

# Understanding Head and Neck Cancers

*A guide for people with cancer, their families and friends*



For information & support, call **13 11 20**

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*Understanding Head and Neck Cancers* is reviewed approximately every 2 years.

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

Editor: Wendy Winkler. Designer: Ali Wright. Printer: IVE Group.

## Acknowledgements

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## 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 booklet 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 8 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](http://cancer.org.au) or call your local Cancer Council.



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



**Cancer Council Australia** Level 2, 320 Pitt Street, Sydney NSW 2000 ABN 91 130 793 725  
**Telephone** 02 8256 4100 **Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

# 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 and include lip or oral cavity (mouth, tongue, jaw and gums), pharyngeal (throat and the area of the throat behind the mouth), laryngeal (voice box), nasopharyngeal (area above the back of the throat and behind the nose), nasal cavity or sinus (nose), and salivary gland cancers.

Every person with head and neck cancer has a different experience, so discuss your treatment options with your doctors. The information in this booklet may answer some of your questions and help you with 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. Some medical terms that may be unfamiliar are explained in the glossary (see page 79). 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.<sup>1-3</sup>



If you or your family have any questions or concerns, 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).

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Icons are used throughout this booklet to indicate:



More information



Alert



Personal story



Tips

# What is cancer?

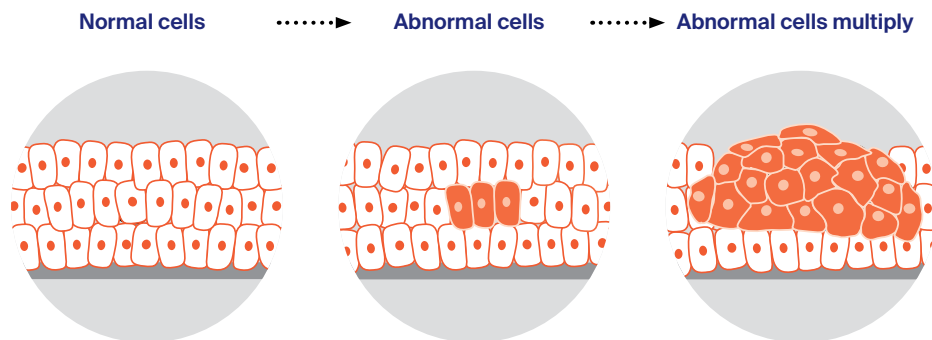
Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

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. These abnormal cells may turn into cancer.

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.

## How cancer starts

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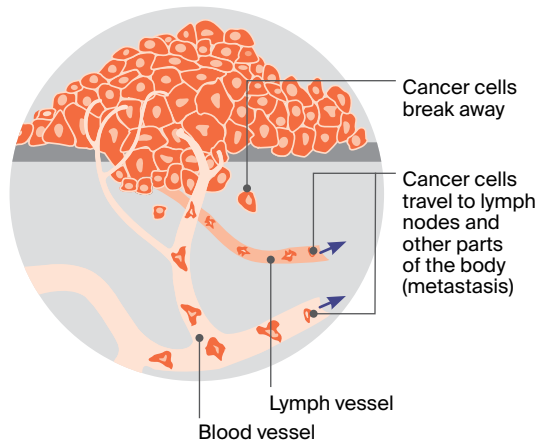
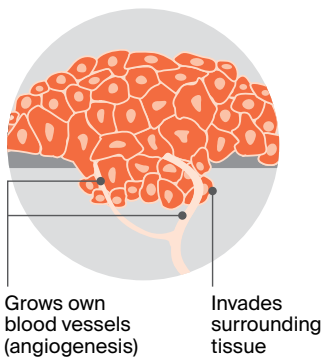


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ 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



# The head and neck

In cancer medicine, the region called “head and neck” includes the:

- **mouth** – made up of the lips and the structures inside the oral cavity, including the tongue, roof of the mouth (the palate), jaw and gums
- **throat** – known as the pharynx
- **voice box** – known as the larynx
- **nose** – made up of the nasal cavity, which is the area inside and behind the nose, and the sinuses
- **salivary glands** – in the floor of the mouth, near the lower jaw and in front of the ear
- **the skin** – on the head and neck.

The thyroid is a hormone-producing gland found at the front of the neck and just below the voice box. Thyroid cancer has a different cause and is managed differently to most head and neck cancers.

► For more information, see our *Understanding Thyroid Cancer* booklet.

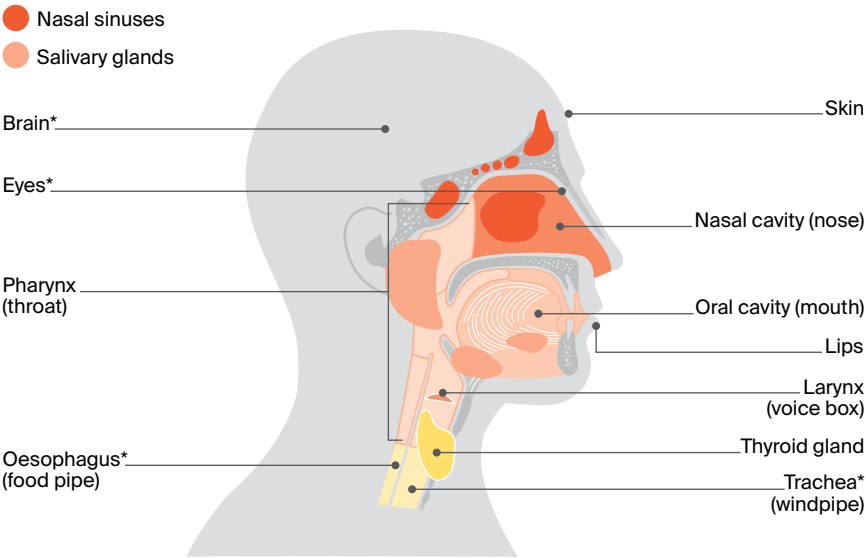
Areas that are not considered part of the head and neck in cancer medicine include the brain, eyes, oesophagus (the food pipe), trachea (the windpipe), and the bones and muscles of the head and neck. These areas may still develop cancer, and they can also be affected by nearby head and neck cancers and their treatment.

**Lymph nodes in the head and neck** – The whole body, including the head and neck, contains many lymph nodes. Lymph nodes are small, bean-shaped structures found throughout the body. They form part of the lymphatic system, which helps protect the body against disease and infection. When cancer spreads, it usually spreads to nearby lymph nodes first.



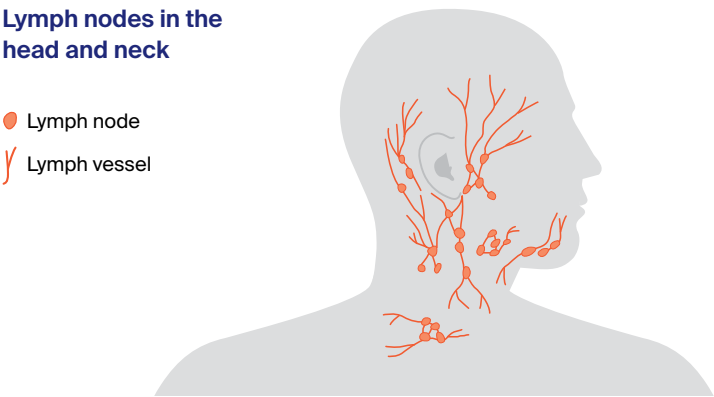
# Anatomy of the head and neck

This diagram gives an overview of the main areas of the head and neck. For more detail, see the diagrams on pages 9–13.



*\* Not considered part of the head and neck region in cancer medicine*

## Lymph nodes in the head and neck



# What are head and neck cancers?

Head and neck cancer is a general term for a range of cancers that start in the head and neck area. About 9 out of 10 head and neck cancers start in the moist lining of the mouth, nose or throat. The lining is called the squamous epithelium, and these cancers are called mucosal squamous cell carcinomas (SCCs). Some head and neck cancers start in glandular cells, and many of these cancers are called adenocarcinomas. SCCs and adenocarcinomas can also occur in other parts of the body.

Non-melanoma skin cancers may also be called head and neck cancers when they start in this part of the body. For more information about these cancers, see our *Understanding Skin Cancer* booklet.

The first sign of many cancers is often a lump under the skin of the neck or cheek. This can happen when cancer has spread to a lymph node. Your doctors will run tests to work out what type of cancer it is. It might be a head and neck cancer or it might be a cancer that has spread from elsewhere in the body. For example, stomach cancer can spread to a lymph node in the neck and will still be considered stomach cancer.

Occasionally, tests show that a cancer in the head and neck started in another part of the body, but it is unclear where it started. This is called cancer of unknown primary (CUP).

► See our *Understanding Cancer of Unknown Primary* booklet.

For details about other cancers, call Cancer Council 13 11 20 or see our other booklets and fact sheets.

## Mouth (lip and oral cavity) cancers

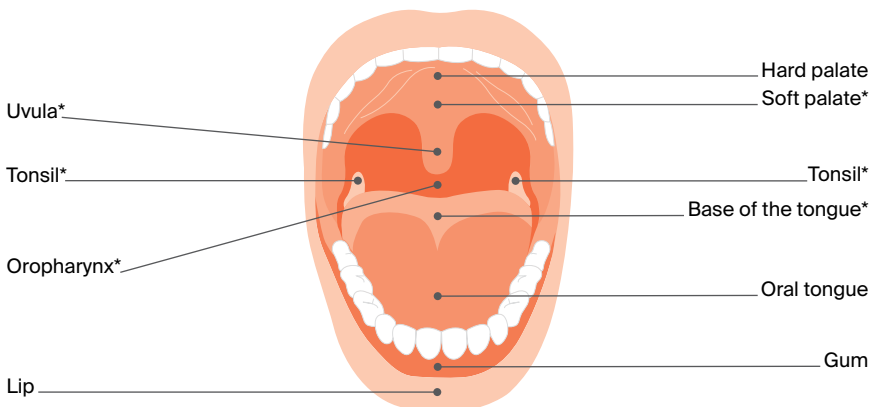
Cancer that starts in the mouth is known as oral cancer. The mouth is made up of the lips and the oral cavity. The oral cavity includes the:

- gums
- lining of the cheeks and lips
- front two-thirds of the tongue (oral or mobile tongue)
- floor of the mouth (under the tongue at the front of the mouth)
- bony roof of the mouth (hard palate)
- small area behind the wisdom teeth (retromolar trigone).

The area at the back of the mouth is called the oropharynx. It includes the base of the tongue, the tonsils, the uvula and the soft palate, as well as the middle section of the throat. Cancer of the oropharynx is known as oropharyngeal cancer (see next page).

### Oral cavity

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*\* Not part of the lip and oral cavity area*

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## Throat (pharyngeal) cancers

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).

