Understanding Head and Neck Cancers
A guide for people with cancer, their families and friends

For information & support, call 131120
Understanding Head and Neck Cancers
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Understanding Head and Neck Cancers is reviewed approximately every two years. Check the publication date above to ensure this copy of the booklet is up to date. To obtain a more recent copy, phone Cancer Council 13 11 20.


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

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

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

Cancer Council Australia
Cancer Council Australia is the nation’s peak non-government cancer control organisation. Together with the eight state and territory Cancer Councils, it coordinates a network of cancer support groups, services and programs to help improve the quality of life of people living with cancer, their families and carers. This booklet is funded through the generosity of the people of Australia. To make a donation and help us beat cancer, visit Cancer Council’s website at cancer.org.au or call your local Cancer Council.

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Introduction

This booklet has been prepared to help you understand more about head and neck cancer, a general term for cancers in the mouth, nose and throat areas.

Many people feel shocked and upset when they are told they have head and neck cancer. We hope this booklet will help you, your family and friends understand how head and neck cancer is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you, but we hope this information will answer some of your questions and help you think about other questions to ask your doctors and treatment team.

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. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed
This booklet was developed with help from a range of health professionals and people affected by head and neck cancer.

If you or your family have any questions, call Cancer Council 13 11 20. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.
What is cancer?

Cancer is a disease of the cells, which are the body’s basic building blocks. 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.

Sometimes cells don’t grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

### How cancer starts

Normal cells

[Diagram showing normal cells]

Abnormal cells

[Diagram showing abnormal cells]

Abnormal cells multiply

[Diagram showing multiplying abnormal cells]

Malignant or invasive cancer

[Diagram showing malignant or invasive cancer]
The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue (local invasion) and can grow its own blood vessels (angiogenesis).

If cancerous 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 person may be experiencing symptoms caused by problems in the lungs.

**How cancer spreads**

- Primary cancer
- Local invasion
- Angiogenesis – tumours grow their own blood vessels
- Lymph vessel
- Metastasis – cells invade other parts of the body via blood vessels and lymph vessels
The head and neck includes the following organs and body parts:

**Mouth (oral cavity)**
The mouth includes the lips, gums and tongue. The muscles of the base of the tongue (tongue base) continue into the upper throat (oropharynx).

The roof of the mouth is called the hard palate. Behind this is the soft palate. The soft palate lifts to close off the passageways to the nose so food does not go through the nose when swallowing.

Under the tongue and near the upper back teeth are salivary ducts that release saliva into the mouth. These are joined to salivary glands. The major glands are in front of the ears, and under the jaw and tongue. There are hundreds of minor glands in the mouth lining.
Throat (pharynx)

The pharynx is a tube that runs from the back of the nose to the gullet (oesophagus) and the windpipe (trachea). The pharynx has three parts: the nasopharynx, oropharynx (including the tonsils) and hypopharynx.

Air passes through the nasopharynx as you breathe in and out. Both food and air pass through the oropharynx and hypopharynx. Food goes into the stomach via the oesophagus, while air goes into the trachea to get to the lungs.
Voice box (larynx)

The larynx is a short passageway that connects the lower part of the pharynx (hypopharynx) with the windpipe (trachea). It contains the vocal folds or vocal cords (glottis), which vibrate when air passes through them to produce sound.

Above the vocal folds is a small flap of tissue called the epiglottis, which prevents food going into the trachea when you swallow. Below the vocal folds is the subglottis.

Under the voice box, in front of the trachea, is the thyroid gland.
Nasal cavity and paranasal sinuses

The nasal cavity is the large, air-filled space behind the nose. The nose and upper respiratory tract warm, moisten and filter the air that you breathe.

Paranasal sinuses are air-filled spaces within your skull that help to lighten the weight of your head. They also produce mucus and vibrate sound when you speak or sing. The sinuses are in four locations: frontal, ethmoid, sphenoid and maxillary.

- **Frontal sinuses** – behind the forehead.
- **Ethmoid sinuses** – between the eyes.
- **Sphenoid sinuses** – in the middle towards the base of the skull.
- **Maxillary sinuses** – under the eyes and within the cheek (maxillary) bones.
Key questions

Q: What is head and neck cancer?
A: Head and neck cancer is a general term used to refer to a range of different cancers that start developing in the head and neck region of the body. This includes the oral cavity, the tongue, palate, jaw, salivary glands, the throat (larynx) and the nose.

Head and neck cancer occurs when malignant tumours grow in any of the tissue or lymph nodes in the head or neck. Not all tumours in the head and neck are malignant.

Q: What are the different types?
A: Most head and neck cancers start in the cells that line the mouth, nose or throat (squamous cells). These are called squamous cell carcinomas. Some cancers start in glandular cells. Many of these are called adenocarcinomas. Squamous cell carcinomas and adenocarcinomas can also occur in other parts of the body.

- **Mouth or oral cancer** – refers to cancer that starts anywhere in the mouth, including the lips, inside cheeks, the front two-thirds of the tongue, floor of the mouth, jaw and the gums.

- **Salivary gland cancer** – refers to cancer that occurs in any of the paired major glands in front of the ears (parotid glands) or beneath the jaw (submandibular glands) or tongue (sublingual glands).
• **Pharyngeal cancer** – refers to cancer that begins in the throat (pharynx): nasopharyngeal, oropharyngeal and hypopharyngeal cancers.

• **Laryngeal cancer** – refers to cancer that starts in the voice box (larynx).

• **Nasal cancer or paranasal sinus cancer** – includes cancer starting in the nose, nasal cavity or the sinuses.

**Q: How common is it?**

**A:** About 4000 people in Australia (approximately 2920 men and 1080 women) are diagnosed with head and neck cancer each year¹ (see page 79 for references).

This includes about 1250 people diagnosed with an oral cancer (mouth and tongue); 900 with lip cancer; 300 with salivary gland cancer; 800 with pharyngeal cancer; 600 with laryngeal cancer; and 150 with nasal or paranasal sinus cancer.

