiation therapy (with or without chemotherapy). If surgery is performed first, radiation therapy (with or without chemotherapy) is usually given after surgery to reduce the chance of the cancer coming back.• Surgery may be given after radiation therapy if the cancer comes back or is not all destroyed by radiation therapy.

Surgery

The aim of surgery is to remove cancerous tissue and, as much as possible, preserve the functions of the head and neck area, such as breathing, swallowing and talking. If you have surgery, the surgeon will cut out the tumour and a margin of healthy tissue, which is checked by a pathologist to make sure all the cancer cells have been removed.

The types of surgery used for the different head and neck cancers are described on the following pages. It can be frightening to think about having surgery to your head and neck. Talking to your treatment team can help you understand your situation.

► See our *Understanding Surgery* booklet.

Removing lymph nodes

If the cancer has spread to the lymph nodes in your neck, or it is highly likely to spread, your surgeon will probably remove some lymph nodes. This operation is called a neck dissection or lymphadenectomy. Your surgeon will let you know if this is recommended.

Most often lymph nodes are removed from one side of the neck, but sometimes they need to be removed from both sides. A neck dissection may be the only surgery needed, or it may be part of a longer head and neck operation. The surgeon will make a cut under your jaw and sometimes down the side of your neck. You will often have a small tube (drain) in your neck to remove fluids from the wound for a few days after the surgery. A neck dissection may affect how your neck or shoulder moves and looks. A physiotherapist can help improve movement and function (see also *Lymphoedema* on pages 67–68).



Tony's story

My dentist suspected I had a tumour in my oral cavity during a check-up for a painful wisdom tooth in my lower left jaw. A biopsy confirmed a squamous cell carcinoma. An x-ray, CT scan, ultrasound and PET scan showed the cancer had spread to my lower left jaw bone and the lymph nodes in my upper left neck.

I had surgery to remove the tumour, the affected jaw bone and lymph nodes. Later my jaw was reconstructed with bone from my leg.

I also had radiation therapy to my lower jaw and neck for six weeks. I recovered well. My only ongoing side effect is a dry mouth.

How the surgery is done

If you have surgery for a head and neck cancer, different surgical methods may be used to remove the cancer. Each method has advantages in particular situations – your doctor will advise which method is most suitable for you. The options may include:

- **endoscopic surgery** – uses a long thin flexible tube with a light and camera that is inserted through the nose or mouth so the surgeon can see and remove the cancer; often used for cancers in the nasal cavity, pharyngeal cancers and laryngeal cancers
- **trans-oral robotic surgery (TORS)** – uses robotic arms to reach cancerous areas through the mouth using standard surgical tools, or specialised tools with laser or robotic technology; often used for oropharyngeal cancers
- **open surgery** – involves making cuts in the neck or the lines of the face to reach and remove cancers; used for larger cancers and those in difficult positions. Bones of the upper and lower jaw or skull may need to be partially removed.

Endoscopic and trans-oral robotic surgery usually mean less scarring, a shorter hospital stay and faster recovery. However, these types of surgery are not possible in all cases, and open surgery is often the best option in many situations.

Reconstructive surgery

After open surgery, reconstructive surgery may be needed to restore functions such as eating, talking and breathing, and to improve how the area looks. Some people have reconstructive surgery at the same time as the surgery, others at a later date.

Reconstructive surgery may involve using skin, bone or tissue from another part of the body to rebuild the area. This is called a free flap. Occasionally synthetic materials such as silicone and titanium are used to recreate bony areas or other structures in the head and neck, such as the palate. This is called a prosthetic reconstruction.

Surgery for oral cancer

The type of surgery will depend on the size and location of the cancer. Localised cancers can be treated by removing part of the tongue, mouth or lip. If the cancer is larger, surgery may be more extensive and you may need reconstructive surgery to help you chew, swallow or speak.

Some tumours can be removed through the mouth, but you may require open surgery for larger tumours. Different types of oral surgery include:

- **glossectomy** – removes part or all of the tongue
- **mandibulectomy** – removes part or all of the lower jaw
- **maxillectomy** – removes part or all of the upper jaw (maxilla).

Surgery for nasal or paranasal sinus cancer

Your doctor may advise you to have surgery if the tumour isn't too close to your brain or major blood vessels. The type of surgery depends on the location of the tumour and, if you have paranasal sinus cancer, the affected sinuses. You will often need to also have reconstructive surgery.

Nasal and sinus cancers are often close to the eye socket, brain, cheek bones and nose. Your surgeon will talk to you about the best approach and whether any additional structures need to be removed to get the best outcome. Different types of surgery include:

- **maxillectomy** – removes part or all of the upper jaw (maxilla); may include the upper teeth, part of the eye socket and/or the nasal cavity
- **craniofacial resection** – removes tissue between the eyes in the nasal cavity; often done endoscopically through the nose but a cut along the side of the nose may also be required; sometimes a neurosurgeon will assist with this surgery
- **orbital exenteration** – removes the eye and may also remove surrounding tissue around the eye socket
- **rhinectomy** – removes part or all of the nose
- **endoscopic sinus surgery** – removes part of the nasal cavity or sinuses through the nostrils, using an endoscope.

The surgeon will consider how the operation will affect how you look, and your ability to breathe, speak, chew and swallow. If your nose, or a part of it, is removed, you may get an artificial nose (prosthesis). This will be synthetic or made of tissue from other parts of your body. In some cases, it can take months to complete the prosthetic or reconstructed nose. Your surgeon will guide you about the timing.

Surgery for salivary gland cancer

Most salivary gland tumours affect a parotid gland. Surgery to remove part or all of a parotid gland is called a parotidectomy. The facial nerve, which controls facial expressions and movement of the eyelid and lip, runs through the parotid gland. If this nerve is damaged during surgery, you may be unable to smile, frown or close your eyes. This is known as facial palsy, and it can take months to a year for movement to improve. In some cases, the facial nerve may need to be repaired with a nerve from another part of the body, often from the leg (nerve graft). If the facial nerve is removed (facial nerve sacrifice), there are procedures that can improve the way your face moves and looks, but it will not look or work the same as before the surgery.

If the cancer affects a submandibular gland or sublingual gland, the gland will be removed, along with some surrounding tissue. Nerves controlling the tongue and lower part of the face may be damaged, causing some loss of function. If the cancer is in a minor salivary gland, it may be removed with endoscopic surgery.

Surgery for pharyngeal cancer

Early pharyngeal cancers are often treated with radiation therapy. Surgery may be an option in some cases depending on where the cancer is located in the throat (pharynx). If the cancer is large or advanced and surgery is an option, the surgery is more likely to be extensive and may require reconstruction. It is also often followed with radiation therapy and possibly chemotherapy.

Some tumours can be removed through the mouth, but you may have open surgery for some advanced cancers. Open surgery is done

through a cut in the neck, which may involve the jaw. Different types of pharyngeal surgery include:

- **pharyngectomy** – removes part or all of the pharynx
- **laryngopharyngectomy** – removes all of the larynx and part of the pharynx. This surgery is rare and your treatment team will provide more information about the procedure.

Surgery for laryngeal cancer

If the laryngeal cancer is at an early stage, it may be removed through the mouth using trans-oral surgery. It may take up to six months for your voice to recover. In some cases, there may be long-term or permanent changes to the pitch, loudness or quality of your voice – see page 59 for more details.

If the cancer has advanced, you may need open surgery to remove the larynx (total laryngectomy). This operation removes the whole larynx and separates the windpipe (trachea) from the oesophagus. Following this surgery, you will be breathing through a new hole in the front of your neck called a stoma. This is a permanent change and you will no longer be able to breathe through your nose and mouth. Because this surgery removes your voice box, you won't be able to speak naturally, but you will work with a speech pathologist to learn new ways to communicate (see page 62).