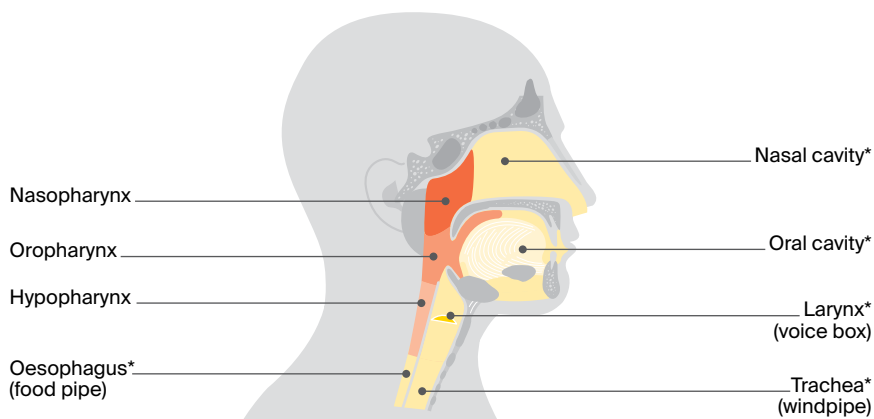
The pharynx has 3 main parts:

- **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.

Cancers in the 3 parts of the pharynx behave differently and are treated differently.

### Pharynx

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*\* Not part of the pharynx*

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## Voice box (laryngeal) cancers

The voice box, also called the larynx, is the entry point to the windpipe (trachea). It contains the vocal cords and protects the lungs. Cancer that starts in the larynx is called laryngeal cancer.

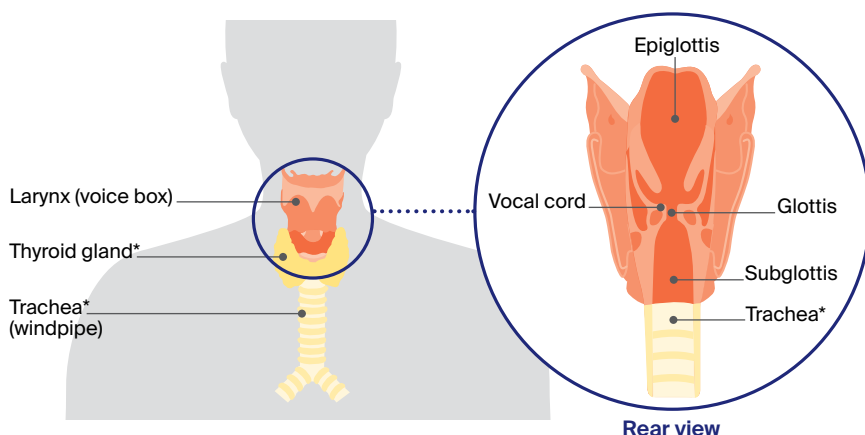
The larynx has 3 main parts:

- **supraglottis** – the area above the vocal cords; includes the epiglottis, a small flap of tissue that covers the larynx when you swallow and prevents food and fluids 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** – the area below the vocal cords leading to the trachea.

The thyroid gland sits in front of the trachea under the voice box. It may be treated by a head and neck doctor, but isn't covered in this booklet.

► For more information, see our *Understanding Thyroid Cancer* booklet.

## Larynx



\* Not part of the larynx

## Nose (nasal cavity and sinus) cancers

The nasal cavity is the large, hollow space behind the nose. It is separated into 2 main cavities by the nasal septum, a thin wall of bone and cartilage in the centre of the nose.

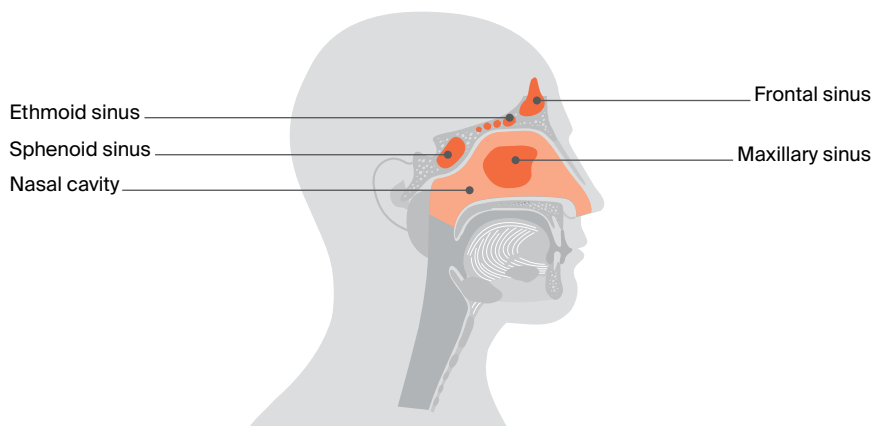
The paranasal sinuses are small, air-filled spaces in the side walls of the nose. They help to warm and moisten air passing to the lungs. They also influence the sound and tone of your voice. There are 4 pairs of paranasal sinuses:

- **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.

Cancer that starts in the upper part of the throat behind the nose is called nasopharyngeal cancer (see page 10).

### Nasal cavity and sinuses

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## Salivary gland cancers

The salivary glands make the watery substance known as saliva. This keeps the mouth moist to help with swallowing and talking, and helps protect the mouth and teeth.

There are 3 pairs of major salivary glands:

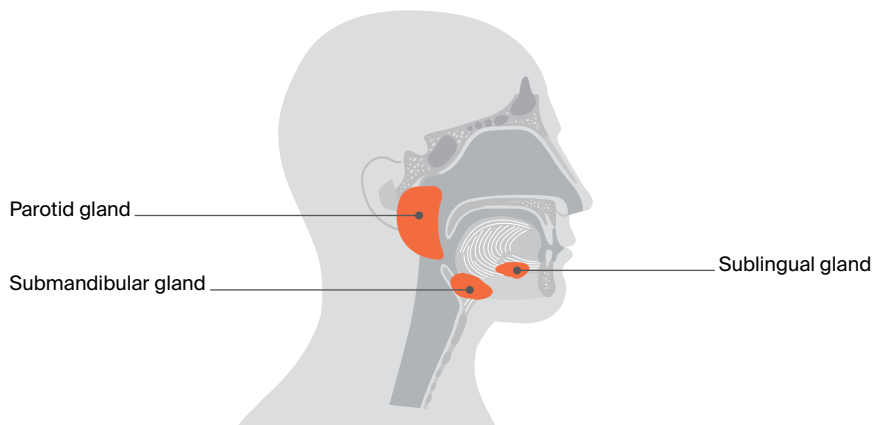
- **parotid glands** – in front of the ears
- **submandibular glands** – under the lower jaw
- **sublingual glands** – under the tongue.

There are also hundreds of smaller glands throughout the lining of the mouth, nose and throat. These are known as the minor salivary glands.

Cancers can start in the major or minor salivary glands. When cancer is found in one of the parotid glands, it may have spread from a skin cancer on the head or neck.

### Salivary glands

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# Key questions

## Q: How common are head and neck cancers?

**A:** Almost 6000 people in Australia are diagnosed with a head and neck cancer each year (excluding skin cancers). This includes about 2100 people with cancer in the mouth or tongue; 1400 with pharyngeal cancer; 570 with laryngeal cancer; 230 with nasal or paranasal sinus cancer; and 360 with salivary gland cancer.<sup>4</sup>

Head and neck cancers are more common after the age of 40. Men are about 3 times more likely than women to develop a head and neck cancer, mainly due to higher smoking and drinking rates (see below). However, the rate of oral cancer in females who don't smoke tobacco is increasing. Aboriginal and Torres Strait Islander peoples are also at increased risk of developing head and neck cancers.

## Q: What are the risk factors?

**A:** The main factors that increase the risk of developing the most common head and neck cancers are:

- smoking tobacco (including cigarettes, cigars and pipes)
- drinking alcohol
- having had human papillomavirus (HPV) (see opposite page).

If you drink *and* smoke, your risk is much greater than if you only drink or only smoke.



For an overview of what you can expect – and what is recommended – at every stage of your cancer care, visit [cancer.org.au/cancercareguides/head-and-neck-cancer](https://cancer.org.au/cancercareguides/head-and-neck-cancer).



Other risk factors account for a smaller proportion of head and neck cancers. These risk factors include:

- having persistent sores or red or white patches in the mouth
- chewing tobacco, snuff, betel nut, areca nut, paan or gutka
- breathing in asbestos fibres, wood dust or certain chemicals
- poor dental health
- having a weakened immune system
- having had radiation therapy to the head or neck area in the past
- having too much sun exposure (for lip cancer and skin cancer)
- having a parent, child or sibling with head and neck cancer (possibly because you have similar lifestyle factors)
- inheriting a condition linked to head and neck cancer (e.g. Fanconi anaemia, Li-Fraumeni syndrome)
- having had Epstein-Barr Virus (also called glandular fever).

Talk to your doctor if you are worried about any risk factors.

## Human papillomavirus (HPV) and cancer risk

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HPV is a group of viruses that affect the surface or lining of parts of the body, including the throat, cervix and skin. It is the most common sexually transmitted infection, and may also be transferred in other ways. About 4 out of 5 people are exposed to HPV in their lifetime and most won't show symptoms or know they've had it.

There are many types of HPV, but only some subtypes are linked to oropharyngeal cancer, which starts

in the tonsils and tongue base. This HPV may be spread through oral sex and kissing.

Most HPV infections are cleared by our immune system. In some people, the virus can lie dormant for years and then cause cancer. We still do not understand why this happens. HPV vaccination can protect you against HPV infection. Talk to your doctor about vaccination or if you are worried about HPV.

## Q: What are the symptoms?

**A:** In the early stages, head and neck cancers may have no symptoms. Many of the symptoms of head and neck cancers are common for other illnesses, so they don't necessarily mean you have cancer – only tests can confirm the diagnosis.



### Mouth (oral) cancers




- mouth pain
- pain when swallowing
- a persistent sore or swelling in the mouth, or the area not healing after having a tooth extracted
- a sore throat that doesn't get better
- unusual bleeding or numbness in the mouth
- red or white patches on the gums, tongue or mouth
- bad breath
- changes in speech or trouble pronouncing words
- difficulty chewing or swallowing food or moving the tongue
- weight loss
- loose teeth, or dentures that no longer fit
- earache
- a lump in the neck



### Throat (pharyngeal) cancers

- a lump in the neck
- a persistent sore throat or cough
- difficulty swallowing or opening the mouth wide
- pain when swallowing
- coughing up bloody mucus
- bad breath
- weight loss
- voice changes or hoarseness
- dull pain around the neck
- earache
- feeling that your air supply is blocked
- numb face
- a blocked nose
- hearing loss
- headache

If you are concerned about any of these symptoms, see your general practitioner (GP) without delay. For oral cancers, your dentist may also be able to give you advice and refer you to a specialist.