**Other cancers in the head and neck area**

Cancer can start in the tissue of the brain, eye, oesophagus, thyroid gland, skin and scalp. It can also start in the bone or muscle of the head and neck. These cancers are not classified as head and neck cancer. For information about these cancers, call Cancer Council 13 11 20.
Q: **What are the symptoms?**

A: There are many possible symptoms of head and neck cancer. However, displaying these symptoms does not necessarily mean you have cancer. Only a qualified medical practitioner can make this diagnosis.

<table>
<thead>
<tr>
<th>Oral cancer</th>
<th>Pharyngeal cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>• mouth pain or pain on swallowing</td>
<td>• throat pain or difficulty swallowing</td>
</tr>
<tr>
<td>• a persistent sore or swelling in the mouth or jaw</td>
<td>• a persistent sore throat or cough</td>
</tr>
<tr>
<td>• unusual bleeding or numbness in the mouth</td>
<td>• coughing up bloody phlegm</td>
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<tr>
<td>• white patches (leukoplakia) or red patches (erythroplakia) on your gums, tongue or mouth</td>
<td>• bad breath</td>
</tr>
<tr>
<td>• changes in speech or difficulty pronouncing words</td>
<td>• weight loss</td>
</tr>
<tr>
<td>• difficulty chewing or swallowing food</td>
<td>• voice changes or hoarseness</td>
</tr>
<tr>
<td>• weight loss</td>
<td>• dull pain around the breastbone</td>
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<tr>
<td>• a lump in your neck</td>
<td>• a lump in the neck</td>
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<tr>
<td>• loose teeth or dentures that no longer fit</td>
<td>• pain in the ear</td>
</tr>
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<td></td>
<td>• feeling that your air supply is blocked</td>
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<td>• numbness of the face</td>
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<tr>
<td>Salivary gland cancer</td>
<td>Salivary gland cancer</td>
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<tr>
<td>swelling or a lump near the ear, jaw, lip, or inside the mouth</td>
<td>swelling or a lump in your neck or throat</td>
</tr>
<tr>
<td>different appearance on each side of the face or neck</td>
<td>a persistent sore throat</td>
</tr>
<tr>
<td>difficulty swallowing or opening mouth widely</td>
<td>a persistent change in the sound of your voice, including hoarseness</td>
</tr>
<tr>
<td>drooping, numbness or muscle weakness on one side of the face (palsy)</td>
<td>difficulty swallowing or painful swallowing</td>
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<tr>
<td></td>
<td>constant coughing</td>
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<td></td>
<td>difficulty breathing</td>
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<td>weight loss</td>
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</table>
Q: What are the risks?
A: A number of factors are associated with increased risk.

**Major risk factors**
Smoking and alcohol consumption are the primary risk factors for most types of head and neck cancer, except for salivary gland cancer. Research indicates that at least 75% of head and neck cancers are caused by a combination of cigarette smoking and alcohol consumption\(^2\).

**Tobacco use** – Smoking (cigarettes, cigars, pipes) is associated with an increased risk of head and neck cancer, especially cancer of the larynx.

**Alcohol use** – Alcohol use may lead to an increased risk, especially in heavy drinkers (3 or more drinks a day). Using both tobacco and alcohol magnifies the risk.

**Other risk factors**

**Age** – Head and neck cancer is most common in people aged 40 years and older.

**Sex** – In Australia, men are about three times more likely than women to get head and neck cancer.

**Viruses** – Human papillomavirus (HPV) has been linked to cancers of the oropharynx, and may play a role in other head and neck cancers. Epstein-Barr virus (EBV) may also have a role in the development of some head and neck cancers.
Genetic factors – People from some cultural backgrounds may be more likely to develop types of head and neck cancer. For example, people from southern China and South-East Asia may have an increased risk of nasopharyngeal cancer.

Occupational and environmental exposures – Breathing in asbestos fibres, wood dust, dry-cleaning solvents or certain types of paint or chemicals is associated with an increased risk of laryngeal squamous cell carcinoma³.

Oral hygiene – Poor oral health and gum disease have been linked to cancers of the oral cavity.

Sun exposure – Ultraviolet (UV) radiation may cause skin cancer on the lip.

Low immunity – People with low immunity have a higher risk of developing oral and oropharyngeal cancer.

Nutrition – A diet low in fruits and vegetables and Vitamin A increases the risk of oral and oropharyngeal cancer⁴.

Areca nut, betel nut, paan or gutka – Chewing this type of palm tree seed, often wrapped in leaves, may cause oral cancer.

Having one or more of these risk factors does not mean you will get a head and neck cancer. Talk to your doctor if you are concerned about these risk factors.
Diagnosis

After initial tests, your general practitioner (GP) will refer you to a specialist for further tests. Depending on your symptoms, tests will include examinations, tissue sampling (biopsy) and imaging tests. You will probably also have blood tests.

Physical examination

Your doctor will examine your mouth, tonsils and soft palate (oropharynx), neck, ears and eyes. A spatula may be used to see inside the mouth more clearly. The doctor may also insert a gloved finger into your mouth to feel areas that are difficult to see, and check your lymph nodes (lymph glands) by gently feeling the sides of your neck.

Some head and neck cavities are difficult to see, so for other locations, such as the nasopharynx, tongue base and pharynx, the doctor may use viewing equipment (see below). A tissue sample (biopsy) may also be taken at this time.

If you notice a sore, swelling or change of colour in your mouth, make an appointment to see your dentist. Any unexplained changes that are present for more than two weeks may need to be biopsied.

Nasendoscopy

A nasendoscopy is an examination of the nose and throat using a flexible fibre-optic tube with a light and camera on the end of it (endoscope). A local anaesthetic is sprayed gently into the nose.
You may find that the spray tastes bitter. Your nose and throat will remain numb for up to 20 minutes.

The doctor will insert the endoscope into your nose to look at your nasal cavity, nasopharynx, oropharynx, hypopharynx and larynx. Images from the endoscope may be projected onto a screen.

A nasendoscopy is not painful as the tube is soft and flexible. However, it can feel unusual. You will be asked to breathe lightly through your nose and mouth. You may be asked to swallow and to make some vocal noises. The doctor may also take some tissue samples. The test takes 5–15 minutes. Afterwards, you can’t eat or drink for about 30 minutes, but you can go home straight away.