If you have a total laryngectomy, your thyroid gland may also be removed (thyroidectomy). If the thyroid is removed, your body will stop producing thyroxine (T4), the hormone that maintains your metabolism, energy levels and weight. You will be prescribed a hormone tablet, which you will need to take every day for the rest of your life.

What to expect after surgery

How long you stay in hospital will depend on the type of surgery you have and how well you recover. If surgery is minor, recovery is usually fast and there are often few long-term side effects. For more advanced cancer, surgery will be more extensive, lasting eight hours or more, and it will often cause permanent side effects.

Side effects after head and neck cancer surgery vary greatly depending on your age, your general health, how extensive the surgery was and whether you also had reconstructive surgery. Your surgeon can give you a better idea of what to expect after the operation. The side effects listed below are often temporary. For more information about ongoing effects, see the *Managing side effects* chapter, pages 50–69.

Pain – You will have some pain and discomfort for several days after surgery, but you will be given pain-relieving medicines to manage this. You may be given tablets, or you may have patient-controlled analgesia (PCA), which delivers a measured dose of pain relief through a drip when you press a button.

Drips and drains – You may have tubes at the surgery site to drain excess fluid from the wound. These are usually removed after a few days, depending on how much fluid is being collected and the type of surgery. You may also have a tube from your bladder to drain urine into a bag. This is known as a catheter.

Speech changes – Your ability to speak may be affected. This side effect is often temporary, but see page 59 if it is ongoing.

Sore throat – You may have some throat discomfort from the anaesthetic tube. This kind of discomfort or irritation usually lasts less than 24 hours. You may also have a sore throat as a result of surgery for pharyngeal or laryngeal surgery; this is usually short-term.

Breathing difficulties – If your mouth, tongue or throat is expected to be swollen after the surgery, it could make breathing difficult. The surgeon may discuss inserting a temporary tracheostomy in your neck to allow you to breathe (see pages 60–62 for more information). Surgery to the nasal cavity may change the way you breathe through your nose. This may be temporary or longer-lasting.

Eating and drinking – You will usually have a drip to give you fluids. You will start with drinking clear liquids, move on to pureed food, and then soft foods. If eating and drinking is going to be difficult or delayed, a temporary feeding tube may be inserted through your nasal passageway for a few days or weeks. Alternatively, a gastrostomy tube, known as a PEG or a RIG feeding tube, may be inserted into your stomach (see pages 56–57 for more information). If you have reconstructive surgery to your mouth or throat, you may have a feeding tube to allow the free flap to heal.

Movement – Your health care team will encourage you to walk the day of the surgery, or the day after, depending on how extensive your surgery was. Moving around as much as possible will speed up your recovery and reduce the chance of blood clots or infections. The nurse or a physiotherapist will show you how to move around safely. A physiotherapist will teach you breathing or coughing exercises to help keep your lungs clear and reduce the risk of getting a chest infection.

Long-term side effects of treatment

After surgery or radiation therapy, many people have to adjust to significant changes. Everyone will respond differently – talk to your doctor about what to expect and try to see a speech pathologist and/or dietitian before treatment starts.

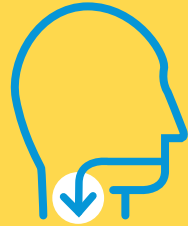


Breathing changes

After some types of throat surgery, you may need help breathing. The surgeon may insert a temporary tracheostomy tube in your neck. If you have a total laryngectomy, you'll need a permanent hole (stoma).

Taste and smell changes

If you have a craniofacial resection, you may lose your sense of smell. Your sense of taste will also be affected. If you have a laryngectomy, air will no longer pass through your nose, which can affect your sense of smell. Surgery in the mouth may also lead to changes in taste.



Swallowing difficulties

Surgery may affect your ability to swallow. A speech pathologist can suggest ways to modify the texture of your food and drink to make them easier to swallow. If you are having difficulty eating or drinking, you may be given a temporary or permanent feeding tube.



Speech or voice changes

Whether you have any changes to how clearly you speak and/or the quality of your voice will depend on the surgery you had. A speech pathologist can provide strategies to help you adjust to these changes.



Appearance changes

Many types of head and neck surgery will cause temporary or permanent changes to the way you look. You may feel distressed or embarrassed about these changes. A reconstructive surgeon is often able to make physical changes (such as scars) less visible. If you have lost teeth, they may be able to be replaced/reconstructed surgically.



Vision changes

If the cancer is in your eye socket, the surgeon may have to remove your eye (orbital exenteration). Your changed vision should not prevent you from continuing activities such as driving or playing sport, but it may take time to get used to the changes.

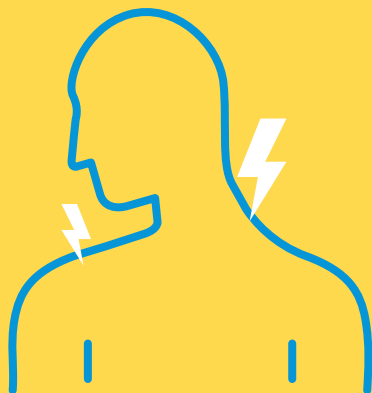
Lymphoedema

If you have lymph nodes removed, you may have persistent swelling in the soft tissue in the head and neck.



Pain and physical discomfort

Sometimes pain in your neck or shoulder lasts longer than a few days after surgery. Your health care team will help you manage this. You may also have numbness, reduced or altered movement, or pain in your neck and shoulder on the side of the surgery. A physiotherapist can help you regain movement, however, any numbness may last for many months or be permanent.



More information: See the *Managing side effects* chapter, pages 50–69.

Radiation therapy

Also known as radiotherapy, this treatment uses a controlled dose of radiation to kill or damage cancer cells. The radiation is targeted at the cancer, and treatment is carefully planned to do as little harm as possible to healthy body tissue near the cancer. Radiation therapy can be given externally or internally, but for head and neck cancers it is usually given externally.

Radiation therapy can be used on its own as the main treatment for pharyngeal and laryngeal cancers, especially to preserve important functions such as speech, swallowing and breathing.

When radiation therapy is used after surgery (adjuvant treatment), the aim is to eliminate any cancer cells that may not have been removed during surgery and reduce the chance of the cancer coming back. You will probably start radiation therapy as soon as your wounds have healed and you've recovered your strength, usually within six weeks. Adjuvant radiation therapy is sometimes given together with chemotherapy (chemoradiation). This is because chemotherapy makes cancer cells more sensitive to radiation.