 <b>Voice box (laryngeal) cancers</b>	 <b>Nose (nasal cavity or sinus) cancers</b>	 <b>Salivary gland cancers</b>
<ul style="list-style-type: none"><li>• a persistent change in the sound of your voice, including hoarseness</li><li>• a sore throat that doesn't get better</li><li>• difficulty swallowing or pain when swallowing</li><li>• coughing all the time</li><li>• difficulty breathing</li><li>• weight loss</li><li>• pain in the ear</li><li>• a lump in the neck</li></ul>	<ul style="list-style-type: none"><li>• reduced sense of smell</li><li>• a persistent blocked nose or ear</li><li>• frequent nosebleeds</li><li>• lots of mucus in the throat or the back of the nose</li><li>• frequent headaches or sinus pressure</li><li>• difficulty swallowing</li><li>• loose or painful upper teeth</li><li>• a lump on the face or in the nose or mouth</li><li>• numb face, upper lip or inside mouth</li><li>• pressure or pain in ears</li><li>• a bulging or watery eye</li><li>• double vision or complete or partial loss of eyesight</li><li>• a lump in the neck</li></ul>	<ul style="list-style-type: none"><li>• swelling or a lump near the ear, jaw or lip, or inside the mouth</li><li>• left and right sides of the face or neck looking different</li><li>• drooping, numbness or muscle weakness on one side of the face (palsy)</li></ul>

## 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

<b>ENT (ear, nose and throat) specialist</b>	treats disorders of the ear, nose and throat
<b>head and neck surgeon</b>	diagnoses and treats cancers of the head and neck; may be an ENT, general, plastic, or oral and maxillofacial surgeon
<b>oral (maxillofacial) surgeon</b>	performs surgery and treats disorders of the mouth, face and jaws
<b>reconstructive (plastic) surgeon</b>	performs surgery that restores, repairs or reconstructs the body's appearance and function
<b>dentist</b>	evaluates and treats the teeth, which can be affected by cancer treatment
<b>oral medicine specialist</b>	evaluates and treats the mouth, face, jaw and salivary glands, which can be affected by cancer treatment
<b>radiation oncologist</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>medical oncologist</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
<b>cancer care coordinator</b>	coordinates your care, liaises with MDT members, and supports you throughout treatment; may be a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)

During and after your treatment, you will see a range of health professionals who specialise in different aspects of your care. It's recommended that complex head and neck cancer is treated in a specialist centre. If you have to travel a long way for treatment, transport and accommodation assistance may be available to you. Call Cancer Council on 13 11 20 for details.

<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>speech pathologist</b>	evaluates and treats communication, voice and swallowing difficulties during and after treatment
<b>dietitian</b>	helps with nutrition concerns and recommends changes to diet during treatment and recovery
<b>social worker</b>	links you and your family to support services and helps with emotional, practical and financial issues
<b>counsellor, psychologist</b>	help you manage your emotional response to diagnosis and treatment
<b>physiotherapist, exercise physiologist</b>	help restore movement and mobility; improve fitness and wellbeing; physiotherapists also help with breathing and airway clearance and managing lymphoedema
<b>occupational therapist</b>	assists in adapting your living and working environment to help you resume usual activities after treatment
<b>Aboriginal and Torres Strait Islander liaison officer</b>	supports Aboriginal and Torres Strait Islander people and their families during treatment and recovery
<b>pharmacist</b>	dispenses medicine and gives advice about medicines, doses and possible side effects or interactions with other drugs

# Diagnosis

If you notice any symptoms, see your GP. You can tell your dentist about any mouth sores, swelling or colour change in your mouth – they are trained to look for signs of mouth cancer. Your GP or dentist may do some general tests and refer you to another specialist. Tests may include biopsies (testing tissue samples) and ultrasound, CT or MRI scans.

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

## Physical examination

Depending on your symptoms, the doctor may examine your mouth, throat, nose, neck, ears and eyes. They may gently press your tongue down to check the mouth or feel the area with a gloved finger. They will feel your neck to check the lymph nodes. For hard-to-see areas, the doctor may use specialised equipment (endoscopy, see below), or suggest a procedure under anaesthetic (microlaryngoscopy, see opposite) to fully examine the area. They may take a tissue sample to test (biopsy).

## Endoscopy

An endoscopy (nasendoscopy or flexible laryngoscopy) looks at the nose and throat area using a thin, flexible tube with a light and camera on the end. The doctor sprays a local anaesthetic (which tastes bitter) into one of your nostrils to numb the nose and throat. The tube is then gently passed into the nostril and down your throat to look at your nasal cavity, the different parts of the throat (nasopharynx, oropharynx, hypopharynx) and voice box (larynx). You will be asked to breathe lightly, and to swallow and make sounds. It may feel uncomfortable but shouldn't hurt.

Images from the camera may be projected onto a screen and the doctor may also take a biopsy (see below). An endoscopy takes a few minutes and is usually done in a doctor's rooms. If you need a biopsy, it may take longer. You shouldn't have hot drinks for about 30 minutes afterwards, but can go home straightaway.

## **Microlaryngoscopy**

A microlaryngoscopy is done in hospital under a general anaesthetic. The doctor will look at your throat and voice box and take a biopsy (see below). They'll insert a stainless steel instrument called a laryngoscope into your mouth to hold the throat open, and use a telescope or a microscope to examine the throat and voice box. A microlaryngoscopy takes 30–60 minutes and you can go home after recovering from the anaesthetic. Your throat may be sore for a couple of days.

## **Biopsy**

A biopsy is when a doctor removes a sample of cells or tissue from a suspicious sore or lump. A specialist doctor called a pathologist examines the sample under a microscope to see if it contains cancer cells, and may do special tests to help guide treatment. The sample may be taken using local anaesthetic during an endoscopy or under a general anaesthetic during a microlaryngoscopy. A needle can also be used to take a biopsy from lumps in the neck or other hard-to-reach areas. This is called a fine needle biopsy or core biopsy. It is often done using a CT scan or ultrasound (see page 22) to guide the needle to the correct place.

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.

## Imaging tests

You will usually have at least one of the imaging tests described below, often before a biopsy is done. These tests give more details about where the cancer is and whether it has spread to other parts of your body.

**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 small device called a transducer is coated with gel and moved over the area. The transducer sends out soundwaves that echo when they meet something dense, like an organ or tumour. A computer creates a picture from these echoes. An ultrasound is painless and takes about 15–20 minutes.

**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 a vein to make 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.

**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.



The lymph nodes in the neck are often the first place cancer cells spread to. If you have a lump in the neck or an imaging scan has shown a suspicious-looking lymph node, your doctor may recommend doing a fine needle or core biopsy of the lymph nodes. It is often done using an ultrasound or CT scan (see above) to guide the needle to the correct place.





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 or breastfeeding.

You may need to fast or follow a special diet the day before this scan, so that you get the most accurate results. Before the scan, you will be injected with a glucose solution that contains some radioactive material. Cancer cells show up brighter on the scan because they take up more glucose solution than the normal cells do.

Next, you will lie down or sit quietly for about an hour as the glucose spreads through your body. Then you have the PET scan, which will usually take about 30 minutes. The CT scan may be done before the PET scan or at the same time.

**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. Before the scan, a dye may be injected into a vein to help make the pictures clearer. During the scan, you will lie on a 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 30–90 minutes.

**X-rays** – Many people will also have a special x-ray called an orthopantomogram (OPG) to check the jaw and teeth.

# Staging head and neck cancers

The tests described on pages 20–23 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 doctors 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 (see table below).

Based on the TNM numbers, the doctor then works out the cancer’s overall stage on a scale of 1–4 (usually written in Roman numerals as I, II, III or IV). Each type of head and neck cancer is staged slightly differently, and oropharyngeal cancers are staged differently depending on whether they are linked to HPV (see page 15).

## TNM staging system

<b>T (tumour)</b> <b>1–4</b>	Indicates the size of the primary tumour. Generally, the higher the number, the larger the cancer or the deeper it has grown into the tissue.
<b>N (nodes)</b> <b>0–3</b>	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 or the more cancer there is within the nodes, the higher the number.
<b>M (metastasis)</b> <b>0–1</b>	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.

In general, stages 1–2 mean the cancer is small and generally hasn't spread from the primary site (early head and neck cancer). Stages 3–4 mean the cancer is larger and has spread (advanced head and neck cancer). It may have spread to nearby tissue or lymph nodes (locally advanced cancer) or to other parts of the body (metastatic cancer).

It is worth noting that compared to other cancers, stage 4 head and neck cancers can often be given curative treatment successfully. The stage 4 category can be split into multiple groups, and only one of these subtypes is unlikely to be cured. Ask your doctor to explain what the stage of the cancer means for 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 outlook for people with the same type and stage of cancer.

To work out your prognosis and advise you on treatment options, your doctor will consider your test results, the type of head and neck cancer, your smoking history, the cancer's HPV status (if relevant), the rate and depth of the cancer's growth, the likelihood of response to treatment, and other factors such as your age, level of fitness and overall health.

In most cases, the earlier head and neck cancer is diagnosed, the better the outcome. People with more advanced head and neck cancer may also respond well to treatment. Oropharyngeal cancers linked with HPV also usually have better outcomes compared with non-HPV oropharyngeal cancers.

## Key points about diagnosing head and neck cancers

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### Main tests

- Your doctor will examine your mouth, throat, nose, neck, ears and eyes.
  - An endoscopy uses a thin flexible tube with a light and camera to look for abnormal tissue in the nose and throat area.
  - Sometimes people need an examination under general anaesthetic. This is known as microlaryngoscopy. It allows the doctor to fully examine the throat and voice box for abnormal tissue.
  - When a tissue sample (biopsy) is removed, a pathologist examines the sample under a microscope to see whether cancer is present and, if so, what type of cancer it is.
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### Other tests

- You may have imaging tests such as an ultrasound; CT, PET-CT and MRI scans; and x-rays.
  - These scans help show where the cancer is and whether it has spread to other parts of the body.
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### Staging and prognosis

- The cancer will be given a stage to describe how far it has spread in the body. This allows your doctors to recommend the best treatment for you.
  - Each type of head and neck cancer is staged slightly differently.
  - 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, as it may not 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 18) 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.

**Record the details** – When your doctor first says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. 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.

## Should I join a clinical trial?

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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](http://australiancancertrials.gov.au).

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

# Treatment

Head and neck cancers may be treated in different ways, depending on the type, location and stage of the cancer, your general health and what is important to you. The key treatments for head and neck cancers are:

- **surgery** – removes cancer or repairs a part of the body affected by cancer; sometimes used as the main treatment (see pages 31–39)
- **radiation therapy** – the use of targeted radiation to kill or damage cancer cells; sometimes used as the main treatment (see pages 40–44)
- **chemotherapy** – the use of drugs that kill cancer cells or slow their growth; usually combined with radiation therapy, which is known as chemoradiation (see pages 44–45)
- **immunotherapy** – the use of drugs that use the body's own immune system to fight cancer (see pages 45–46)
- **targeted therapy** – the use of drugs that target specific features of cancer cells to stop the cancer from growing and spreading (see pages 45–46).

You may have one or more treatments. You may be able to have new treatments through clinical trials (see opposite page). Treatment will be tailored to your situation. For complex cancers, treatment options should be discussed at a multidisciplinary team meeting (MDT, see page 18) in a specialised head and neck cancer centre.



There can be extra costs during cancer treatment, even if you have private health insurance or are a public patient. Health care providers must tell you how much you'll pay for tests, treatments, medicines and hospital care. This is called informed financial consent. Call Cancer Council on 13 11 20 and ask for more information about informed financial consent.

## How to prepare for treatment

It is important to look after your health before treatment begins. This will help you cope with side effects and can improve treatment outcomes.

### Stop smoking



If you smoke, aim to quit before starting treatment. If you keep smoking, you may not respond as well to treatment, side effects may be worse and you will have a higher risk of a new cancer. See your doctor or call Quitline on 13 7848.

### Begin or continue an exercise program



Exercise will help build up your strength for recovery. Talk to your doctor, physiotherapist or an exercise physiologist about the right type of exercise for you.

### See a dentist



Treatments for head and neck cancer can affect your mouth, gums and teeth. Your specialist may refer you to a dentist or oral medicine specialist who understands the treatments you will be having. You will need a full check-up and an oral health care plan covering any dental work you need and how to care for your mouth.