**Laryngoscopy**
A laryngoscopy is a procedure that allows a doctor to examine your larynx and pharynx, and take a tissue sample (biopsy) from your larynx. A tube with a light and camera on it (laryngoscope) is inserted into your mouth and throat and shows the area on a screen.

The procedure is done under a general anaesthetic and will take 10–40 minutes. You can go home when you’ve recovered from the anaesthetic. You may have a sore throat for a couple of days.

A bronchoscopy is similar to a laryngoscopy, but it allows doctors to examine the airways to see if cancer has spread to the lungs. The tube (bronchoscope) is inserted into the lungs via the mouth and throat. It may be done under a local or general anaesthetic.
Biopsy
A biopsy is used to diagnose all head and neck cancers. During a biopsy, a small amount of tissue is removed from the affected area under local or general anaesthetic. The sample is sent to a lab where a pathologist examines the tissue under a microscope. This test enables the pathologist to see whether cancer cells are present, and determine what type of cancer it is. Biopsy results are usually available in about a week.

If you have a biopsy on a lump in your neck or on a tumour that is difficult to access, it will probably be done with a needle that is guided using an ultrasound (see page 20) or a CT scan (see below).

CT scan
A CT (computerised tomography) scan is used to assess the extent of many head and neck cancers. A CT scan uses x-ray beams to take pictures of the inside of your body. Before the scan, you may have iodine contrast injected into a vein in your arm to show the blood vessels and make the pictures clearer. The dye may make you feel flushed or hot for a few minutes.

You will lie still on a table that moves slowly through the CT scanner. The scanner is large and round like a doughnut. The CT scan itself takes a few minutes and is painless, but the preparation takes 10–30 minutes. You can go home when the scan is complete.
MRI scan

An MRI (magnetic resonance imaging) scan is used to assess the extent of many head and neck cancers. An MRI uses magnetism and radio waves to build up detailed cross-section pictures of the body. As with a CT scan, a dye may be injected into your veins before the scan to make the pictures clearer. The pictures are taken while you lie on a table that slides into a narrow metal cylinder – a large magnet – that is open at both ends.

An MRI takes about an hour and you will be able to go home when it is over. The test is painless, but the noise of the machine can be a source of distress. In addition, some people feel anxious or claustrophobic lying in such a confined space. If you think this will be a problem, let the doctor or nurse know beforehand, as they can give you medication to help you relax. Cancer Council also has a number of relaxation and meditation resources, which may assist. Call Cancer Council 13 11 20 or visit your local Cancer Council website for more information.

You will not be able to have an MRI if you have a pacemaker or another iron-based metallic object in your body, because the scan may damage these devices.
**PET scan**

A PET (positron emission tomography) scan is nearly always recommended to help diagnose oral, pharyngeal or laryngeal cancer, or to see if the cancer has spread.

A PET scan is a specialised imaging test that is available at most major hospitals. Before the scan, you will be injected with a glucose solution that contains some radioactive material. You will be asked to wait for 30–90 minutes as the solution spreads through your body. You will need to lie still during this time.

The glucose solution gathers in the cells, including cancer cells, which are using more energy. These show up as ‘hot spots’ during the scan. Not all PET hot spots indicate cancer. The scan itself takes around 30 minutes.

If you have diabetes, you may need to follow a different procedure for a PET scan. Your blood sugar levels may need to be checked before the scan. Tell your doctor so the test can be adjusted.

**Ultrasound**

An ultrasound is sometimes used to assess pharyngeal cancer or to see if another type of cancer has spread.

A gel will be spread over your neck, and a paddle-shaped device called a transducer will be moved over the same area. The transducer creates soundwaves that echo when they meet something dense like...
an organ or a tumour. The ultrasound images are then projected on to a computer screen. An ultrasound is painless and takes about 15 minutes to perform.

**X-rays**
You may need standard x-rays of your head and neck to check for tumours or damage to the bones. X-rays are quick and painless and may include the following:

- **Orthopantomogram (OPG)** – Used to examine the jaw and teeth of people with mouth cancer.

- **Chest x-ray** – Sometimes used to check the general health of people with mouth, pharyngeal or laryngeal cancer, or to see whether the cancer has spread to the lungs. However, most people have CT scans and PET scans to look at these areas.

- **X-ray of facial bones** – Used in the case of nasal or paranasal sinus cancer to check whether the cancer has spread.

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**Cancer of Unknown Primary (CUP)**

CUP, or cancer of unknown primary, is a metastatic cancer (cancer that has spread) with an unknown starting point. If CUP first shows up as a tumour in the head or neck, doctors may call it metastatic neck cancer and treat it like a head and neck cancer.
Staging head and neck cancer

Staging determines how large the cancer is and whether the cancer has spread from the original site to nearby structures and other parts of the body. Your doctor will give the cancer a stage from 1–4 to help determine the best treatment.

The head and neck staging system is called the TNM system. This system is also used to stage cancers in other parts of the body.

<table>
<thead>
<tr>
<th>TNM system</th>
<th>Description</th>
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<tbody>
<tr>
<td><strong>T (Tumour)</strong></td>
<td>Refers to the size of the primary tumour. The higher the number, the larger the cancer.</td>
</tr>
<tr>
<td>1–4</td>
<td></td>
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<tr>
<td><strong>N (Nodes)</strong></td>
<td>Shows whether the cancer has spread to the regional lymph nodes of the neck. No nodes affected is 0; increasing node involvement is 1, 2 or 3.</td>
</tr>
<tr>
<td>0–3</td>
<td></td>
</tr>
<tr>
<td><strong>M (Metastasis)</strong></td>
<td>Cancer has either spread (metastasised) to other organs (1) or it hasn’t (0).</td>
</tr>
<tr>
<td>0–1</td>
<td></td>
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Prognosis

Prognosis means the expected outcome of a disease. However, it is impossible for any doctor to predict that exact course of the disease. Test results, the type and stage of the cancer, how well you respond to treatment, and factors such as age and medical history are all important in assessing your prognosis. The results of head and neck cancer treatment are best when the cancer is found and treated early.
Which health professionals will I see?
Your GP will usually arrange the first tests to assess your symptoms. If you need further tests, you will be referred to a specialist, who will make a diagnosis and advise you about treatment options. You will be cared for by a team of health professionals who meet regularly to discuss and plan your treatment. This team may include some or all of the health professionals listed on the following pages.