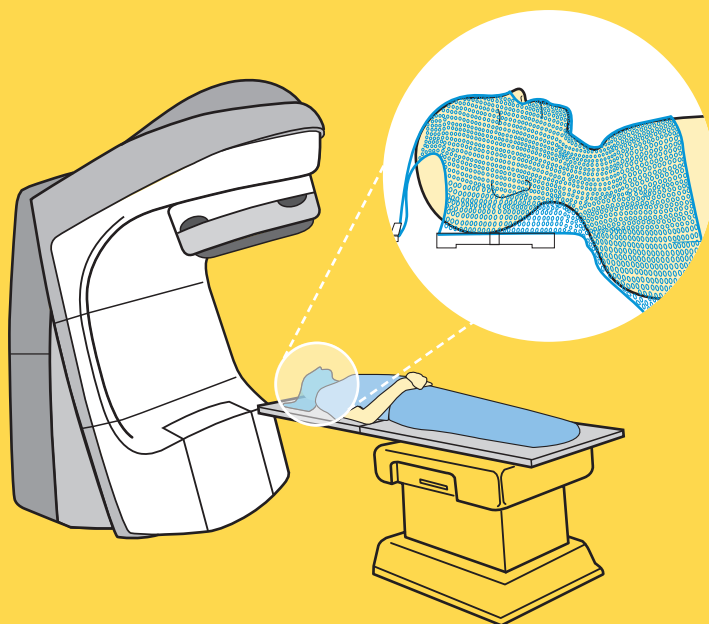
External beam radiation therapy

External beam radiation therapy is commonly used to treat oral, salivary gland, pharyngeal, laryngeal, nasal and paranasal sinus cancers. The treatment can be delivered in different ways, including intensity-modulated radiation therapy (IMRT), volumetric modulated arc therapy (VMAT), and TomoTherapy. These techniques deliver radiation precisely to the affected area, which reduces treatment time and side effects.

Having external beam radiation therapy

Before radiation therapy starts you will be fitted for a plastic mask, called an immobilisation mask. Wearing the mask will help you keep still and ensure the radiation is targeted at the same area during each session. You can see and breathe through the mask, but it may feel strange and claustrophobic at first.

During treatment, you will lie on a table under a machine called a linear accelerator. You will wear the mask for 10–20 minutes during treatment (longer during the planning session). Treatment itself is painless and is usually given Monday–Friday as outpatient treatment for 6–7 weeks. You will be monitored by the radiation therapists throughout. Let them know if wearing the mask makes you feel uncomfortable, as this can be managed.



Side effects of radiation therapy

The side effects vary depending on the area treated, the number of treatments, the type of radiation therapy you have and whether it is combined with chemotherapy.

Side effects often peak in the final week of treatment, or shortly afterwards, then start to ease 2–3 weeks after treatment ends. Some side effects may last longer, be ongoing or appear several months or years later. For information about managing side effects, see pages 50–69. The most common short-term and long-term side effects are listed below.

During or immediately after treatment – fatigue, mouth sores, taste changes, loss of appetite, dry mouth and thick saliva, skin redness and burning in the area treated, breathing difficulties, weight loss.

Ongoing or permanent – dry mouth, thick saliva, difficulties with swallowing and speech, changes in taste, fatigue, muscle stiffness, neck swelling, appetite and weight loss, oral thrush, hoarseness, dental problems, difficulty opening the mouth, hair loss.

Some people find that food and fluid goes into the windpipe instead of the food pipe. This is called aspiration and it can block the airways and cause difficulty breathing (see pages 54–55). Some people develop an underactive thyroid (hypothyroidism) and may need to take thyroid hormone replacement tablets after radiation therapy (see page 37).

➤ See our *Understanding Radiation Therapy* booklet.

Osteoradionecrosis

Radiation therapy to the head and neck can damage blood vessels, causing bone in the lower jaw to die. This is called osteoradionecrosis (ORN).

ORN affects around 5–7% of people who have radiation therapy to the head and neck. It can occur months or years after treatment.

Having any necessary dental work before treatment starts reduces the risk of ORN.

Treatment may include antibiotics, other medicines or surgery. To help the bone heal, you may also have hyperbaric oxygen treatment (breathing in concentrated oxygen in a pressurised chamber.)

Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells while causing the least possible damage to healthy cells. You will probably receive chemotherapy by injection into a vein (intravenously) at treatment sessions over several weeks.

Chemotherapy may be given for a range of reasons:

- in combination with radiation therapy (chemoradiation), to increase the effects of radiation
- before surgery or radiation therapy (neoadjuvant chemotherapy), to shrink a tumour
- after surgery (adjuvant chemotherapy), along with radiation therapy, to reduce the risk of the cancer returning
- as palliative treatment to relieve pain and improve quality of life (see page 48).

Side effects of chemotherapy

Chemotherapy can affect the healthy cells in the body and cause side effects. Everyone reacts differently to chemotherapy, and effects will vary according to the drugs you are given. Some people may have few side effects, while others have many. Often, chemoradiation causes more severe side effects than if you have chemotherapy and radiation therapy separately. Your medical oncologist or nurse will discuss the likely side effects with you, including how they can be prevented or controlled with medicine.

Common side effects include tiredness and fatigue; nausea and/or vomiting; tingling or numbness in fingers and/or toes (peripheral neuropathy); changes in appetite and loss of taste; diarrhoea; hair loss; low red blood cell count (anaemia); hearing loss; ringing in the ears (tinnitus); a drop in levels of white blood cells, which may increase the risk of infection; and mouth sores.

Keep a record of the names and doses of your chemotherapy drugs handy. This will save time if you become ill and need to visit the hospital emergency department.

➤ See our *Understanding Chemotherapy* booklet.

Targeted therapy

Targeted therapy drugs affect specific features of cancer cells to block their growth. One targeted therapy drug called cetuximab is available in Australia for squamous cell carcinomas in the head and neck area, when people cannot take the standard chemotherapy drug. Cetuximab is a monoclonal antibody that binds to the surface of

cancer cells and stops them growing and dividing. Cetuximab is given through a drip into a vein. For head and neck cancer, it is used with radiation therapy.

Side effects of targeted therapy

The most common side effects of cetuximab are skin problems (such as redness, swelling, an acne-like rash or dry, flaky skin), mouth sores, tiredness and diarrhoea. Your doctor may be able to prescribe medicine to prevent or treat side effects.

► See our *Understanding Targeted Therapy* fact sheet.

Immunotherapy

Immunotherapy is a type of cancer drug treatment that focuses on using the body's own immune system to fight cancer. Some cancer cells create barriers known as "checkpoints" to block the immune system. Drugs called checkpoint inhibitors help make the cancer cells visible to the body's own immune system. Once the barrier is removed, the immune system can recognise and destroy the cancer.

Nivolumab is a checkpoint inhibitor used to treat some types of advanced head and neck cancer. Nivolumab is usually administered into a vein (intravenously). Pembrolizumab has also been approved to treat squamous cell carcinomas in the head and neck, but is not yet subsidised on the PBS for head and neck cancers (as of August 2019).

Side effects of immunotherapy

The side effects of immunotherapy are caused by an overactive immune system attacking the normal parts of the body. Not everyone



Other targeted therapy and immunotherapy drugs are being studied in clinical trials (see page 27). Talk with your doctor about the latest developments and whether you are a suitable candidate. You may also find it useful to listen to our “New Cancer Treatments” podcast episode.

will experience the same effects. Common side effects include fatigue, skin rash and diarrhoea, but as any part of the body can be attacked by the immune system, other side effects can occur. Early side effects can usually be controlled before they become severe, so let your treatment team know as soon as they appear.

➤ See our *Understanding Immunotherapy* fact sheet.

Palliative treatment

Palliative treatment helps to improve people’s quality of life by managing the symptoms of cancer without trying to cure the disease. Many people think that palliative treatment is for people at the end of their life. However, it may be beneficial for people at any stage of advanced head and neck cancer.

As well as slowing the spread of cancer, palliative treatment can help manage symptoms such as pain and help you live as fully and comfortably as possible. Treatment may include radiation therapy, chemotherapy or other drug therapies.

➤ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets and listen to *The Thing About Advanced Cancer* podcast.



Key points about treatment

Surgery

- Surgery is commonly used to remove head and neck cancers.
- For cancers that are easily accessible, surgery is usually straightforward. Most people recover quickly and manage any side effects well.
- For some head and neck cancers, surgery may be more extensive and lead to long-term side effects.
- Lymph nodes may also be removed during surgery (neck dissection or lymphadenectomy).
- Some people need to have surgery to restore function (reconstructive surgery).