### Improve diet and nutrition



A dietitian can suggest ways to get the right nutrition before, during and after treatment by changing your diet or taking liquid nutritional supplements. This will help maintain your weight and muscle mass, improve your strength and energy levels, and may mean the treatment works better.



### Avoid alcohol

Alcohol irritates mouth sores from the cancer or treatment.



## Surgery

The aim of surgery is to completely remove the cancer and 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 cancer and a margin of healthy tissue, which is checked by a pathologist to make sure all the cancer cells have been removed. Often some lymph nodes will also be removed (see below).

The types of surgery used for the different head and neck cancers are described on the following pages. Thinking about having surgery to your head and neck area can be frightening. Talking to your treatment team can help you understand what will happen. You can also ask to see a social worker or psychologist for emotional support before or after the surgery.

► See our *Understanding Surgery* booklet.

## Removing lymph nodes

If the cancer has spread to the lymph nodes in your neck, or it is very likely to spread, your surgeon will probably remove some lymph nodes. This operation is called a neck dissection or lymphadenectomy. Your surgeon will tell you if this is needed and explain the procedure.

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 shoulder moves and your neck looks after surgery. A physiotherapist can help improve movement and function. (Also see *Lymphoedema* on page 68.)

## How the surgery is done

Depending on the type of head and neck cancer you have, 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.

Your surgical options for head and neck cancers may include:

- **endoscopic surgery** – the surgeon inserts a rigid instrument with a light and camera through the nose or mouth to see and remove some cancers, particularly cancers from the nose and sinuses
- **transoral laser microsurgery (TLM)** – a microscope (usually with a laser attached) is used through the mouth to remove cancers, particularly of the larynx and lower throat
- **transoral robotic surgery (TORS)** – the surgeon uses a 3D telescope and instruments attached to robotic arms to reach the cancer through the mouth; often used for oropharyngeal cancers
- **open surgery** – the surgeon makes cuts in the skin of the head and neck to remove cancers; used for larger cancers and those in difficult positions. Part of the upper and lower jaw or skull may need to be removed and then replaced or reconstructed (see below).

Minimally invasive surgery such as endoscopic, TLM and TORS may mean less scarring, a shorter hospital stay and faster recovery. However, these types of surgery are not suitable for all cases, and open surgery is often the best option.

## Reconstructive surgery

After open surgery, you may need reconstructive surgery to rebuild your tongue, mouth or jaw and help with speech and swallowing, and to improve how the area looks. It is usually part of the operation to remove the cancer, but is sometimes done later.

## How long will I stay in hospital?

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How long you stay in hospital depends on the type of surgery you have, the area affected, and how well you recover. Surgery to remove some small cancers can often be done as a day procedure. Recovery is usually fast and there are often few long-term side effects. Surgery for more advanced cancers often

affects a larger area, can involve reconstructive surgery and may take all day. You may need care in the intensive care unit before being transferred to a general ward, and side effects may be long term or permanent. Once you return home, nurses may be able to visit to provide follow-up care.

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In reconstructive surgery, a combination of skin, muscle and sometimes bone is used to rebuild the area. This can be taken from another part of the body and is called either a “free flap” or a “regional flap”.

Occasionally synthetic materials such as silicone and titanium are used to re-create bony areas or other structures in the head and neck, such as the palate. This is called a prosthetic.

## Surgery for oral cancer

The type of surgery used depends on the cancer’s size and location. Localised cancers can be treated by removing part of the tongue, mouth or lip. For larger cancers, the surgery will affect a bigger area and you may need reconstructive surgery to continue to chew, swallow or speak.

Some tumours can be removed through the mouth, but you may need 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 (mandible)
- **maxillectomy** – removes part or all of the upper jaw (maxilla).

## Surgery for pharyngeal cancer

Pharyngeal cancers are treated differently depending on which part of the pharynx is affected. Surgery can be used for many oropharyngeal and hypopharyngeal cancers. Nasopharyngeal cancers are rarely treated with surgery. They may be treated with chemotherapy (often before radiation therapy), radiation therapy (for early-stage cancers), or chemoradiation.

Small oropharyngeal and hypopharyngeal cancers can often be treated with minimally invasive surgery, which is sometimes followed by radiation therapy with or without chemotherapy. If the cancer is large or advanced and surgery is an option, it is more likely to be open surgery through a cut in the neck. Surgery is often followed with radiation therapy and possibly chemotherapy. If surgery is not possible due to the size or location of the tumour, radiation therapy or chemoradiation is usually given instead.

Different types of pharyngeal surgery include:

- **hypopharyngectomy** – removes part of the hypopharynx (lower throat)
- **pharyngolaryngectomy** – removes all of the larynx and part of the pharynx; this surgery is less common and is similar to a total laryngectomy (see below)
- **oropharyngectomy** – a less common surgery that removes some of the oropharynx (the part of the throat behind the mouth).

## Surgery for laryngeal cancer

If laryngeal cancer is at an early stage, you may have surgery to remove part of the larynx (partial laryngectomy). The surgery may be minimally invasive or open. Your voice may be hoarse or weak afterwards, and may take up to 6 months to recover. In some cases, the changes to the voice may be permanent (see page 59).

If the cancer has advanced and chemoradiation isn't an option, you may need open surgery to remove the larynx (total laryngectomy). This operation removes the whole larynx and separates the windpipe (trachea) from the food pipe (oesophagus). After this surgery, you will breathe through a hole in the front of your neck called a laryngectomy stoma. This is a permanent change and you will no longer be able to breathe through your nose and mouth. Because this surgery removes the voice box, you won't be able to speak in the same way. These changes can be hard to adjust to. A speech pathologist will teach you new ways to talk and communicate (see pages 19 and 59).

If you have a total laryngectomy, part or all of your thyroid gland may be removed (thyroidectomy). The thyroid produces thyroxine (T4), the hormone that controls your metabolism, energy levels and weight, so you may need to take thyroid hormone replacement tablets every day for the rest of your life. Talk to your doctor about this.

## **Surgery for nasal or paranasal sinus cancer**

Your doctor may advise you to have surgery for nasal or paranasal sinus cancer if the tumour isn't too close to your brain or major blood vessels. The type of surgery will depend on where the tumour is and, if you have paranasal sinus cancer, which sinuses are affected. You will often need to have reconstructive surgery as well.

Nasal and sinus cancers are often close to the eye socket, brain, cheekbones and nose. Your surgeon will talk to you about the most suitable approach and whether any other parts of the head or neck may need to be removed to get the best outcome.

The surgeon will also consider how the operation will affect how you look, and your ability to breathe, speak, chew and swallow.

Different types of surgery for nasal and sinus cancer 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
- **skull base surgery** – also known as a craniofacial resection, this surgery removes part of the nasal cavity or sinuses; often done endoscopically through the nose, but a cut along the side of the nose may be needed; sometimes a neurosurgeon assists with this surgery
- **orbital exenteration** – removes the eye and may also remove tissue around the eye socket
- **rhinectomy** – removes part or all of the nose.

If your nose, or a part of it, is removed, you may need to have an artificial nose (prosthesis) or the nose may be reconstructed using tissue from other parts of your body. The process for completing the prosthetic or reconstructed nose may take several months. Your surgeon will give you more information about the process and how long this is likely to take. A prosthetic eye may also be an option.

## **Surgery for salivary gland cancer**

Most salivary gland tumours affect one of the parotid glands, which sit in front of the ears. Surgery to remove part or all of a parotid gland is called a parotidectomy.

The facial nerve runs through the parotid gland. This nerve controls facial expressions and movement of the eyelid and lip. If the facial nerve is damaged during surgery, you may be unable to smile, frown or close your eyes. This is known as facial palsy, and it will usually improve over several months.

In some cases, the facial nerve needs to be cut so the cancer can be removed. This will affect how your face looks and moves. There are

various procedures that can help improve this, such as using a nerve from another part of the body (nerve graft).

If the cancer affects a gland under the lower jaw (submandibular gland) or under the tongue (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, which may cause some loss of function (e.g. how you speak, eat or close your mouth).

## Side effects of surgery

Most surgeries for head and neck cancer will have some short-term side effects, such as discomfort and a sore throat. Recovery after a larger surgery may be more challenging, especially at first. See pages 38–39 for information on what to expect in the first days after surgery.

Depending on the type of surgery you've had, after a period of recovery, you may not have any ongoing issues. However, some people do need to adjust to permanent changes after head and neck surgery.

Long-term side effects can include:

- reduced energy levels
- difficulty eating (e.g. chewing or problems with teeth)
- speech changes
- breathing changes
- change in appearance
- changes to intimacy and your sex life
- vision and hearing changes
- pain, numbness, swelling (lymphoedema) or less movement in the area.

Talk to your treatment team about what side effects you can expect. Tell them if you experience any worrying side effects after surgery. For more information and tips, see *Managing side effects*, pages 48–69.

## What to expect after surgery

How you will feel after head and neck cancer surgery will vary greatly depending on your age, your general health, the size of the affected area and whether you

### Pain



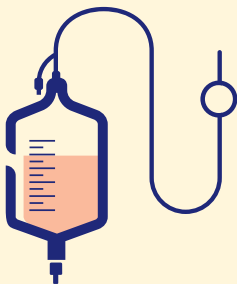
You will have some pain and discomfort for several days after surgery, but you will be given pain medicines to manage this. You may take tablets or be given injections, or you may have patient-controlled analgesia (PCA), which delivers a measured dose of pain medicine through a drip when you press a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

### Eating and drinking



You will usually wake up from surgery with a drip in your arm to give you fluids. You usually won't be allowed to eat or drink for several hours or sometimes days. Depending on the surgery, you may then start with clear liquids, move on to puréed food, and then soft foods.

### Drains and catheters



For a few days, you may have tubes at the surgery site to drain fluid from the wound into small containers. You may also have a catheter, a tube from your bladder that drains urine into a bag.

### Feeding tube

Eating and drinking may be difficult after some surgeries. A temporary feeding tube may be inserted through your nose into your stomach (nasogastric or NG tube) to allow the surgery area to heal. Another option is a gastrostomy or PEG or RIG tube inserted directly into your stomach (see pages 56–57). A nutritional formula is then given through these feeding tubes.



also have 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.

## **Movement**

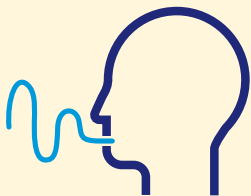


After some surgeries, you may be in bed for a time. A physiotherapist will teach you breathing exercises to help clear your lungs and reduce the risk of a chest infection. As soon as possible, your team will encourage you to sit in a chair and walk around. This will speed up recovery.

## **Breathing difficulties**

If surgery is likely to cause your mouth, tongue or throat to become swollen, your surgeon will talk to you about having a temporary tracheostomy. This is a breathing tube in your neck that helps you to breathe (see pages 60–61).

## **Speech changes**



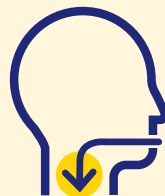
Some surgeries may affect your ability to speak clearly, but your team will discuss this with you beforehand. You will usually see a speech pathologist who will help you improve your speech (see page 59).

## **Sore throat**



It's common to have a sore throat after mouth or throat surgery, but you will be given medicine to control any pain. You may also have some throat discomfort from the anaesthetic tube for a few days.