Reene’s story
The first indications of a problem were food getting stuck in my throat and soreness there. Later a lump developed on the right side of my neck.

My GP referred me to an ENT specialist. He did a biopsy of the lump on my neck, which showed it was a squamous cell carcinoma. I also had x-rays, a CT scan, and a second biopsy in my throat area. They found a primary oropharyngeal cancer in my tonsil and at the back of my tongue. The lump on my neck was a secondary tumour. In hospital, I had several scans to see whether the cancer had spread beyond my neck.

I had radiotherapy to both sides of my throat, as well as chemotherapy. I had to have my back teeth removed as they were in the path of the radiation. Six months later, I had a neck dissection to remove the lymph nodes on the left side.

I now have a dry mouth and difficulty swallowing. Exercises to strengthen my neck muscles have improved my swallowing.

I am grateful for the wonderful care I received in hospital during pre/post treatment and the supportive friendships found at my head and neck cancer support group.
<table>
<thead>
<tr>
<th>Health professional</th>
<th>Role</th>
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<tbody>
<tr>
<td><strong>ENT (ear, nose and throat) specialist</strong></td>
<td>treats disorders of the ear, nose and throat</td>
</tr>
<tr>
<td>head and neck surgeon</td>
<td>ENT or general surgeon specialising in cancer of the head and neck</td>
</tr>
<tr>
<td>oral (maxillofacial) surgeon</td>
<td>specialises in surgery to the face and jaws</td>
</tr>
<tr>
<td>reconstructive surgeon</td>
<td>performs surgery that restores, repairs or reconstructs the body’s appearance and function</td>
</tr>
<tr>
<td>medical oncologist</td>
<td>prescribes and coordinates chemotherapy, hormone therapy and targeted drug therapies</td>
</tr>
<tr>
<td>audiologist</td>
<td>diagnoses and treats hearing problems</td>
</tr>
<tr>
<td>dietitian</td>
<td>supports and educates patients about nutrition, diet and tube feeding</td>
</tr>
<tr>
<td>gastroenterologist</td>
<td>specialises in disorders of the digestive system, and inserts a feeding tube if required</td>
</tr>
<tr>
<td>Health professional</td>
<td>Role</td>
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<tr>
<td>---------------------------------------------------------</td>
<td>----------------------------------------------------------------------</td>
</tr>
<tr>
<td>radiation oncologist</td>
<td>prescribes and coordinates radiotherapy</td>
</tr>
<tr>
<td>dentist or oral medicine specialist</td>
<td>evaluates and treats the mouth and teeth</td>
</tr>
<tr>
<td>radiation therapist</td>
<td>plans and delivers radiotherapy treatment</td>
</tr>
<tr>
<td>prosthodontist</td>
<td>specialises in replacing any missing teeth</td>
</tr>
<tr>
<td>nurses and cancer nurse coordinators</td>
<td>coordinate your care and support you throughout treatment</td>
</tr>
<tr>
<td>speech pathologist</td>
<td>helps with communication and swallowing</td>
</tr>
<tr>
<td>social worker, psychologist and counsellor</td>
<td>provide emotional support and help manage anxiety and depression</td>
</tr>
<tr>
<td>physiotherapist and occupational therapist</td>
<td>assist in restoring range of movement after surgery</td>
</tr>
</tbody>
</table>
Key points

- You will have several tests to diagnose a head and neck cancer. These tests are arranged by your GP or specialists.

- Your doctor will do a physical examination of your oral cavity, neck, ears and eyes.

- You may have a nasendoscopy to check the tissue in your nose and throat. A flexible tube with a camera on it (endoscope) is inserted into your nose, and the images appear on a screen.

- A laryngoscopy allows the doctor to examine the larynx and pharynx. This is done while you are under general anaesthetic.

- A bronchoscopy examines the airways. This is also done under general anaesthetic.

- A tissue sample (biopsy) is taken to examine the cells under a microscope to see whether cancer is present. A biopsy is either done during a physical examination or under anaesthetic.

- A range of imaging tests will be done to take different types of pictures of the body. These will show where the cancer is located and whether it has spread from its original site.

- The tests help the doctors to stage the cancer, and work out the best treatment and the expected outcome of the disease (prognosis). Staging indicates how large the cancer is and how far it has spread.

- You will be cared for by a team of health professionals but will have one primary doctor.
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. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that’s based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 73 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.
A second opinion
You may want to get a second opinion from another specialist to confirm or clarify your doctor’s recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor 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 doctor who provided the second opinion.

Taking part in a clinical trial
Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call the Cancer Council 13 11 20 for a free copy of Understanding Clinical Trials and Research or visit australiancancertrials.gov.au.
The main treatments for head and neck cancers are surgery, radiotherapy and chemotherapy. These treatments may be used on their own, or in combination.

The choice of treatment will depend on:
• the type, size and location of the tumour
• your age, medical history and general health
• whether the cancer has spread
• the types of symptoms and side effects you experience.

How different cancers are treated

**Oral cancer** – is commonly treated with surgery, then radiotherapy if required. Chemotherapy is sometimes used in combination with these treatments.

**Salivary gland cancer** – is usually treated by surgery, followed by radiotherapy. Chemotherapy is not usually given unless the cancer has spread. Chemotherapy may also be offered as palliative treatment (see page 45).

**Pharyngeal cancer** – is usually treated with surgery or radiotherapy, or both. Chemotherapy may also be offered, usually with radiotherapy.

**Laryngeal cancer** – is treated with either laser surgery or radiotherapy in the early stages. For larger cancers, radiotherapy is usually combined with chemotherapy (chemoradiation). Chemotherapy may be given first to ease the pressure on a person’s
airway. For advanced cancer, surgery is used only if the cancer comes back or it’s not all destroyed by radiotherapy. Radiotherapy (with or without chemotherapy) will be given after surgery to reduce the chance of the cancer coming back.

**Nasal or paranasal sinus cancer** – is commonly treated with surgery, followed by radiotherapy and/or chemotherapy.

**Preparing for treatment**

Treatment for head and neck cancer, particularly radiotherapy, can cause dental problems. However, these problems can often be prevented.