Radiation therapy

- Radiation therapy, used alone or with other treatments, is commonly used.
- Before radiation therapy, you may be advised to see a dentist to reduce the chance of future problems with your teeth and jaw.
- During radiation therapy, you will need to wear a specially made mask to keep you still during treatment.

Drug therapies

- Chemotherapy can be used before or after surgery or radiation therapy, or at the same time as radiation therapy (chemoradiation).
- Targeted therapy may be used for some people with advanced cancer to stop the cancer cells growing.
- Immunotherapy may be used for some types of head and neck cancer to help the immune system fight the cancer.



Managing side effects

It will take some time to recover from the physical and emotional changes caused by treatment for a head and neck cancer. Side effects can be temporary or permanent, and some will require ongoing management and rehabilitation.

This chapter provides information and tips to help you manage common side effects, including changes to eating, speech, breathing, appearance, sexuality and vision, ongoing pain and lymphoedema. If you experience any of these problems, talk to your doctor, speech pathologist or dietitian. For more support, information and referral to services, call Cancer Council 13 11 20.

Mouth problems

Mouth sores and ulcers – Mouth sores and ulcers are a common side effect of chemotherapy and radiation therapy. This is known as oral mucositis. The sores can form on any soft tissue in your mouth, making eating, swallowing and talking difficult. This is usually short-term and goes away as you recover from treatment.

Your doctor can give you medicines to reduce the pain when you eat, drink or speak. Some pain relief medicines can be applied directly to the mouth sores to numb them.

Your dietitian can suggest foods to reduce discomfort. You may need to choose softer foods and nourishing fluids. If you are unable to eat and drink enough to meet your nutritional needs, you may need a feeding tube to support you during recovery (see pages 56–57).

➤ See our *Mouth Health and Cancer Treatment* fact sheet.



How to relieve mouth problems

Mouth sores and ulcers

- Talk to your doctor about mouthwashes or medicines to relieve pain and to help with healing.
- Use a soft-bristled toothbrush and replace it often to reduce infections. Brush gently after meals and before going to bed.
- Suck on ice cubes.
- Avoid rough, crunchy or dry foods (e.g. chips, nuts, toast, crackers). Also avoid vinegar, spices, salty foods, alcohol, very hot or very cold foods and drinks, and citrus or tangy tomato-based food and juice.
- Gargle with ½ tsp salt plus ½ tsp baking soda in a glass of warm water. Use frequently as a mouthwash.
- Use a lip balm to keep your lips moist.
- Tell your doctor or dietitian if you are eating and drinking less because it is difficult to swallow.

Dry mouth

- Ask your dentist about an oral care plan and have regular check-ups.
- Carry a water bottle and have regular sips throughout the day.
- Limit alcohol and caffeinated drinks as these are dehydrating, and avoid smoking.
- Add moisture to meals with extra sauce or gravy.
- Chew sugar-free gum to encourage the flow of saliva.
- Soften food by dipping it into milk or soup, or moisten it with gravy, sauce, cream or custard.
- Take drinks with meals to help soften the food and make it easier to swallow.
- Acupuncture may help to improve dry mouth. Talk to your doctor before trying acupuncture.
- Use artificial saliva, lubricating agents or dry mouth gels available from the chemist. Swirl grapeseed oil in your mouth and then spit out.

Dry mouth – Radiation therapy to the head or neck area can cause dry mouth (xerostomia), which is often long-lasting. This can make chewing, swallowing and talking difficult. A dry mouth can also make it harder to keep your teeth and mouth clean, which can increase the risk of damage to your teeth. See the table on the previous page for some ways to manage a dry mouth.

Taste, smell and appetite changes

Some treatments to the head, neck and mouth area may affect your sense of taste and smell. Treatment may change the way the salivary glands work and affect the flavour of food. Food may taste bitter or metallic, or may not have as much flavour as before.

It is important to try to keep eating well so your body gets the nourishment it needs to maintain your weight. If you lose most or all of your sense of taste, focus on other appealing aspects of food, such as the colours and presentation of the meal. You could try experimenting with different textures and temperatures to make food more enjoyable.

It can take several months for taste and smell changes to return to normal, and this may affect your appetite. If you do not regain your full sense of smell, a speech pathologist may be able to teach you a technique to help you regain your ability to smell. In some cases, taste changes may be permanent.

- ▶ See our *Nutrition and Cancer* booklet and *Understanding Taste and Smell Changes* fact sheet, or listen to our “Appetite Loss and Nausea” podcast episode.



How to manage taste and smell changes

Taste	Smell
<ul style="list-style-type: none">• Add extra flavour to food if you find it tastes bland, e.g. use fresh herbs.• Rinse your mouth before eating to clean any coating from your tongue and help improve taste.• If you smoke, try to quit. Smoking reduces appetite and changes the taste of food. Call the Quitline on 13 7848 for support.• Drink through a paper or plastic straw so the taste of drinks isn't as strong. Metal straws may add a metallic taste.• Stimulate your appetite with aromatic foods and ingredients.• If food tastes "off", rinse your mouth by drinking tea, or eating ice-cream and soft fruits such as watermelon.• Brush your teeth after each meal and use mouthwashes as recommended by your treatment team.• Ask to see a dietitian for more suggestions.	<ul style="list-style-type: none">• If you lose your sense of smell, take precautions such as checking the use-by dates of foods and ensuring that the smoke detectors in your home work.• If food smells bother you, ask your family and friends to cook for you.• Find ways to enjoy food more. Choose foods that are fresh and full-flavoured for a sensation on your tongue.• If smell changes stop you eating enough, you may lose weight. Use nutritional supplement drinks to increase your nutrient intake and help maintain your strength and energy, e.g. Sustagen, Ensure or Resource. These are available from many pharmacies and supermarkets.

Swallowing difficulties

Chewing and swallowing involve your lips, teeth, tongue and the muscles in your mouth, jaw and throat working together. Many people with a head and neck cancer have difficulty swallowing (dysphagia) before, during or after treatment. This may be because of the tumour or the treatments, and it may be short-term or long-term. Being able to swallow is important to ensure you are eating and drinking enough.

Signs that swallowing is difficult include: taking longer to chew and swallow; coughing or choking while eating or drinking; or food sticking in your mouth or throat like a ball.

Surgery to the jaw, mouth or throat areas – This may make chewing and swallowing difficult because tissue has been removed or reconstructed, or because of a dry mouth.

Surgery to the larynx or pharynx – The larynx and epiglottis act like valves and shut off the airway when swallowing so liquid or food don't go into the lungs. Surgery to the larynx or pharynx may cause food to go down the wrong way into the lungs (aspiration). Signs of aspiration include coughing during or after swallowing, increased shortness of breath during or after a meal, and recurrent chest infections. A speech pathologist will help to manage this side effect and give you strategies to help you eat and drink safely.

Radiation therapy – This can cause dry mouth, pain, and changes to the strength of the muscles and nerves used in swallowing. These effects could be worse if you also have chemotherapy at the same time as radiation therapy (chemoradiation).

Swallowing test

You may have a test before and after treatment to look at what happens when you swallow. A speech pathologist uses a movie-type x-ray known as a videofluoroscopic swallow study (VFSS) or modified barium swallow (MBS) to check that foods and liquids are going down the correct way. If more information is needed, you may have a fibre-optic endoscopic evaluation of swallowing (FEES) test during a nasendoscopy (see pages 18–19). The test results will help plan your treatment.