## **Swallowing**



Surgery will sometimes change the way you swallow and this can often be difficult at first. A speech pathologist will assess your swallowing and help you regain your ability to swallow.

## Radiation therapy

This treatment (also called radiotherapy) uses a controlled dose of radiation to kill or damage cancer cells. For head and neck cancer, it is most often given with external beam radiation therapy (EBRT). A technique called intensity modulated radiation therapy (IMRT) targets the radiation precisely to the cancer, which reduces treatment time and causes as little harm as possible to nearby healthy tissue.

**Radiation therapy as the main treatment** – For some pharyngeal and laryngeal cancers, radiation therapy will be the main treatment. The aim is to destroy the cancer while maintaining normal speech, swallowing and breathing. Sometimes chemotherapy will also be used to help the radiation work better (chemoradiation). Radiation treatment usually is given daily for 7 weeks for mucosal head and neck cancers, but this may vary from person to person.

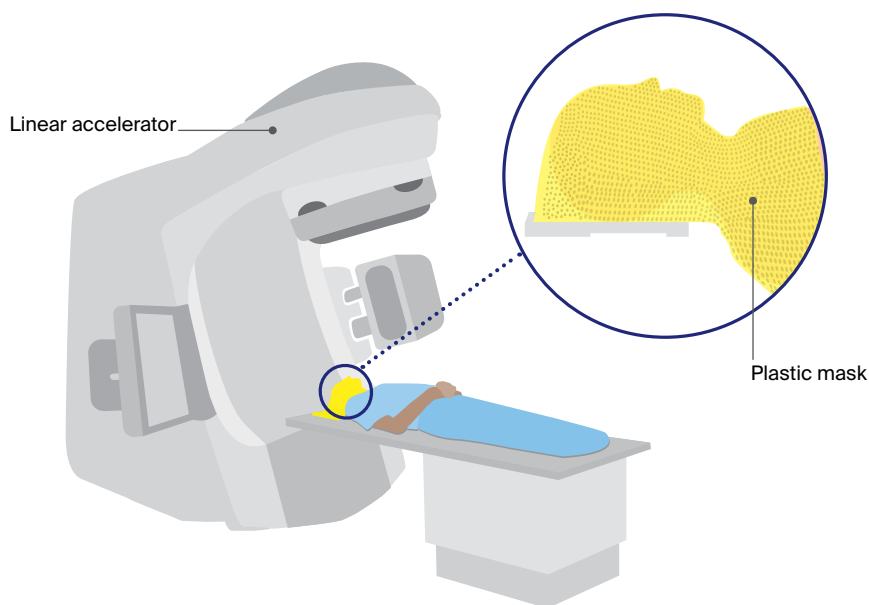
**Radiation therapy after surgery** – Radiation therapy is often used after surgery for head and neck cancers. This is known as adjuvant treatment. The aim is to destroy any remaining cancer cells and reduce the chance of the cancer coming back. You will probably start radiation therapy as soon as your wounds have healed and you've recovered your strength, which should be within 6 weeks. Adjuvant radiation therapy is sometimes given together with chemotherapy (chemoradiation). This is usually given for about 6–7 weeks, but may vary person to person.

Before radiation therapy, you meet with a radiation oncologist to work out whether radiation therapy is right for you. You will have a planning session with a CT scan to show the exact area that needs the radiation. You will also be fitted for a plastic mask called an immobilisation mask (see page opposite). You will wear this at each treatment session.

► See our *Understanding Radiation Therapy* booklet.

## External beam radiation therapy

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### Having radiation therapy

Radiation therapy is carefully planned to make sure enough radiation reaches the cancer, while as little as possible reaches healthy organs and tissues. During treatment sessions, you will lie on a table under a machine called a linear accelerator, which precisely delivers the radiation. The treatment is painless and is usually given Monday to Friday for 6–7 weeks. You usually won't need to stay in hospital.

### Wearing the mask

You wear the plastic mask for 10–20 minutes at each session. It helps you keep still and makes sure the radiation is targeted at the same area at each treatment session. You can see and breathe easily, but it may feel strange and confined at first. Tell the radiation therapists if you have claustrophobia or the mask makes you feel uncomfortable – you can talk to someone or may be offered medicine to help you relax.



## 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 4 cancer in my tonsils, throat and tongue into remission.*

*For several weeks, I had chemotherapy once a week and radiation therapy every weekday.*

*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 its 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, dietitians, psychologists and senior nurses, as well as the medical team. Find a dentist who understands the effects of treatment and get advice for the long-term health of your teeth. Tell your trusted family members and friends what you need, and ask directly for help.*

***“I had to wear a special mask to keep me totally still while the radiation treatment took place.”***

## Side effects of radiation therapy

Radiation therapy side effects vary depending on the area treated, the number of sessions, and whether it is combined with chemotherapy. Side effects often get worse 1–3 weeks after treatment ends and then start to improve. Some side effects may last longer, be ongoing or appear several months or years later. Some may be permanent. It is important to talk to your treatment team if you have any concerns or questions on how the treatment may affect you. The most common short-term and long-term side effects are listed below. For information about managing side effects, see pages 48–69.

**During or immediately after treatment** – Short-term side effects can include fatigue, mouth sores, taste changes, nausea, loss of appetite, mouth infection (oral thrush), dry mouth, thick saliva and phlegm, swallowing difficulties, skin redness, burning and pain in the area treated, breathing difficulties and weight loss.

**Ongoing** – Longer-term or permanent side effects may include dry mouth, thick saliva, difficulties with swallowing and speech, changes in taste, fatigue, muscle stiffness, neck swelling, appetite and weight loss, mouth infection (oral thrush), hoarseness, dental problems such as tooth decay and gum disease, difficulty opening the mouth, and hair loss.

**Aspiration** – Some people develop a temporary or ongoing problem where fluid or food enters the windpipe (trachea) while swallowing. This is called aspiration and it can cause coughing, lung infections such as pneumonia and, sometimes, difficulty breathing (see pages 60–61).

**Thyroid damage** – If the treatment damages the thyroid, it can cause an underactive thyroid (hypothyroidism). This can be managed with thyroid hormone replacement tablets.

**Osteoradionecrosis of the jaw** – Radiation therapy can damage blood vessels, reducing the blood supply to the area treated. Occasionally, the bone starts to die, leading to pain, infection and fractures. This is known as osteoradionecrosis, or ORN. About 5–7% of people who have radiation therapy to the head and neck develop ORN of the jaw. It can occur months or years later, most commonly after having dental work such as the removal of teeth, when the bone is unable to heal itself. This is why you will usually see a dentist before your cancer treatment, so any dental issues can be treated before there is a risk of ORN.

It is very important to tell your dentist that you have had radiation therapy before beginning any dental work. Treatment for ORN 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 usually receive chemotherapy by injection into a vein (intravenously), although it is occasionally given as tablets. How often you have chemotherapy sessions will depend on the treatment plan.

Chemotherapy may be given for a range of reasons:

- in combination with radiation therapy (chemoradiation), to increase the effects of radiation (see page 40)
- before surgery or radiation therapy (neoadjuvant chemotherapy), to shrink a tumour

- after surgery (adjuvant chemotherapy), given along with radiation therapy, to help reduce the risk of the cancer returning
- as palliative treatment to help relieve symptoms (see page 46).

## 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. Not all chemotherapy causes nausea. Your medical oncologist or nurse will discuss likely side effects, including how these can be prevented or controlled with medicine.

Common side effects can 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 or constipation; hair loss; low red blood cell count (anaemia); hearing loss; ringing in the ears (tinnitus); lower 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 go to the hospital emergency department.

► See our *Understanding Chemotherapy* booklet.

## Other drug therapies

Head and neck cancer that has advanced is often treated with other drug therapies that reach cancer cells throughout the body (systemic therapies). This may include targeted therapy and immunotherapy, which work in different ways to chemotherapy. They can be combined with other treatments such as chemotherapy or radiation therapy.

**Targeted therapy** – Targeted therapy targets specific features of cancer cells to stop the cancer growing and spreading. Each targeted therapy drug works on a particular feature, and the drug will only be given if the cancer cells have that feature. For some head and neck cancers, a targeted therapy drug called cetuximab is occasionally used when people cannot take the standard chemotherapy drug or the cancer is advanced.

► See our *Understanding Targeted Therapy* fact sheet.

**Immunotherapy** – Immunotherapy uses the body's own immune system to fight cancer. The main type of immunotherapy drugs used in Australia are known as checkpoint inhibitors. These drugs help the immune system to recognise and attack cancer cells. Nivolumab and pembrolizumab are some checkpoint inhibitors that may be used to treat some types of advanced head and neck cancer.

► See our *Understanding Immunotherapy* fact sheet.

New targeted therapy and immunotherapy drugs are being studied in clinical trials (see page 28). Talk with your doctor about the latest developments and whether a clinical trial would be an option for you.

## Palliative treatment

In some cases of very advanced head and neck cancer, the treatment team may talk to you about palliative treatment. This aims to improve your quality of life by managing the symptoms without trying to cure the disease. When used as palliative treatment, radiation therapy and chemotherapy or other drug therapies can help manage pain and other symptoms, and may slow the cancer's spread.

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



## Key points about treating head and neck cancers

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### Before treatment

- You can prepare for treatment by stopping smoking, avoiding alcohol and getting regular exercise.
- It is a good idea to see a dietitian and a dentist before treatment begins.

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### Surgery

- Surgery is commonly used to remove many types of head and neck cancers.
- For cancers that are easy to reach, 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).
- Some people need to have reconstructive surgery to help maintain function and appearance.

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### Radiation therapy

- Radiation therapy is a common treatment. It may be used alone, in combination with chemotherapy (chemoradiation), or after surgery.
- Before radiation therapy, you may be advised to see a dentist to reduce the chance of future problems with your teeth and jaws.
- During radiation therapy, you will need to wear a specially made plastic mask to keep you still during treatment.

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### Drug therapies

- Chemotherapy is most often used in combination with radiation therapy (chemoradiation).
- Targeted therapy and immunotherapy are sometimes used for people with advanced head and neck cancer.

# Managing side effects

Treatment for head and neck cancer is often difficult both physically and emotionally, and it will take some time to recover. Side effects may be temporary, long-lasting or permanent, and some will need ongoing management and treatment. This chapter has information and tips to help you manage any side effects you may have, including:

- fatigue
- mouth sores, ulcers and dry mouth
- changes to taste, smell and appetite
- swallowing problems, including using a feeding tube
- not getting enough fluids
- malnutrition and weight loss
- changes to how you talk
- breathing changes, including having a breathing tube (tracheostomy) or hole (stoma), and restoring speech
- ongoing pain, numbness and stiffness
- changes to how you look
- impact on sexuality and intimacy
- changes to vision or hearing
- ongoing swelling known as lymphoedema.

Your treatment team will explain what to expect and watch for. Tell them of any side effects and ask which health professionals can help you.



Head and neck cancer can be emotionally challenging. Your treatment team can offer support or you may like to talk to a social worker or psychologist or call Cancer Council on 13 11 20.

## Fatigue

It is common to feel very tired during or after treatment, and you may lack the energy to carry out day-to-day activities. Fatigue for people with cancer is different from tiredness, as it may not go away with rest or sleep. You may lose interest in things that you usually enjoy doing or feel unable to concentrate on one thing for very long. For some people, fatigue continues for months or years after treatment ends.