Before starting cancer treatment it is recommended that you see a dentist or oral medicine specialist for a thorough oral examination and to get an oral health care plan. The plan outlines if any dentistry work is needed to reduce the chance of future dental problems. An oral health care plan also helps you learn good oral health care before, during and after treatment.

The dentist will probably recommend that any teeth that might be affected by radiotherapy are taken out. These teeth may be removed during cancer surgery or before radiotherapy.

*If you hold a Pensioner Concession Card or Health Care Card you may be eligible for free or low cost public dental services.*
Surgery

The aim of surgery is to remove cancerous tissue and preserve the functions of the head and neck, such as breathing, swallowing and speech, as much as possible.

Before recommending treatment, doctors determine how easy it is to access a tumour using surgery, the likely success of a surgery, and whether it will cause major side effects. They weigh up the benefits and impacts of all the treatments, while taking into account your wants, and your general health. For more information about making treatment decisions, see pages 27–28 of this booklet.

If surgery is minor, recovery is usually fast. There are likely to be few long-term side effects. For more advanced cancer, surgery will be more extensive, lasting up to twelve hours and often causing longer-lasting or permanent side effects.

If a head and neck cancer has spread to the lymph nodes in your neck, or if there is a chance it will spread, your surgeon will probably remove the nodes. This operation is called a neck dissection or lymphadenectomy. In some cases, this may be the only surgery you have, as the primary cancer will be treated with radiotherapy.

The surgeries for the different head and neck cancers are described on the following pages. For more information call Cancer Council 13 11 20 for a free copy of Understanding Surgery or visit your local Cancer Council website.
Types of surgery

There are two main types of surgery for head and neck cancer: surgery to remove the cancer (resection surgery) and surgery to repair any affected areas (reconstructive surgery).

Resection surgery
The surgery used depends on the size of the cancer and its position, and may involve:

- **Endoscopic surgery** – uses telescopes and microscopes through the nose and mouth to remove cancers.
- **Transoral surgery** – involves removing cancers through the mouth using standard surgical tools, or specialised tools incorporating laser or robotic technology.
- **Open Surgery** – involves making cuts in the neck or the lines of the face to access and remove cancers. Used for larger cancers and those in difficult positions. Bones of upper and lower jaw or skull may need to be removed.

Endoscopic and transoral surgeries minimise damage to surrounding tissues and are often done as a day or overnight procedure. Reconstruction may be required after open surgery.

Reconstructive Surgery
After surgery to remove advanced cancer, reconstructive surgery may be required to repair defects or restore function. Reconstructive surgery is either carried out at the same time as the resection, or at a later date. It may involve:

- **Skin, bone or tissue grafts** – involves use of skin, bone or tissue from another part of the body to rebuild the area.
- **Prosthetic reconstruction** – involves use of synthetic material.
Oral cancer surgery

Localised cancers can be treated with simple day surgery to remove part of the tongue or mouth. This will heal without side effects in a few weeks. If the cancer is larger, surgery may be more extensive and may require a reconstruction to help you chew, swallow or speak. You may also need a neck dissection to remove lymph nodes if there is a chance of the cancer spreading.

Different types of oral surgery include:
- **glossectomy** – removes part of the tongue
- **mandibulotomy** – cuts through the lower jaw
- **mandibulectomy** – removes part/all of the lower jaw
- **maxillectomy** – removes part/all of the upper jaw (hard palate)
- **transoral primary tumour resection** – removes the tumour through the mouth.

Tony’s story

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

I had surgery to remove the tumour, the affected jaw bone and lymph nodes. Later my jaw was reconstructed with bone from my leg. I also had radiotherapy to my lower jaw and neck for six weeks.

I recovered well. My only ongoing side effect is a dry mouth.
Salivary gland cancer surgery

Most salivary gland tumours affect the parotid gland, which has two parts. Surgery to remove this gland is called a parotidectomy. Surgeons can often cut inside or under the jaw to reach the area but sometimes they need to cut through the jaw. Reconstructive surgery will restore any removed tissue.

The facial nerve, which controls movement and muscle tone in the face, runs through the parotid gland. If the nerve is damaged or removed during the surgery, it may be repaired using a replacement nerve from another part of the body, often the leg (a nerve graft). If successful, this will improve movement and appearance on that side of the face.

If the cancer begins under the jaw or tongue, the entire gland will be removed, along with some surrounding tissue. Nerves controlling the tongue and lower part of the face may be damaged, causing some loss of function. If the cancer is in a minor salivary gland, in a paranasal sinus or the larynx, it may be removed with endoscopic surgery.

Some tumours found in the salivary glands are benign, but surgery is the same as for malignant tumours.

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

Early pharyngeal cancers may be treated with either surgery or radiotherapy. If you have surgery, the surgeon will cut out the tumour and a margin of tissue, which is checked by a pathologist to make sure all the tumour has come out.

If the cancer is large or advanced, the surgery is often combined with radiotherapy and possibly chemotherapy. The surgery is more likely to be extensive and may require reconstruction.

Often, lymph nodes will be removed from your neck (neck dissection or lymphadenectomy) to prevent the cancer spreading. This may affect the movement and appearance of your neck or shoulder. See pages 61–62 for more information.

Different types of pharyngeal surgery include:

- **pharyngectomy** – removes part or all of the pharynx
- **mandibulotomy** – cuts through the lower jaw
- **mandibulectomy** – removes part or all of the lower jaw
- **maxillectomy** – removes part or all of the upper jaw
- **laryngopharyngectomy** – removes part or all of the voice box (larynx) and pharynx.

Laryngeal cancer surgery

If the cancer is at an early stage, you may be offered transoral surgery using standard surgical techniques (cold steel surgery) or laser surgery. The time it takes for your voice to recover will depend on the extent of the surgery and may take up to six months.
In some cases, there may be long term or permanent changes to the pitch, loudness or quality of your voice. The surgeon will work with a speech pathologist to preserve as much of your ability to speak and swallow as possible.

If the cancer has advanced, you may need open laryngeal surgery. This will involve either a partial or total laryngectomy:

- **Partial laryngectomy** – Used for small laryngeal cancers, this surgery removes the part of the larynx where the cancer is. You will keep parts of your voice box and be able to speak and swallow. However, your voice may be hoarse after surgery. A speech pathologist can assist with retraining. This is now a rare surgery because endoscopic surgery has become more common.