How to manage swallowing difficulties

- See a speech pathologist for ways to change your chewing and swallowing action to help reduce discomfort or food going down the wrong way (aspiration). They can also show you swallowing exercises to complete during treatment and ways to change your posture. To find a speech pathologist, speak with the health care team at your treatment centre or visit speechpathologyaustralia.org.au.
- Continue to eat and drink whenever possible during treatment to keep your swallowing muscles moving and working. This will reduce the likelihood of long-term swallowing problems.
- Ask your doctor for medicines to relieve discomfort when swallowing. Some medicines come as mouth rinses.
- Talk to a speech pathologist about ways to adjust the consistency of food to make it easier to swallow.
- Talk to a dietitian to make sure you are getting enough nutritious food and drinks.
- › See the recipes in *Beyond the Blender: Dysphagia Made Easy*. Visit griffith.edu.au and search for “Beyond the Blender”.

Feeding tube

After surgery or during a course of radiation therapy, you may find eating and swallowing uncomfortable or difficult. A feeding tube may be inserted to help you get the nutrition you need while your throat heals. This tube is usually temporary, but sometimes it is permanent.

A feeding tube can help ensure you stay well nourished and hydrated. It can also help you maintain or gain weight. If you can't swallow medicines, check with your doctor or nurse whether these can also be given through the feeding tube. Your health care team will show you

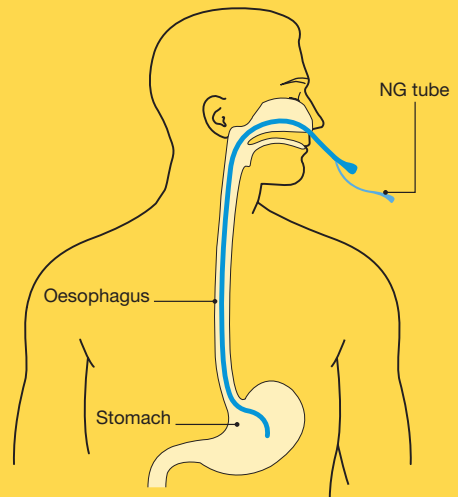
Types of feeding tubes

Temporary feeding tube

A thin tube is put through your nostril, then down the throat and oesophagus into the stomach. This is called a nasogastric or NG tube.

This is usually used if you need a feeding tube for less than 4 weeks – for example, for the first few days or weeks after surgery when you're unable to eat.

The NG tube is usually put in and removed by a doctor or nurse. You will be given specially prepared liquid nutrition through this tube.



Malnutrition and weight loss

The side effects discussed on pages 50–57 may make eating difficult, which can cause you to lose weight. Even a small drop in your weight (e.g. 3–4 kg), particularly over a short period of time, may put you at risk of malnutrition. You can be malnourished even if you are overweight.

Significant weight loss and malnutrition can reduce your strength, energy and quality of life. This can affect how you respond to treatment, and side effects may be more severe and your recovery slower. During treatment and recovery, a dietitian can assess whether a feeding tube will help you maintain or gain weight.

► See our *Nutrition and Cancer* booklet.



How to prevent unplanned weight loss

- Treat food like medicine: something you have to have in order to feel better.
- Eat 5–6 small meals rather than three large ones each day.
- Include high-energy and high-protein foods at every meal or snack. For example, drink milk rather than water and choose cheese and biscuits over lollies.
- Try ready-to-use nutritional supplement drinks. Examples include Sustagen, Ensure and Resource. Many pharmacies and supermarkets sell these specially formulated drinks. You don't need a prescription.
- If you are having trouble swallowing, talk to a speech pathologist for advice on thickening the supplement.
- Keep a selection of snacks handy, e.g. in your bag or car.
- Talk to your doctor, nurse or dietitian if you are losing weight, or if you have pain or discomfort when swallowing.

Changes to speech

The ability to talk can be affected by surgery and radiation therapy, either from the treatment itself or from side effects such as swelling after surgery or a tracheostomy (see pages 60–61). You may lose the ability to speak clearly (dysarthria) or experience changes to your voice (dysphonia). The extent of any changes will vary depending on where the cancer is located and the type of treatment you had.

Talking will take time and practice – it's natural to feel distressed, frustrated and angry at times. You will need to get used to the way your new voice sounds. Use the National Relay Service to make phone calls (visit relayservice.gov.au).



How to manage changes to speech

- Try non-verbal ways to communicate – gesture, point, nod, smile, mouth words, write things down on a notepad or ring a bell to call people.
- Use technology (e.g. a computer, tablet or mobile phone) to write and send notes.
- Work with a speech pathologist to improve your speech and learn strategies for communicating with your family and friends. The speech pathologist may give you some exercises to improve strength and range of motion of the lips, tongue, jaw and larynx.
- Encourage family and friends to be honest if they don't understand you and to learn new ways to communicate with you.
- Speak to a counsellor or psychologist about any problems or frustrations.
- See also *Restoring speech after a laryngectomy*, page 62.

Breathing changes

Depending on the location of the cancer, you may have difficulty breathing. People with nasal cancer may find it hard to breathe through the nose. People with cancers of the throat and larynx may feel it is harder to get air in.

Your surgeon may need to create an alternative airway in the front of your neck to bypass the tumour and help you breathe freely. This is known as a tracheostomy. The surgeon will make a hole in the front of your neck under general anaesthetic and then place a tracheostomy tube through the hole into the windpipe (trachea). You may find the thought of a tracheostomy scary, but being able to breathe easily will make you feel more comfortable.

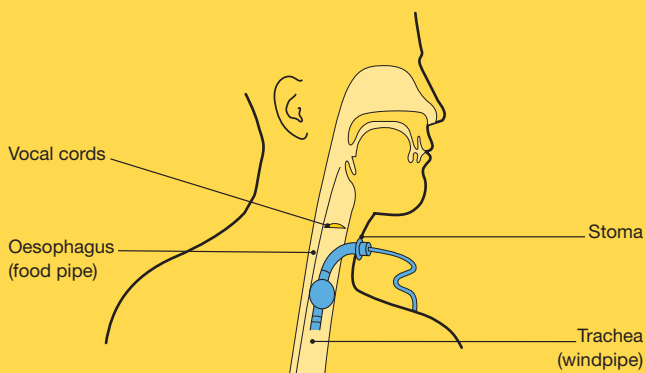
You may have a temporary tracheostomy during radiation therapy or after some types of surgery, particularly when swelling is expected to the mouth and throat. Your surgeon will let you know if this is likely. With a temporary tracheostomy, the tube will usually be removed after a recovery period, and the hole will close up within a few days or weeks. At first your voice may be weak and breathy, but it should return to normal once the hole has healed. A speech pathologist can teach you to speak and assess your swallowing, and a physiotherapist can show you exercises and airway clearance techniques to make breathing easier.

If you have a total laryngectomy, a permanent stoma or breathing hole will be created at the time of the surgery. If you need a permanent stoma, your health care team will discuss this with you and teach you how to look after it.

Types of alternative airways for breathing

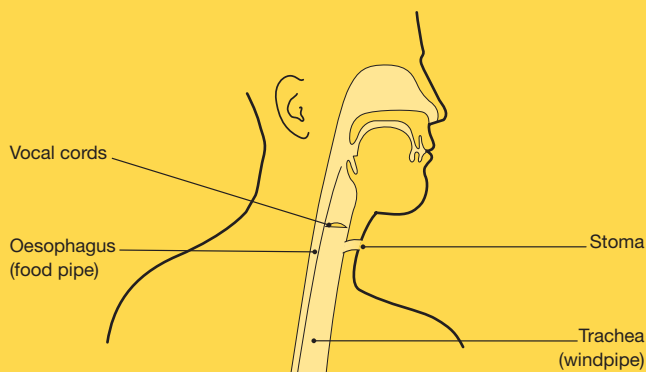
Tracheostomy

A tracheostomy is a surgically created hole (stoma) in your windpipe (trachea) that provides an alternative airway for breathing. A tracheostomy tube is inserted through the hole, and it may be temporary or permanent.