Let your treatment team know if you are struggling with fatigue. Sometimes fatigue can be caused by a low red blood cell count or be a side effect of drugs or a sign of depression, which can all be treated. There are often programs available through hospitals and treatment centres to help you manage fatigue. A referral to an occupational therapist can also assist with managing fatigue.

- ▶ See our *Understanding Fatigue and Cancer* fact sheet and listen to our “Managing Cancer Fatigue” podcast episode.



### Tips for managing fatigue

- Plan your day. Set small manageable goals and rest before you get too tired.
- Keep to a regular schedule if possible. Avoid sleeping in, go to bed at your usual time, and take a short nap if you get tired during the day.
- Don't expect to be able to do everything you used to be able to right away. Gradually increase the activity you do each day.
- Eat a healthy, well-balanced diet to keep energy levels up.
- Regular light-to-moderate exercise has been shown to reduce fatigue. Even a walk around the block can help. A physiotherapist or exercise physiologist can make an exercise program for you.
- Ask for and accept help with shopping or childcare. Try apps like Gather My Crew.

## Mouth problems

Some cancer treatments cause mouth sores and ulcers and saliva changes, which make eating difficult. But there are ways to manage this.

**Mouth sores and ulcers** – A common side effect of chemotherapy and radiation therapy, these are called oral mucositis. They form on soft tissue in your mouth and make eating, swallowing and talking hurt. They usually go away as you recover from treatment.

Your doctor can give you medicines to reduce the pain when you eat, drink or speak. Some pain medicines can be applied directly to the mouth sores to numb them. You may use more than one type of medicine to control the pain.

Keep your mouth clean during treatment to lessen the risk of infection. Alcohol-free mouthwashes help keep your mouth as clean as possible.

Ask your speech pathologist and dietitian what to eat to help with any pain. You may find soft, smooth or cooler foods and nourishing fluids are best. If you can't eat and drink enough, you may need a feeding tube to support you during treatment and recovery (see pages 56–57).

**Dry mouth and saliva changes** – Radiation therapy to the head or neck area and surgery that affects the salivary glands can reduce the amount of saliva in your mouth, make your mouth dry or make your saliva thick and sticky. This is known as xerostomia and is often long-lasting. Xerostomia can make chewing, swallowing and talking difficult. A dry mouth can also make it harder to keep your teeth and mouth clean, and can increase the risk of tooth decay. Be careful to keep your mouth and teeth clean and have regular dental checks.

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



## How to relieve mouth problems

### Mouth sores and ulcers

- Rinse your mouth often – when you wake up, after you eat, and at bedtime. Ask your doctor or nurse what alcohol-free mouthwash to use. They may suggest a homemade mouthwash or a specific mouthwash to help with mouth ulcers.
- Talk to your doctor and nurse about medicines to relieve pain and help with healing.
- Use a soft toothbrush and replace it often to reduce the risk of infections. Brush gently after meals and before bed. If brushing is too painful, try using a water flosser on a low setting.
- Suck on ice cubes.
- Avoid rough, crunchy or dry foods (e.g. chips, toast), vinegar, spices, salty foods, alcohol, very hot or cold things, and citrus, tangy or tomato-based food or juice.
- Use a lip balm for moist lips.
- Tell your doctor, dietitian or speech pathologist if it is hard for you 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 caffeine (these can be dehydrating) and avoid smoking.
- Chew sugar-free gum to help the flow of saliva.
- Put lanolin on your lips (but avoid products containing petroleum).
- Soften food by dipping it into milk or soup, or moisten it with gravy, sauce, cream or custard.
- Drink fluids 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 it.
- Use artificial saliva, dry mouth gels or lubricating agents from the chemist. Swirl grapeseed oil in your mouth and then spit it out.

## Taste, smell and appetite changes

Having treatments to the head, neck and mouth area may affect your sense of taste and smell.

After some surgeries to the nasal cavity, you may lose your sense of smell, and your sense of taste may also be affected. If you have a laryngectomy, air will no longer pass through your nose, which can affect your sense of smell. Surgery to the mouth may also change how food tastes.

Some treatments, especially radiation therapy, can 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 enough nourishment to maintain your weight. If you lose most or all of your sense of taste, experiment with different textures and temperatures to make food more enjoyable. You could also focus on other appealing aspects of food, such as the colours and presentation of the meal. Another option is to do something else while eating, such as watching TV or reading a book – this might distract you from the food not tasting like it did before.

It can take several months for your sense of taste and smell to return to normal, and this may affect your appetite. If your sense of smell continues to be affected, 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 for People Living with Cancer* booklet and *Understanding Taste and Smell Changes* fact sheet, and listen to our “Appetite Loss and Nausea” podcast episode.



## How to manage taste and smell changes

### Taste

- Add extra flavour with herbs if food tastes bland.
- Rinse your mouth before eating to clean any coating from your tongue and help improve taste.
- After each meal, brush your teeth and rinse with the mouthwash recommended by your treatment team.
- If you smoke, try to quit. Smoking reduces appetite and changes the taste of food. Call the Quitline on 13 7848 for support.
- Use a paper or silicone straw so the taste of drinks isn't as strong. (Metal straws may add a metallic taste.)
- Add more nutrition and energy to your food by using butter or milk.
- Encourage your appetite with aromatic foods.
- If food tastes "off", freshen your mouth by drinking a fruit or herbal tea, or eating sorbet or soft fruits such as watermelon.
- Ask to see a dietitian for more suggestions.

### Smell

- If you lose your sense of smell, take extra care with safety issues. Check the use-by dates of foods, turn off gas appliances properly, and make sure that the smoke detectors in your home are working.
- If food smells bother you, ask your family and friends to cook for you, or try cold meats and salads, and cold desserts and fruit.
- Choose foods that are fresh and full-flavoured.
- If taste and smell changes stop you eating enough, you may lose weight. Use nutritional supplement drinks (e.g. Sustagen, Ensure, Resource) to help maintain your strength and energy. You can find them in many pharmacies and supermarkets.
- You may also want to see a dietitian for help. Some nutritional supplements, such as Resource 2.0, are only available with a dietitian prescription.

## Swallowing difficulties

Your lips, teeth, tongue and the muscles in your mouth, jaw and throat all work together to help you chew and swallow. Difficulty swallowing (dysphagia) before, during or after treatment is common. This may be because of the cancer or the treatments, and may be short or long term. Swallowing is important to make sure you eat and drink enough. Signs of swallowing difficulties include: taking longer to chew and swallow; taking longer to eat a meal than your family and friends; coughing or choking while eating or drinking; food sticking in your mouth or throat; or pain when swallowing.

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

**Surgery to the larynx or pharynx** – This may make swallowing difficult and cause food to go down the wrong way and into the lungs (aspiration). (This is unlikely after a laryngectomy.) 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 can check how your swallowing is working (see *Swallowing test*, below) and give you strategies to help you eat and drink safely.

**Radiation therapy** – This can cause dry mouth, pain, and weaken the muscles and nerves used to swallow. It may be worse if you have chemoradiation (chemotherapy and radiation therapy at the same time).

## 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 or modified barium swallow study



to check that foods and liquids are going down the correct way. You may also have a test called a fibre-optic endoscopic evaluation of swallowing during a nasendoscopy to see how well you can swallow. The test results will help the treatment team plan how any swallowing issues are treated.



## How to eat when swallowing is difficult

- See a speech pathologist for ways to chew and swallow to help reduce discomfort or food going down the wrong way (aspiration). They can show you swallowing and vocal exercises and ways to change your posture that may help. To find a speech pathologist, ask the team at your treatment centre or visit [speechpathologyaustralia.org.au](http://speechpathologyaustralia.org.au).
- Continue to eat and drink when possible throughout treatment to keep your swallowing muscles working and reduce the likelihood of long-term problems. Even if you have a feeding tube, eating and drinking small amounts can help with swallow recovery, as long as there is no risk of aspiration.
- Ask your doctor about medicines to relieve any discomfort. Medicines may include mouth rinses.
- A speech pathologist can suggest ways to adjust the consistency of food to make it easier to swallow.
- If it is hard to swallow fluids without choking, a speech pathologist can advise ways to thicken supplement drinks. Thicker fluids are easier to control in your mouth so there is less chance of them going down the wrong way.
- See a dietitian to make sure you are getting enough nutrition and hydration.
- Try the recipes in 2 free online books from Griffith University – *From Treatment to Table* and *Beyond the Blender: Dysphagia Made Easy*. You can find them by putting the titles into your web search engine.

## Using a feeding tube

As a result of surgery or radiation therapy, you may find eating and swallowing uncomfortable or difficult. A feeding tube may be inserted either before, during, or after your surgery or radiation therapy to help you get the nutrition you need. This tube is usually temporary, but sometimes it is permanent.

A feeding tube can help ensure you maintain your weight and energy. It is important to avoid losing a lot of weight during treatment and to have enough kilojoules and fluids. If you can't swallow medicines, check with your doctor, nurse or pharmacist whether these can also be given through the feeding tube.

Your health care team will explain how to:

- care for the tube to prevent it leaking or becoming blocked
- avoid infections – this may include washing your hands before using the tube, and keeping the tube and your skin dry
- monitor for signs that the tube needs to be replaced
- handle issues such as what to do if the tube falls out – while this is very rare it is important to let your treatment team know immediately if this happens
- ensure the tape is secure, especially after a shower – if it's not secure, the tube can be accidentally bumped out of place.

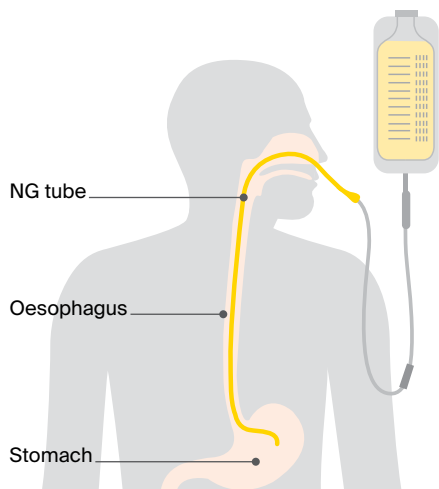
If you have a feeding tube, it is still important to brush your teeth and keep your mouth clean even though you are not eating or drinking.

The thought of having a feeding tube can be frightening, and it is common to have a lot of questions. Getting used to a feeding tube takes time. Talking to a dietitian or nurse can help, and a psychologist or counsellor can provide emotional support and suggest ways to cope.

## Types of feeding tubes

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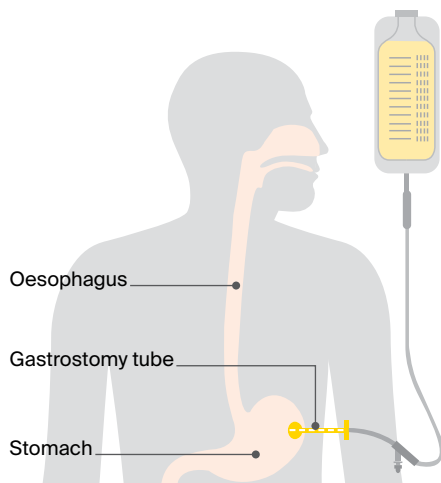
### Temporary feeding tube



A thin tube is put into a nostril, then down the throat and oesophagus into the stomach. This is called a nasogastric or NG tube. It is mostly used if you need a feeding tube for a short time (e.g. the days or weeks after surgery when you can't eat).