- **Total laryngectomy** – This removes the larynx and separates the windpipe (trachea) from the oesophagus. Without your vocal cords, you won’t be able to speak naturally after this procedure, but you will work with a speech pathologist to learn ways to communicate. See pages 57–59 of this booklet for more information.

If you have a total laryngectomy, your thyroid gland will be removed during surgery (thyroidectomy). Once the thyroid is removed, you will no longer produce thyroxine (T4), the hormone that maintains your metabolism. After surgery, you will be prescribed an oral hormone tablet. You will need to take this hormone replacement daily for the rest of your life. This can be distressing, but talking to someone about how you feel may help.
Nasal and paranasal sinus cancer surgery

Your doctor may advise you to have surgery if the tumour isn’t too close to your brain, eyes or major blood vessels. The aim of surgery is to remove all of the tumour and a small area of normal tissue.

The type of surgery depends on the location of the tumour and, in the case of paranasal sinus cancer, the affected sinuses.

Different types of surgery for nasal cancer include:

- **maxillectomy** – removes part or all of the upper jaw, possibly including upper teeth, part of the eye socket and/or the nasal cavity
- **craniofacial resection** – removes tissue between the eyes, requiring a cut along the side of the nose
- **lateral rhinotomy** – cuts along the edge of the nose to gain access to the nasal cavity and sinuses
- **orbital exenteration** – removes the eye
- **rhinectomy** – removes part or all of the nose
- **endoscopic sinus surgery** – removal of part of the nasal cavity or sinuses through the nostrils, using an endoscope
- **midface degloving** – accesses your nasal cavity or sinuses by cutting under the upper lip, which avoids scarring of the face.

Some people also have surgery to remove lymph nodes in the neck (neck dissection or lymphadenectomy).

Your surgeons will plan carefully to avoid damaging healthy tissue. You may have open surgery, or you may have endoscopic surgery or midface degloving so that no cuts are made to the face.
The surgeons will consider how the operation will affect your appearance, and your ability to breathe, speak, chew and swallow. If your nose, or a part of it, is removed, you may get an artificial nose (prosthesis). This will be synthetic or made of tissue from other parts of your body – see pages 59–60 for more information.

**After surgery**

**Short-term side effects**

After surgery for localised cancer, side effects are often minor, and generally temporary. Short-term side effects vary depending on the surgery, but may include:

- **Sore throat** – Usually lasts for less than 24 hours, but may be longer in the case of pharyngeal or laryngeal surgery. You may have tubes at the surgery site to drain excess fluid.

- **Breathing changes** – If your mouth is swollen and breathing is difficult, the surgeon will create a breathing hole in your lower neck (tracheostomy). The tracheostomy is usually temporary. See page 55 for more information.

- **Dietary changes** – You will usually start with fluids, move on to puréed food, and then soft foods. A temporary feeding tube may be inserted through your nasal passageway for a few days or weeks. Alternatively, a gastrostomy tube, known as a PEG feeding tube, may be inserted. See page 51 for more information on managing dietary changes.
**Long-term side effects**

After surgery for localised or early stage cancer, there are generally few long-term side effects. However, after more extensive surgery, many people have to adjust to significant changes. You may also see a speech pathologist and/or dietitian before surgery to discuss these issues. Talk to your doctor about what to expect. Long-term side effects may include:

- **Breathing changes** – After certain throat surgeries, the surgeon will create a hole in your neck (stoma) so you can breathe. This can be temporary, or permanent in the case of a total laryngectomy. See page 55 for more information.

- **Taste and smell changes** – If you have a craniofacial resection, you may lose your sense of smell, and your sense of taste will be affected. If you have a laryngectomy, air will no longer pass through your nose, which can affect your sense of smell. See pages 50–51 for more information.

- **Swallowing difficulties** – Surgery may affect your ability to swallow. A speech pathologist will let you know safe ways to eat and drink and a dietitian can assist with diet modifications. If you are having difficulty eating or drinking, you may be given a temporary or permanent feeding tube. See pages 52–54.

- **Speech changes** – Changes to how clearly you speak and/or the quality of your voice depend on the surgery you had. Speech therapy can assist you in adjusting to these changes. See pages 57–59 for more information.
• **Appearance changes** – Many types of head and neck surgery will cause temporary or permanent changes to appearance. You may feel distressed or embarrassed about these changes. A reconstructive surgeon is often able to make physical changes (such as scars) less visible. See pages 59–61.

• **Pain and physical discomfort** – If you have lymph nodes removed, you may have numbness, reduced movement and/or pain in your neck or shoulder on the side of surgery. Sensation may gradually improve over 12 months and rehabilitation with a physiotherapist can help you regain movement. See pages 60–61.

• **Vision changes** – If the cancer is in your eye socket, the surgeon may have to remove your eye (orbital exenteration). Your changed vision should not prevent you from continuing activities such as driving or playing sport, but it may take time to get used to – and accommodate – the changes. See pages 61–62.

• **Lymphoedema** – If you have lymph nodes removed, you may experience persistent swelling in the soft tissue of the affected head and neck area. See page 62.

For detailed information about adapting to and managing side effects from surgery and other cancer treatments, see pages 48–62.

> It was good to be prepared about what all the tubes were and why they were there when I woke up from the operation.  
*Peter (nasopharyngeal cancer)*
Radiotherapy

Radiotherapy uses x-rays or electrons to kill or harm cancer cells so they can’t grow and multiply. It can be used alone or with other treatment. Radiotherapy can be given externally or internally.

External beam radiotherapy

External beam radiotherapy is common for oral, salivary gland, laryngeal, pharyngeal, nasal and paranasal sinus cancers.

Treatment is often given using a machine called a linear accelerator. You will lie on a treatment table while radiation is directed from a machine into your body. Treatment itself is painless and is usually given daily (Monday–Friday) as outpatient treatment for 6–7 weeks. You will be monitored by the radiation therapist team throughout. Many people are able to return to their usual activities 4–5 weeks after treatment ends.