Laryngectomy stoma

A laryngectomy stoma is a permanent opening in your neck that allows you to breathe. It does not require a tube to keep it open, but some people have a laryngectomy tube to keep the hole from getting smaller.



Living with a tracheostomy or stoma

Having a tracheostomy or stoma is a big change and takes some getting used to. Your specialist, nurse or speech pathologist can explain ways to manage the following changes:

- **caring for the tube or stoma** – your health care team will show you how to clean and care for the tracheostomy tube or stoma
- **copng with dry air** – the air you breathe will be much drier since it no longer passes through your nose and throat, which normally moistens and warms the air. This can cause irritation, coughing and excess mucus coming out of the tracheostomy tube or stoma. There are products available that cover the stoma or attach to the tracheostomy tube to provide heat and moisture for the trachea
- **swimming and bathing** – you will need to use special equipment to avoid water getting into the windpipe, even in the shower. If you have a laryngectomy stoma, you may not be able to go swimming.

Restoring speech after a laryngectomy

Mechanical speech – A battery-powered device called an electrolarynx is used to create a mechanical voice. The device is held against the neck or cheek or placed inside the mouth. You press a button on the device to make a vibrating sound.

Tracheoesophageal puncture (TEP) speech – Your surgeon creates a puncture between

your trachea and oesophagus. A small voice prosthesis (or valve) is inserted to direct air from your trachea to the oesophagus. This creates a low-pitch, throaty voice.

Oesophageal speech – You swallow air and force it up through your oesophagus to produce a low-pitched burp. This technique can be difficult and you will need training.

Pain and physical discomfort

Pain – Ongoing pain following surgery or cancer treatment may lead to distress, low mood, fatigue or reduced appetite. These can all affect your quality of life. Speak to your doctor about pain management options.

Your physiotherapist may also give you advice on positioning for comfort, suggest exercises, or recommend other pain relief options such as transcutaneous electrical nerve stimulation (TENS).

- See our *Overcoming Cancer Pain* booklet or listen to our “Managing Cancer Pain” podcast episode.

Stiff neck and shoulder – If you have lymph nodes removed or radiation therapy, you may have stiffness and numbness in your neck, and pain in your shoulder. This may restrict neck movement and make lifting the arm difficult. Nerve damage usually heals within 12 months, and sensation should return for many people. In some cases, these issues can be permanent.

A physiotherapist can help reduce pain and improve posture, movement and function. Your physiotherapist may also suggest using a postural brace for shoulder support. Some regular gentle exercise will help maintain neck, jaw and shoulder range of motion.

Reduced mouth opening – Not being able to fully open the mouth or jaw is known as trismus. It can occur after radiation therapy or surgery, and can affect eating, speech and oral hygiene. Trismus can be temporary or permanent. A speech pathologist or physiotherapist can help improve motion, and you can have medicines to reduce pain.

Changes to appearance

Many types of surgery for head and neck cancers will change the way you look. Common physical changes include: weight loss; tube feeding; having a tracheostomy; and using speech devices. These changes may be temporary or permanent. Other common changes include:

Scars – Improved surgical techniques mean that scarring is unlikely to be significant for most people. Scars from surgery are often hidden in the neck or in skin creases on the face, and usually fade over time.

Face – If your eye or part of the jaw, nose, ear or skin is removed, your face will look different. This is the case for many people who have had extensive surgery for head and neck cancer. Some people will have reconstructive surgery using tissue from another part of the body, which may also change their appearance. Other people may have a prosthesis, which is a soft plastic replacement for the tissue that has been removed (for example, a nose prosthesis). A prosthesis is fitted by a specialist in facial prosthetics and blends in well with your own features. If it is likely you will need a prosthesis, the doctor will discuss this with you before the operation.

Jaw – In some cases, your surgeon will cut through your jaw (mandibulotomy) and reconstruct it with a plate. This involves a cut through your chin and lip, and the scars will be visible for some time.

Swelling – Surgery or radiation therapy can damage lymph nodes and this can cause swelling in the tissues in the head and neck. Sometimes the swelling develops internally and is difficult to see. This swelling is known as lymphoedema (see pages 67–68).

Tips for adjusting to appearance changes

You may be distressed or embarrassed about significant changes to the way you look. You may feel that any noticeable changes make you less attractive and worry that others will reject you.

Give yourself time to get used to any physical changes. Try to see yourself as a whole person (body, mind and personality) and not just focus on the part of you that has changed. Many people find it helps to talk about their concerns with a family member, friend or counsellor.

Talk to your doctors about how surgery and reconstruction will affect your appearance and the possibility of having plastic surgery or a facial prosthesis to rebuild parts of your face and neck. They may be able to suggest strategies to help you cope with the changes and refer you to support services.

You may also like to get in touch with the Look Good Feel Better program. This free two-hour program explains how to use skin care, hats and wigs to help restore appearance and self-esteem during and after treatment. It is aimed at men and women. Visit lgfb.org.au for more information and to book into a workshop.



Fatigue, or feeling exhausted and lacking energy for daily activities, is a common side effect of cancer treatment. It can continue for months or years after treatment ends. For suggestions on how to manage fatigue, call Cancer Council **13 11 20** or talk to your treatment team.

► See our *Fatigue and Cancer* fact sheet or listen to our “Managing Cancer Fatigue” podcast episode.

Impact on sexuality and intimacy

Head and neck cancer can affect your sexuality in emotional and physical ways. You may worry that you are less sexually attractive to partners or you may be grieving the loss of your former body. Reduced interest in sex (low libido) is common during cancer treatment. Tiredness, or anxiety about cancer returning, may also affect your sexual wellbeing.

Surgery to the mouth may reduce sensation in the tongue or lips. This can affect the enjoyment and stimulation from kissing, but sensation should return in 12–18 months. Side effects such as dry mouth, bad breath, poor tongue and lip movement, facial palsy, scars, or a stiff neck and jaw can also make kissing and oral sex difficult or less pleasant.

Surgery to your face and mouth may also cause problems with controlling saliva. If you have a dry mouth, kissing and oral sex may be uncomfortable. If your speech is affected, this may affect your self-esteem and ability to express yourself during sex.

You or your partner may be afraid of having sex if the cancer was HPV-related (see page 13). Research has shown that it is uncommon for long-term partners of people infected with oral HPV to also be infected. New partners may be at risk and may want to use barrier contraception, but in most people the virus is cleared by the immune system.

Some people choose to express their feelings in other ways, such as hugging, holding hands or touching cheek-to-cheek. You may wish to talk to a counsellor or sexual health professional, by yourself or with a partner, to help you find solutions to any sexual changes.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

Vision changes

If the cancer is in your eye socket, the surgeon may have to remove your eye (orbital exenteration). The empty eye socket will be replaced by a sphere of tissue from another part of your body. This keeps the structure of the eye socket.

Later you can be fitted for an artificial eye, which is painted to look like your remaining eye and surrounding tissue. The eye is like a large contact lens that fits over the new tissue in the eye socket.