A doctor may put in an NG tube during an operation when you are asleep. Or a nurse or doctor may put in or remove the NG tube while you're awake. A spray is usually used to numb the area to make it less uncomfortable to insert the tube. You will be given specially prepared liquid nutrition through this tube.

### Long-term or permanent feeding tube



A tube is inserted through a hole in your belly into the stomach. This is called a gastrostomy tube. It may be used if you need a feeding tube for a longer time, such as during a recovery period from radiation therapy or after a very big operation.

Depending on the way the tube is inserted, it may be done while you're awake or under anaesthetic. The tube may be inserted by endoscope (percutaneous endoscopic gastrostomy or PEG tube), using an x-ray (radiologically inserted gastrostomy or RIG tube), or surgically (surgical gastrostomy).

## Malnutrition and weight loss

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

Unplanned 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 for People Living with Cancer* booklet and listen to our “Appetite Loss and Nausea” podcast episode.



### How to prevent unplanned weight loss

- Treat eating and drinking like medicine: something that you have to do to feel better.
- Eat 5–6 small meals a day rather than 3 large ones.
- Keep a selection of snacks and drinks handy for when you feel up to having them. Keep something in your bag, at work or in the car.
- Include high-energy and high-protein foods at every meal or snack. For example, try having milk-based drinks rather than water and choose cheese and biscuits instead of eating lollies.
- Try ready-to-use nutritional supplement drinks available from supermarkets and pharmacies (e.g. Sustagen, Ensure, Resource).
- Talk to your doctor, nurse or dietitian if you are losing weight, or if you have discomfort or pain when you are swallowing.

## Changes to speech

How you talk can be affected by surgery and radiation therapy. This may be because of side effects such as swelling and irritation, because of a tracheostomy or laryngectomy, or because other structures have been removed. You may find it hard to speak clearly or notice your speech is slurred, or your voice may change. The extent of any changes will vary depending on the location of the cancer, how advanced it was, and the 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. The National Relay Service can help you make phone calls ([visit accesshub.gov.au](http://visit.accesshub.gov.au)).



### How to manage speech changes

- Try non-verbal ways to communicate – gesture, point, nod, smile, mouth words, write things down or ring a bell to call people.
- Use a computer, tablet, phone, text-to-speech apps or notebook to write notes.
- A speech pathologist can improve your speech and offer ways to communicate with family and friends. They may give you some exercises to improve the strength and range of motion of your 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. Ask them not to avoid conversation even if it is difficult. They need to give you time to respond.
- It can be frustrating and difficult when you can't communicate. It may help to have someone you trust to advocate for you or explain what you're trying to say.
- See a counsellor or psychologist if you are finding it difficult to cope.

## Breathing changes

Some people treated for head and neck cancer need a tracheostomy. This is an alternative airway created in the front of the neck so they can keep breathing freely.

**Having a tracheostomy** – If you have a tracheostomy, a small cut in the lower neck allows a tube to be inserted into the windpipe. This can be used for breathing during and after surgery when the mouth or throat becomes swollen. It will also make it easier for you to cough up mucus after a long operation. The tube is usually removed within one week of surgery once the swelling has gone down. In some cases, a tracheostomy is needed for longer than this. It is sometimes needed during radiation therapy, though this is uncommon.

The thought of a tracheostomy may be confronting and scary – talk to your treatment team about how you are feeling and ask them to explain why the tracheostomy is needed. Initially you may not be able to speak, but you will be supported by your treatment team while you have a tracheostomy in place. The speech pathologist and physiotherapist will play an important role in your care.

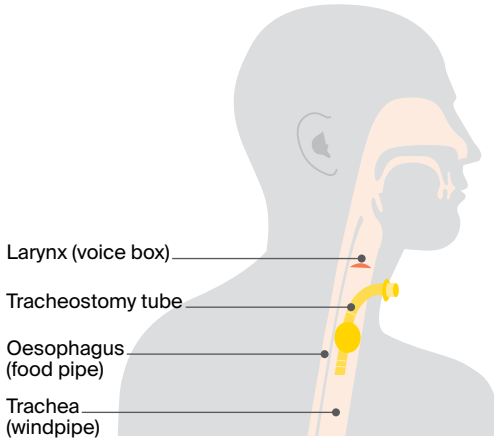
Once the tracheostomy tube is removed, the hole in your neck normally closes within days. During this time, your voice may be weak and breathy, returning to normal when the hole closes.

**Having a laryngectomy** – If you have a total laryngectomy (see pages 34–35), a permanent stoma or breathing hole will be created in your lower neck at the time of the surgery. This will be discussed with you before surgery so you know exactly what to expect, including how you will speak again. If you need a permanent stoma, the speech pathologist and nurses will teach you how to look after it.

## Types of alternative airways for breathing

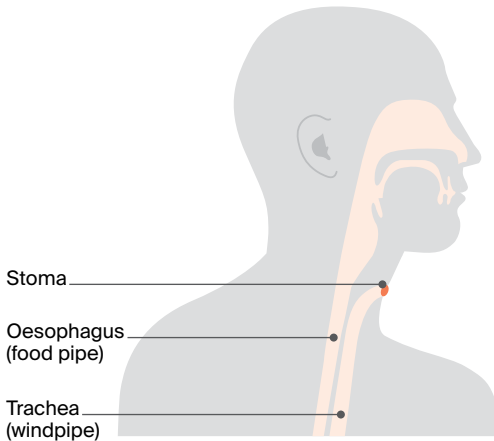
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### Tracheostomy



A tracheostomy is a surgically created hole (stoma) in your windpipe (trachea) that provides another 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 stop the hole 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, physiotherapist or speech pathologist can explain ways to manage the following concerns:

- **caring for the tube or stoma** – you will be shown 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 mouth, which normally moistens and warms the air. This can cause irritation, coughing and extra 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 windpipe. Your treating team will recommend which option is best for you
- **swimming and bathing** – you will need to use a special stoma cover 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.

## Speaking after a laryngectomy

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If the larynx (voice box) is removed, there are various ways to speak.

**Voice prosthesis speech** – The surgeon makes an opening between your trachea and oesophagus. This is called a tracheoesophageal fistula or puncture. A small voice prosthesis (or valve) is inserted to direct air from your trachea to the oesophagus. This will allow you to speak clearly in a low-pitched, throaty voice.

**Mechanical speech** – A battery-powered device (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.

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

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## Pain, numbness and stiffness

Ongoing pain, numbness and restricted movement in the head and neck area can be upsetting and cause low mood, fatigue or reduced appetite. These can all affect your quality of life. Speak to your treatment team about ways to manage pain and regain movement, which may include medicines, positioning for comfort, exercises and other methods.

Your specialist, cancer care coordinator or GP can suggest other health professionals to see, such as a physiotherapist, occupational therapist, speech pathologist, massage therapist, psychologist or pain specialist.

► See our *Understanding Cancer Pain* booklet and listen to our podcast episodes on managing pain.

**Nerve damage** – If you have lymph nodes removed from your neck, you may have pain and stiffness in your shoulder, or nerve damage that makes your neck feel tight and numb. This may affect how you are able to move your neck or it may make it hard to lift your arm. Partial nerve damage usually heals within 12 months, and feeling should return for many people. In some cases, issues to do with nerve damage are permanent.

**Swelling and pain** – Some swelling, pain and stiffness in the head and neck area is common after surgery or if you have radiation therapy as your main treatment. This gradually improves with time. Sometimes swelling called lymphoedema can last longer (see page 68).

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

**Pins and needles or numbness** – Some chemotherapy drugs can cause nerve damage that leads to tingling, pain or numbness in the hands and feet. This is known as peripheral neuropathy and may affect walking or balance. It is often temporary but can be permanent.

You may have difficulty feeling things in your hands and feet, or persistent feelings of having cold feet. Let your treatment team know about any tingling, pain or numbness, as there are ways to manage these symptoms.

► See our *Understanding Peripheral Neuropathy and Cancer* fact sheet.

## Changes to appearance

Many types of surgery for head and neck cancer will cause temporary or permanent changes to the way you look.

**Weight loss** – It is common to lose weight during treatment and many people find it hard to put the weight back on.

**Feeding tubes and stomas** – People who need a feeding tube or tracheostomy tube or who have a stoma following a laryngectomy may feel self-conscious about it.

**Scars** – Improved surgical methods mean that most people won't have major scarring. Surgeons will try to hide scars in skin creases in the neck or on the face, and the scars usually fade over time. Scars from radiation therapy may change the colour or texture of the skin.

**Face** – In some cases, removing the cancer means removing an eye or part of the jaw, nose, ear or skin. Some people have reconstructive surgery using tissue from another part of the body. Other people may

have a prosthesis (e.g. a nose prosthesis), a soft plastic replacement for the tissue that has been removed. A prosthesis will be specially fitted to blend in well with your own features. If you are likely to need a prosthesis, the surgeon will discuss it with you before the operation.

**Jaw and teeth** – For certain cancers, your surgeon will need to 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 noticeable for some time. If you have lost teeth due to cancer treatment, you may be able to have further surgery to replace or reconstruct them.

**Swelling** – Surgery or radiation therapy can damage lymph nodes, and cause swelling called lymphoedema (see page 68).



## Tips for adjusting to appearance changes

- Try to see yourself as a whole person (body, mind and personality) rather than focusing only on the part of you that has changed.
- Talk about how you are feeling with a family member, friend, social worker, occupational therapist or psychologist.
- Look Good Feel Better workshops can be booked at [lgfb.org.au](http://lgfb.org.au). They show you how to use hats, wigs and skin care to boost self-esteem, and are for all genders.
- Ask your treatment team how surgery will affect your appearance and if you will be offered reconstructive surgery or a prosthesis to rebuild parts of your face and neck. Your team can suggest ways to cope and refer you to support services.
- Give yourself time to get used to any changes. Some may be temporary or improve with time.

## Sex and intimacy

Head and neck cancer can affect your sex life in emotional and physical ways. Less interest in sex (low libido) is common. Continuing to feel tired after treatment and feeling anxious about cancer returning may also affect your sexual wellbeing. If your appearance has changed, you may grieve for how you used to look or worry about feeling attractive.

Treatment may cause side effects such as dry mouth, bad breath, thick and sticky saliva, poor tongue and lip movement, facial palsy, scars, or a stiff neck and jaw. Mouth surgery may reduce feeling in the tongue or lips, but feeling should return in 12–18 months. These changes can make kissing and oral sex difficult, while any altered speech may affect your self-esteem and ability to express yourself during sex.

During chemotherapy, use barrier contraception (e.g. condoms) during sexual intercourse to avoid exposing your partner to chemotherapy risks and to avoid getting pregnant. It is important to discuss this with your doctor to keep your partner safe and to prevent pregnancy.

You or your partner/s may worry about having sex if the cancer was HPV-related (see page 15). A long-term partner is likely to have already had the virus and cleared it without having symptoms. Their immune system remembers it and stops an infection developing again. Talk to your doctor about the risk of passing on HPV to a new partner.

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

► See our *Sexuality, Intimacy and Cancer* and *LGBTQI+ People and Cancer* booklets.