Specialised forms of external beam radiotherapy used to treat head and neck cancers include intensity modulated radiation therapy (IMRT), Volumetric Modulated Arc Therapy (VMAT), and TomoTherapy. These techniques allow multiple radiation beams to be delivered from a variety of angles. This reduces the treatment time, and limits the impact of radiation on normal tissues.

Radiotherapy to the throat area may cause an underactive thyroid. Some people may need to take thyroid medication after radiotherapy.
Internal radiotherapy

Also known as brachytherapy, this treatment is occasionally used for oral cancers. Small tubes containing radioactive material are inserted into and around the tumour. Your doctor will give you more information about this treatment.

Immobilisation mask

Before radiotherapy you may need to be fitted for a plastic mask. Wearing the mask will assist you to keep very still during the treatment. This ensures that the radiotherapy is targeted to the correct area, and the same location is treated at each session.

You will wear the mask for up to an hour in the planning session, but only for 5–40 minutes during treatment, depending on the location of the cancer. You can see and breathe through the mask, but it may feel strange and claustrophobic at first. The radiation therapy care team can help you manage this.

Hyperbaric treatment

Radiotherapy to the head and neck can affect your teeth and bones, possibly causing osteoradionecrosis (ORN). Your health care team should include a dentist who takes measures to prevent this damage before treatment begins. However, if ORN does occur your doctors may treat it with hyperbaric oxygen treatment. This treatment delivers concentrated oxygen to the bone to help it heal. During this treatment, you will sit or lie in a pressurised chamber while oxygen is pumped in for you to breathe.
**Radiotherapy side effects**

Side effects vary according to the location of treatment, how long you have treatment for, and the type of radiotherapy you have. Side effects often peak in the final week of treatment, or shortly afterwards, then start to ease 2–3 weeks after treatment ends. Some side effects may last longer or be ongoing.

For information about managing side effects, see pages 48–62. Or call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy* or visit your local Cancer Council website.

### Possible side effects from radiotherapy

- dry mouth
- dental problems
- thick saliva
- damage to the jaw bone (osteoradionecrosis)
- difficulty swallowing
- swollen salivary glands
- difficulty opening the mouth fully (trismus)
- changes in sense of taste
- hair loss in the treated area
- loss of sweat glands in the treatment area
- fatigue
- muscle weakness in the treatment area
- appetite and weight loss
- nausea or gagging due to a build-up of phlegm
- hypothyroidism (underactive thyroid)
- skin soreness, redness, burning or ulceration
- damage to sight
- inflammation in the mouth or throat (mucositis)
- thrush in the mouth
- hoarseness
Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. The aim of chemotherapy is to destroy cancer cells while doing the least possible damage to healthy cells. You will probably receive chemotherapy by injection into a vein (intravenously) at treatment sessions over several weeks. Chemotherapy may be given in a number of ways, for a range of reasons:

- in combination with radiotherapy (chemoradiation) to increase the effects of radiation
- to shrink a tumour before surgery or radiotherapy (neoadjuvant chemotherapy)
- after surgery, along with radiotherapy, to reduce the chances of the cancer coming back (adjuvant chemotherapy)
- as a palliative treatment to reduce pain or discomfort by stopping or slowing the cancer from growing and pressing on nerves and other tissue.

Chemotherapy side effects

There are many possible side effects of chemotherapy, depending on the drugs you are given. Many side effects are preventable and treatable. Combined chemoradiation may cause more severe side effects than if you have chemotherapy and radiotherapy separately, but the side effects can be managed. The combined treatment approach is almost always only used when the aim of treatment is cure or prolonged remission.

Call Cancer Council 13 11 20 for your free copy of *Understanding Chemotherapy* or visit your local Cancer Council website.
Possible side effects from chemotherapy

- tiredness and fatigue
- nausea and/or vomiting
- tingling due to nerve damage
- taste changes
- poor appetite
- diarrhoea
- hair loss
- anaemia
- hearing loss
- an increased risk of infection
- mouth sores
- memory problems (chemo brain)

Palliative treatment

Palliative treatment helps to improve people’s quality of life by reducing symptoms of cancer without aiming to cure the disease.

Palliative treatment can assist with managing symptoms such as pain and nausea, as well as slowing the spread of cancer. In rare cases, palliative treatment is offered in an attempt to delay the onset of symptoms. Treatment may include radiotherapy, chemotherapy or other medications and always involves consideration of the potential benefits and side effects.

Palliative treatment may be beneficial for people at any stage of advanced disease, as well as those requiring end-of-life care.

Call Cancer Council 13 11 20 for more information about palliative care, advanced cancer and cancer pain.
Julie’s story

The treatment from my multidisciplinary team sent the stage 4 cancer in my tonsils, throat and tongue into remission in 2013. My cancer was caused by the HPV virus. I hadn’t drunk alcohol or smoked for over 30 years.

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 20kg over six to eight weeks. I lost the capacity to talk for quite a few weeks. I used an iPad to communicate.

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

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

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

I really recommend asking for help from speech pathologists, nutritionists, psychologists and senior nurses, as well as the medical team. Find a dentist who understands the effects of treatment and get advice for the health of your teeth long term. Tell your trusted family members and friends what you need and ask directly for help. Do everything you can to survive because life is precious and sweet.
Key points

- Head and neck cancer is commonly treated with surgery, radiotherapy, or chemotherapy, either alone or in combination.

- The type of surgery depends on the part of the head and neck affected.

- Not everyone with a head and neck cancer will have surgery. Many people with advanced cancer will have radiotherapy.

- For cancers that are easily accessible, surgery is straightforward. Most people recover quickly and manage any side effects well.

- For some head and neck cancers surgery may be more invasive and lead to long-term side effects that require ongoing rehabilitation.

- Reconstructive surgery, if required, can be carried out at the same time as the main operation or at a later stage.

- Radiotherapy, used alone or with other treatment, is a common treatment for head and neck cancer.

- Radiotherapy can be given externally (VMAT, IMRT, TomoTherapy) or internally (brachytherapy).

- Before radiotherapy, you may be advised to have a dental appointment to reduce the chance of serious future problems with your teeth and jaw.

- Chemotherapy can be used before or after surgery or radiotherapy, or at the same time as radiotherapy (chemoradiation).

- Palliative treatment is given to alleviate symptoms, such as pain. It may include radiotherapy, chemotherapy or medications.
Managing side effects

Head and neck cancer, and its treatment, can cause temporary or permanent side effects that require ongoing management and rehabilitation.