You will still be able to see with your remaining eye, but your depth perception and peripheral vision will be poorer. Your changed vision should not prevent you from continuing activities such as driving or playing sport, but it may take time to get used to these changes. Before you start driving again, tell your driver licensing authority about the changes in your vision so that they can guide you on any restrictions that may apply. The licensing authority may request information from your doctor to decide if you are medically fit to drive.

Lymphoedema

Lymphoedema is swelling that occurs in soft tissue. If lymph nodes have been removed in a lymphadenectomy or damaged during surgery or radiation therapy, it may prevent lymph fluid from draining properly. This causes fluid build-up and swelling in the neck and face.

People who have had surgery followed by radiation therapy to the neck are more at risk, especially if both sides are treated. The likelihood of developing lymphoedema will also depend on the

number of lymph nodes removed during surgery. Lymphoedema can be temporary or permanent and may change your appearance.

Symptoms of lymphoedema are easier to manage if the condition is treated early. The main signs of lymphoedema include swelling, redness and skin warmth, which may come and go. It is important to look out for these signs and to see your doctor if they appear.

Preventing and managing lymphoedema

Sometimes the swelling and other signs of lymphoedema can take months or years to develop, although some people who are at risk never develop the condition.

Some hospitals have specialist physiotherapists who can teach you simple exercises to reduce your risk of developing lymphoedema or show you ways to manage it if you have developed it. There are also outpatient and private lymphoedema practitioners.

Lymphoedema practitioners can provide education on prevention and provide a personalised treatment program. This may include lymphatic drainage massage, exercises, low level laser therapy, skin care and compression garments, if needed.

▶ See our *Understanding Lymphoedema* fact sheet.



To find a practitioner who specialises in the management of lymphoedema, visit the Australasian Lymphology Association's website at lymphoedema.org.au and click on "Find a Practitioner".



Key points about managing side effects

Common side effects

- People with a head and neck cancer often experience side effects. Some changes are temporary and go away after treatment. Other changes are permanent and need ongoing management and/or rehabilitation.
- Common side effects include mouth problems, changes to eating, breathing and speech, swallowing difficulties and changes to appearance.

Mouth problems

- A dry mouth or mouth sores can make it difficult to eat, drink or speak.
- You may experience changes in taste, smell and appetite. These changes are usually temporary, but some people may lose their sense of smell permanently.
- Difficulty swallowing is common and can be managed using exercises, medicines and diet.
- Tube feeding may be useful if you have difficulties eating. This may be for a few weeks or it may be long-term.

Physical changes

- Surgery may change the way you look. If you find this distressing or embarrassing, speak to a counsellor or psychologist.
- You may have a tracheostomy or stoma to help you breathe. Support is available.
- You may need therapy after surgery to learn how to speak or communicate in other ways.
- Some people get swelling in the neck or face (lymphoedema). A lymphoedema practitioner can show you ways to manage this.



Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.

▶ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

▶ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

▶ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

- See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

- See our *Emotions and Cancer* booklet.

Sexuality – Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

- See page 66 and our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

- See our *Fertility and Cancer* booklet.



Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to “normal life”. It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

► See our *Living Well After Cancer* booklet.

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression.

This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline **13 11 14** or visit lifeline.org.au.

Follow-up appointments

After treatment ends, you will have regular appointments with your specialist to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. You may have blood tests and imaging scans, as well as physical and visual examinations of your head and neck. You will also be able to discuss how you're feeling and any other concerns. You will receive continued support from a speech pathologist, dietitian and physiotherapist if you need it. You may also be asked to see your dentist regularly.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety. Check-ups will become less frequent if you have no further problems. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

What if the cancer returns?

For some people, head and neck cancer does come back after treatment, which is known as a recurrence. This is why it's important to have regular check-ups.

If the cancer is only in the head and neck, you may have surgery to remove the cancer, or you may be able to have radiation therapy, depending on your previous treatment. If you are offered radiation therapy, it may be given with chemotherapy, or you may just be given chemotherapy by itself to try to control the cancer for as long as possible. Your doctor will discuss the types of treatment available to you.



Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

Some states have support groups for people with head and neck cancers. To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ My family members don’t really understand what it’s like to have cancer thrown at you, but in my support group, I don’t feel like I have to explain. ” *Sam*

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit cancercouncil.com.au/OC.



Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Cancer Council Online Community	cancerCouncil.com.au/OC
<i>The Thing About Cancer</i> podcast	cancerCouncil.com.au/podcasts
Australasian Lymphology Association	lymphoedema.org.au
Australian and New Zealand Head & Neck Cancer Society	anzhnCS.org
Beyond Five	beyondfive.org.au
Dietitians Association of Australia	daa.asn.au
Healthdirect Australia	healthdirect.gov.au
Radiation Oncology: Targeting Cancer	targetingcancer.com.au
Speech Pathology Australia	speechpathologyaustralia.org.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Head and Neck Cancer Alliance (US)	headandneck.org
Head & Neck Cancer Guide (US)	headandneckcancerguide.org
Mouth Cancer Foundation (UK)	mouthcancerfoundation.org
The Oral Cancer Foundation (US)	oralcancerfoundation.org
The Swallows Head & Neck Support Group (UK)	theswallows.org.uk
Web Whispers (US)	webwhispers.org



Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

Support services – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

Carers Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

- ▶ See our *Caring for Someone with Cancer* booklet or listen to our “Cancer Affects the Carer Too” podcast episode.



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of head and neck cancer do I have?
- Has the cancer spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this cancer available in this hospital?
- Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Are there any complementary therapies that might help me?
- Will my face or neck have significant scarring or will I look different?
- Will I need to have a tracheostomy or stoma? Will my speech be affected?
- What kind of rehabilitation can I have?

After treatment

- How often will I need check-ups after treatment?
- If the cancer returns, how will I know? What treatments could I have?



Glossary

advanced cancer

Cancer that is unlikely to be cured. In most cases the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes a temporary loss of consciousness.

benign

Not cancerous or malignant.

biopsy

The removal of a sample of tissue from the body for examination under a microscope to help diagnose a disease.

cells

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

chemoradiation

Treatment that combines chemotherapy with radiation therapy. Also called chemoradiotherapy.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or with other treatments.

craniofacial resection

Surgical removal of tissue between the eyes in the nasal cavity.

dysarthria

Difficulty speaking clearly.

dysphagia

Difficulty swallowing.

dysphonia

Difficulty producing voice.

endoscopic surgery

A type of surgery for cancers that can be accessed through the nose or mouth. Tissue is removed using a thin flexible tube with a fine cutting instrument and camera on the end (endoscope).

energy

Energy is obtained from food and drink, and provides fuel for daily activities.

epiglottis

The small cartilage flap that prevents food from going into the food pipe (trachea) when a person swallows.