## 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, painted to look like your other 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 won't be as good. The physiotherapist and occupational therapist can assist you to manage any changes to your vision after surgery. You will usually still be able to drive and play sport, but it may take time to get used to the changes. Before you start driving again, tell your driver licensing authority about the changes in your vision, as there may be restrictions you have to follow. The licensing authority may ask for information from your doctor to decide if you are medically fit to drive.

## Hearing loss

Ask your treatment team whether you are at risk of hearing loss and if you should have your hearing tested after treatment ends.

**Chemotherapy** – Some drugs can cause hearing loss. The first sign may be ringing in the ears (tinnitus), so tell your doctors if you notice this.

**Radiation therapy** – This can damage the internal structure of the ear, cause fluid build-up behind the eardrums and lead to loss of hearing.

**Surgery** – Some surgeries, especially for nasopharyngeal cancer, can cause temporary or permanent hearing loss.

## Lymphoedema

If lymph nodes have been removed in a neck dissection (see page 31) or damaged by radiation therapy, this may prevent lymph fluid from draining properly. The fluid can build up and cause swelling in the neck, face and throat. This is known as lymphoedema. It can be temporary or permanent and may change your appearance. People who have had surgery followed by radiation therapy to the neck are more at risk, especially if both sides of the neck are treated. You are also more likely to develop lymphoedema if a lot of lymph nodes were removed.

Symptoms of lymphoedema can be 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. Sometimes the swelling develops internally and is hard to see but the area may feel different (e.g. mild tingling). It is important to look out for these signs and to visit 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 and occupational therapists who can teach you simple exercises to reduce your risk of developing lymphoedema, or show you ways to manage it if you have it already. There are also private lymphoedema practitioners who can help with prevention and offer treatments such as lymphatic drainage massage, exercises, low-level laser therapy, skin care and compression garments, if needed. To find a lymphoedema practitioner, visit [lymphoedema.org.au](http://lymphoedema.org.au).

► See our *Understanding Lymphoedema* fact sheet.

## Key points about managing side effects

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### 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 treatment.
- Common side effects include mouth problems; changes to eating, breathing and speech; swallowing difficulties; and other physical changes.

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### Mouth and eating 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 permanently lose their sense of smell.
- Difficulty swallowing is common and can be managed using exercises, medicines and diet.
- Using a feeding tube may be helpful if you have trouble eating. This may be for a few weeks or it may be long term.

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### Other 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 for People Living with 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, may prevent successful treatment of the cancer and can be harmful. 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 whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

► See our *Cancer and Your Finances* and *Cancer, Work and 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. The experience of cancer 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 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 to 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 head and neck 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

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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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. 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](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline 13 11 14 or visit [lifeline.org.au](http://lifeline.org.au).

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## Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. During these check-ups, 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 mention any other concerns. You will receive continued support from a speech pathologist, dietitian, occupational therapist, physiotherapist, psychologist and social worker 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. You will usually continue to have check-ups for 5 years, but they 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. Sometimes this will be another cancer of the head and neck, but it can also be the original cancer that has spread to another part of the body. This is why it's important to have check-ups.

If the cancer does come back or you develop a new cancer, it is important that you are reviewed by an experienced multidisciplinary team. The treatments you are offered will vary depending on your previous treatments. Surgery, radiation therapy, chemotherapy and immunotherapy may all be options. Targeted therapy is rarely used.

# 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.

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 by location.

### Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

### Information resources



Cancer Council produces booklets and fact sheets on more than 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.

### Legal and financial support



If you need advice on legal or financial issues, we may be able to refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. To find out more, call Cancer Council 13 11 20.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### 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](http://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	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Guides to Best Cancer Care	<a href="http://cancer.org.au/cancercareguides">cancer.org.au/cancercareguides</a>
Australasian Lymphology Association	<a href="http://lymphoedema.org.au">lymphoedema.org.au</a>
Australian and New Zealand Head & Neck Cancer Society	<a href="http://anzhnscs.org">anzhnscs.org</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Dietitians Australia	<a href="http://dietitiansaustralia.org.au">dietitiansaustralia.org.au</a>
Head & Neck Cancer Australia	<a href="http://headandneckcancer.org.au">headandneckcancer.org.au</a>
Head & Neck Cancer Video Series	<a href="http://headneckcancerforum.com">headneckcancerforum.com</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Services Australia (including Centrelink and Medicare)	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>
Radiation Oncology: Targeting Cancer	<a href="http://targetingcancer.com.au">targetingcancer.com.au</a>
Speech Pathology Australia	<a href="http://speechpathologyaustralia.org.au">speechpathologyaustralia.org.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
The Swallows Head & Neck Cancer Support Group (UK)	<a href="http://theswallows.org.uk">theswallows.org.uk</a>



# 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 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](http://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 Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://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.

## Question checklist

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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.

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### Diagnosis

- What type of head and neck cancer do I have?
  - Has the cancer spread? What do the staging numbers mean?
  - 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?
  - 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 side effects of treatment? Will they be permanent?
  - 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?
  - How will my eating be affected? Will I need a feeding tube?
  - 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

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## **advanced cancer**

For head and neck cancer, this means a cancer that has spread beyond the initial site. It may have spread to nearby tissue and lymph nodes (locally advanced) or it may have spread to other parts of the body (secondary or metastatic cancer).

## **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.

## **aspiration**

Food or drink going into the lungs when swallowing.

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## **benign**

Not cancerous or malignant.

## **biopsy**

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

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## **carcinoma**

A cancer that starts in the tissue cells lining the skin and internal organs of the body.

## **cells**

The basic building blocks of the body.

A human is made of billions of cells that perform different functions.

## **chemoradiation**

Treatment that combines chemotherapy with radiation therapy. Also known as 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**

See skull base surgery.

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## **dysphagia**

Difficulty swallowing.

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## **endoscopic surgery**

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

## **endoscopy**

An examination of the inside of the body using a thin, flexible tube with a light and camera on the end. An endoscopy of the nose and throat area may be called a nasendoscopy or flexible laryngoscopy.

## **energy (kilojoules/calories)**

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

## **epiglottis**

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

## **ethmoid sinuses**

Sinuses located above the nose and between the eyes.

## **external beam radiation therapy (EBRT)**

Radiation therapy delivered to the cancer from outside the body.

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## **facial nerve**

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

## **feeding tube**

A flexible tube used to provide liquid nutrition to people unable to swallow.

### **frontal sinuses**

Sinuses located behind the forehead.

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### **gastrostomy tube**

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

### **glossectomy**

Surgery to remove part or all of the tongue.

### **glottis**

The part of the larynx containing the vocal cords.

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### **human papillomavirus (HPV)**

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

### **hypopharyngectomy**

Surgery to remove part of the lower throat.

### **hypopharynx**

The lowest part of the back of the throat.

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### **immobilisation device**

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

### **immunotherapy**

Drugs that use the body's own immune system to fight cancer.

### **intravenous (IV)**

Injected into a vein.

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### **laryngectomy**

Surgery to remove the larynx. In a partial laryngectomy, part of the larynx is removed. In a total laryngectomy, the whole larynx is removed.

### **laryngoscopy**

A procedure where the doctor examines the back of the throat, larynx and pharynx. See also endoscopy and microlaryngoscopy.

### **larynx**

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

### **lymphadenectomy**

See neck dissection.

### **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 (lymph glands)**

Small bean-shaped structures that collect and destroy bacteria and viruses.

### **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.

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### **malignant**

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

### **malnutrition**

An imbalance of energy and nutrients in the body that can affect overall health and how the body responds to cancer treatment and recovery.

### **mandible**

The lower jaw.

### **mandibulectomy**

Surgery to remove part or all of the lower jaw.

### **mandibulotomy**

Cutting through the lower jaw to reach 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 jaw.

### **maxillary sinuses**

Sinuses located under the eyes and in the cheek area.

### **maxillectomy**

Surgery to remove part or all of the upper jaw.

### **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 known as secondary cancer.

### **microlaryngoscopy**

A procedure using a stainless steel instrument called a laryngoscope to examine the throat and voice box and take a tissue sample. It is done under general anaesthetic.

### **mucus**

A slippery, stringy substance produced by the lungs, nose and sinuses.

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### **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 thin, flexible tube with a light and camera on the end.

### **nasogastric (NG) tube**

A thin feeding tube that is passed through a nostril, down the throat and into the stomach.

### **nasopharynx**

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

### **neck dissection**

Surgery to remove lymph nodes from the neck. Also known as lymphadenectomy.

### **nutrition**

The process of eating and digesting food to obtain the nutrients the body needs.

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### **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.

### **oral cavity**

The mouth, including the gums, cheek linings, the roof and floor of the mouth, front two-thirds of the tongue, and the small area behind the wisdom teeth.

### **orbital exenteration**

Surgery to remove the eye and other tissue around the eye socket.

### **oropharyngectomy**

Surgical removal of some of the throat behind the mouth.

### **oropharynx**

The middle part of the throat behind the mouth. It 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 potential side effect of radiation therapy in which bone tissue breaks down.

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### **palliative treatment**

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms or side effects.

### **paranasal sinuses**

Small, air-filled spaces in the side walls of the nose.

### **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 using endoscopy.

### **peripheral neuropathy**

Weakness, numbness, tingling or pain, usually in the hands and feet, which is caused by damage to the nerves that are located away from the brain and spinal cord (peripheral nerves). This damage can be a side effect of chemotherapy.

### **pharyngectomy**

Surgery to remove part or all of the throat.

### **pharyngolaryngectomy**

Also called laryngopharyngectomy. Surgery to remove all of the larynx and most of the pharynx.

### **pharynx**

The throat. This is a hollow tube that starts behind the nose. It connects the mouth and nose with the windpipe (trachea) and the food pipe (oesophagus).

### **prosthesis**

An artificial replacement for a lost or damaged body part.

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### **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 known as 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**

Surgery to remove part or all of the nose.

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### **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. They include the parotid glands (in front of the ears), the submandibular glands (under the lower jaw) and the sublingual glands (under the tongue).

### **skull base surgery**

Surgery to remove part of the nasal cavity or sinuses. Also known as craniofacial resection.

### **sphenoid sinuses**

The sinuses located behind the nose and between the eyes.

### **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 lower jaw.

---

### **targeted therapy**

Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

### thyroid

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

### tonsils

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

### trachea

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

### tracheoesophageal fistula or puncture

A surgically created opening 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). A tracheostomy tube will be inserted into this hole to keep it open and allow you to breathe freely.

### transoral laser microsurgery (TLM)

Surgery using a microscope with a laser to remove a tumour through the mouth.

### transoral robotic surgery (TORS)

Surgery to remove a tumour through the mouth using surgical instruments attached to robotic arms.

### 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).

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### ultrasound

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

### uvula

A small piece of soft tissue hanging down from the soft palate above the throat.

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### vocal cords

The part of the larynx that vibrates to make sounds needed for speech. See also glottis.

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### xerostomia

Dry mouth.

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## Can't find a word here?

For more cancer-related words, visit:

- [cancercouncil.com.au/words](https://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](https://cancervic.org.au/glossary)

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# 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 experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [accesshub.gov.au](http://accesshub.gov.au)

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*Cancer Council services and programs vary in each area.*

*13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support  
on cancer-related issues,  
**call Cancer Council 13 11 20**

## Visit your local Cancer Council website

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**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council Australia**  
[cancer.org.au](http://cancer.org.au)

*This booklet is funded through the generosity of the people of Australia.  
To support Cancer Council, call your local Cancer Council or visit your local website.*