Epstein-Barr virus (EBV)

A common virus in the herpes family that may increase a person's risk of developing some types of cancer.

ethmoid sinuses

Sinuses located above the nose behind the ethmoid bone in the skull.

external beam radiation therapy (EBRT)

Radiation therapy delivered to the cancer from outside the body.

facial nerve

A major nerve in the skull that controls muscle movement in the face. It runs through the parotid salivary gland.

feeding tube

A flexible tube used to provide liquid nutrition to people having difficulty eating.

frontal sinuses

Sinuses located behind the forehead.

gastrostomy tube

A feeding tube inserted directly into the stomach through the abdomen. Also called a PEG or RIG tube.

glossectomy

The surgical removal of part or all of the tongue.

glottis

The part of the larynx containing the vocal cords.

human papillomavirus (HPV)

A group of viruses that can cause infection in the skin surface of different areas of the body. HPV is a risk factor for some head and neck cancers.

hypopharynx

The lowest part of the back of the throat.

immobilisation device

A device, such as a mask or wedge, that helps keep a person in a fixed position during radiation therapy.

immunotherapy

Treatment that uses the body's own immune system to fight cancer.

intravenous (IV)

Injected into a vein.

laryngectomy

The surgical removal of the larynx. In a partial laryngectomy, part of the larynx is removed. In a total laryngectomy, the whole larynx is removed.

laryngopharyngectomy

The surgical removal of all of the larynx and part of the pharynx.

laryngoscopy

A procedure that allows the doctor to

closely examine the back of the throat, including the larynx and pharynx, using a laryngoscope (a tube with a light on the end) or a mirror.

larynx

The voice box. The larynx is the part of the throat that contains the vocal cords and connects the pharynx with the trachea.

lateral rhinotomy

A cut along the edge of the nose to access the nasal cavity and sinuses.

lymphatic system

A network of vessels, nodes and organs that removes excess fluid from tissues, absorbs fatty acids, transports fat, and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph nodes

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

lymphoedema

Swelling caused by a build-up of lymph fluid. This happens when lymph vessels or nodes can't drain properly because they have been removed or damaged.

malignant

Cancerous. Malignant cells can spread (metastasis) and eventually cause death if they cannot be treated.

malnutrition

An imbalance of energy, protein or other nutrients in the body, which can affect overall health and how the body responds to cancer treatment and recovery.

mandible

The lower jawbone.

mandibulectomy

Removal of part or all of the lower jaw.

mandibulotomy

Cutting the lower jaw to access the mouth or throat.

margin

The edge of tissue removed during surgery. Clear or negative margin means no cancer cells were found on the edge. Positive margin means cancer cells were found on the edge.

maxilla

The upper jawbone.

maxillary sinuses

Sinuses located under the eyes and within the maxillary (cheek) bones.

maxillectomy

Removal of part or all of the upper jaw or hard palate.

mechanical speech

The use of a battery-powered device such as an electrolarynx to create vocal sounds.

metastasis (plural: metastases)

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

nasal cavity

The large, hollow space located behind the nose and in the middle of the face.

nasendoscopy

An internal examination of the nose and upper airways using a long, flexible tube with a light and camera on the end called a nasendoscope.

nasogastric (NG) tube

A plastic feeding tube that is passed through the nose into the stomach.

nasopharynx

The part of the pharynx that lies behind the nose and above the soft palate.

neck dissection

Surgery to remove lymph nodes in one or both sides of the neck. Also called lymphadenectomy.

nutrition

The process of eating and digesting the food the body needs.

oesophageal speech

Forcing air into the top of the oesophagus and then out again to produce a voice.

oesophagus

The food pipe. The passage that carries food from the throat into the stomach.

open surgery

A surgical method where the surgeon makes one large cut (incision) in the body to view and access the organs.

oral cavity

The mouth – includes the lips, gums, cheeks, the roof and floor of the mouth, front two-thirds of the tongue, and the area behind the wisdom teeth.

orbital exenteration

The surgical removal of the eye and other contents of the eye socket.

oropharynx

The part of the pharynx that includes the soft palate, tonsils and tongue base.

orthopantomogram (OPG)

Special x-ray used to examine the jaw and teeth of people with mouth cancer.

osteoradionecrosis (ORN)

A condition in which bone tissue of the jaw breaks down, causing pain or infection.

palliative treatment

Medical treatment for people with advanced cancer to help them manage physical and emotional symptoms.

paranasal sinuses

Small, air-filled spaces within the head that lighten the weight of the skull.

parotidectomy

Surgery to remove a parotid gland.

parotid glands

One of the sets of major salivary glands. They are found just in front of the ears.

percutaneous endoscopic gastrostomy (PEG) tube

A feeding tube inserted directly into the stomach through the abdomen.

pharyngectomy

The surgical removal of part or all of the pharynx.

pharynx

The throat. This is a muscular tube at the back of the nose that connects the mouth and nose with the oesophagus and trachea.

prosthesis

An artificial replacement for a lost or damaged body part.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

radiologically inserted gastrostomy (RIG) tube

A feeding tube inserted directly into the stomach through the abdomen using x-rays or other scans.

reconstructive surgery

Surgery to rebuild an area of the body that has been damaged.

rhinectomy

The surgical removal of part or all of the nose.

saliva (spit)

The watery substance released into the mouth from salivary ducts.

salivary ducts

Small openings in the oral cavity that release saliva into the mouth. The ducts are connected to the salivary glands.

salivary glands

Glands where saliva is made. Includes the parotid glands (front of the ears) and the sublingual and submandibular glands (under the oral cavity).

sphenoid sinuses

The sinuses located at the centre of the base of the skull.

staging

Performing tests to work out how far a cancer has spread.

stoma

A surgically created opening of the body. Also called an ostomy.

sublingual glands

One of the sets of major salivary glands. They are found under the tongue.

submandibular glands

One of the sets of major salivary glands. They are found under the jawbone.

targeted therapy

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread.

thyroid

A butterfly-shaped endocrine gland located at the base of the neck. It produces hormones to control the body's metabolism and calcium levels.

tonsils

Small masses of lymphatic tissue on either side of the back of the mouth that help to fight infection.

trachea

The windpipe. The airway that brings air inhaled from the nose and mouth into the lungs.

tracheoesophageal puncture (TEP)

A surgically created valve between the trachea (windpipe) and oesophagus (food pipe) to create a low-pitched voice.

tracheostomy

Surgery to make a hole at the base of the neck into the trachea (windpipe), which allows you to breathe. A tracheostomy tube will be inserted into this hole to keep it open and allow you to breathe freely.

trans-oral robotic surgery (TORS)

Surgery to remove a tumour using robotic surgical equipment.

trismus

Difficulty opening the mouth fully, with usually less than 2 cm between top and bottom teeth.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

ultrasound

A scan that uses soundwaves to create a picture of part of the body.

vocal cords

The part of the larynx that vibrates to produce the sounds required for speech. Also called the glottis.

xerostomia

Dry mouth.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary

References

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2. National Comprehensive Cancer Network (US), *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): Head and Neck Cancers*, Version 1.2019.
3. V Grégoire et al. on behalf of the EHNS-ESMO-ESTRO Guidelines Working Group, "Squamous cell carcinoma of the head and neck: EHNS-ESMO-ESTRO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 21 (suppl. 5), 2010, v184–186.
4. Australian Institute of Health and Welfare (AIHW), *Cancer in Australia 2019*, AIHW, Canberra, 2019.



How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and other Pink events, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council

13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

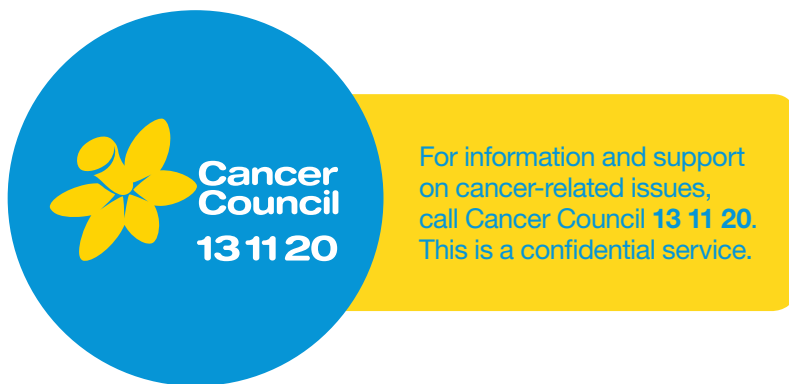
If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*