The following pages contain information and tips to help you manage side effects, including coping with changes in your eating, breathing, speech, and managing pain. For additional support, information and referral advice call Cancer Council 13 11 20.

Mouth problems

Dry mouth

Radiation to the head or neck can cause dry mouth (xerostomia). This can make chewing difficult and increase your risk of developing cavities in your teeth, so maintaining good oral hygiene is essential.

Managing dry mouth

- Speak to your dentist about an oral care plan and have regular check-ups.
- Carry a water bottle and have frequent sips of fluid with your meals.
- Avoid fluids that are dehydrating, e.g. alcohol or highly caffeinated drinks.
- Avoid dry foods, hard lollies, chips, nuts, crackers and toast.
- To stimulate saliva, try tangy foods, such as lemons or fruit, or sugar-free pastilles, mints or jubes.
- Make soft, moist meals, e.g. add gravies or sauces, use minced meat, have soups and casseroles, and add custard or cream to desserts.
- Acupuncture may assist in increasing saliva.
Mouth sores and ulcers
Mouth sores are common during chemotherapy and radiotherapy treatment. The sores can form on any soft tissue in your mouth, causing difficulty in eating, talking and swallowing.

Your doctor can give you medicines to reduce the pain when you eat, drink or speak. You may also use pain relief medications that can be applied directly to the mouth sores to numb them.

Your dietitian may assist you with choosing foods to minimise discomfort. You may need to choose softer foods and nourishing fluids. Depending on the severity of your pain, a feeding tube may be needed to meet your nutritional needs.

Managing mouth sores and ulcers
• Talk to your doctor about mouthwashes or medication to relieve ulcers and to keep your mouth fresh.
• Replace your toothbrush often to reduce infections. Run warm water over bristles before brushing, and brush gently.
• Avoid vinegar, spices, salty foods, alcohol, very hot or very cold foods and drinks, citrus and tomato-based food or juice.
• Try drinking diluted non-citrus juices such as pear or mango.
• Rinse your mouth and throat with warm saltwater or a mix of 1 tsp salt, 1 tsp baking soda and 4 cups of water.
• Don’t use mouthwashes with alcohol, as they may irritate ulcers.
• Tell your doctor or dietitian if you have ongoing or severe difficulty swallowing.
**Difficulty kissing**

Surgery to the mouth may reduce sensation in the tongue or lips, which can affect the enjoyment and stimulation from kissing. This feeling should return in 12–18 months. Some side effects (such as dry mouth, bad breath due to changes in oral bacteria, poor tongue and lip movement, scars, or a stiff neck and jaw) can also make kissing difficult.

Some people eventually regain some movement or choose to express their feelings in other ways, such as hugging, holding hands or touching cheek-to-cheek. However, if you or your partner are distressed by these changes, it may help to talk things through with a counsellor.

**Taste, smell and appetite changes**

Some treatments, particularly craniofacial resection and laryngectomy, can affect your sense of taste and smell.

You may never regain your full sense of smell, but a speech pathologist may be able to teach you a new technique. It can take several months for your sense of taste to return to normal, and in the meantime, you may experience changes to your appetite. See the tip box on the facing page for some ideas on how to manage changes to your taste, smell and appetite.

For further information, you can also call Cancer Council 13 11 20 to obtain your free copy of the booklet *Nutrition and Cancer* or visit your local Cancer Council website.
Managing changes in taste, smell and appetite

- Use marinades, or add flavour by using garlic, spices, herbs, cheese or bacon.
- Stimulate your digestive enzymes by adding lemon, ginger or vinegar to your cooking.
- Freshen your mouth with sugar-free mints or gum, and brush your teeth after meals.
- If you smoke, try to quit. As well as damaging your health, smoking reduces appetite and changes the taste of food. Call 13 QUIT (13 78 48) or visit quitnow.gov.au.
- Use a drinking straw to bypass your tastebuds.
- Use salt, lemon juice or coffee powder if food is too sweet; try sugar or honey if food tastes metallic or salty.
- Stimulate your appetite with aromatic foods and ingredients, e.g. freshly baked bread.
- Avoid bitter or metallic tasting foods such as coffee and chocolate.
- If food tastes ‘off’ rinse your mouth by drinking tea, ginger ale, or fruit juices mixed with club soda, lemon ice or lemon sorbet.
- Drink more water with meals to help with swallowing or to rinse away bad tastes.
- If you don’t feel like cooking, ask your family or friends to prepare meals for you, or try pre-cooked meals.
- Use liquid nutrition products to fill in the nutrition gaps if nutritional intake is inadequate.
- Choose foods that are colourful, fresh and full-flavoured.
- If you lose your sense of smell, take precautions such as installing smoke detectors in your home and checking the use-by dates of foods.
Swallowing difficulties
Many people with head and neck cancer have difficulty swallowing (dysphagia) before, during or after treatment.

Surgery in your jaw, mouth or throat – may affect your ability to swallow because of a dry mouth or because tissue has been removed or reconstructed.

Radiotherapy – can cause dryness, pain, and changes to the strength of the muscles used in swallowing.

A partial laryngectomy – may cause food to go down the wrong way into the lungs (aspirate). This is because the larynx and epiglottis are also important for swallowing; they act like valves and shut off the airway when swallowing so liquid or food doesn’t go into the lungs.

If swallowing is painful, ask your doctor about taking pain relief medications. You may also use other types of soothing agents to prevent your mouth and throat from becoming irritated. Your dietitian can help you to modify your diet to minimise pain. A speech pathologist can assess how you swallow, and suggest changes to your swallowing action to help reduce discomfort or concerns of food going down the wrong way (aspiration).

See the Laryngectomee Association of NSW’s book for swallowing and chewing difficulties at stilltalking.org/#cookbook.
**Tube feeding**

Tube feeding (also called enteral feeding) can help you stay nourished if you are struggling to eat or swallow. You may need tube feeding on either a temporary or long-term basis.

If you have a long-term feeding tube, flexible tubing may protrude 8–10 cm from your abdomen. Your health care team will advise you on how to keep the tube clean to prevent wear, leakage and blockages, and when the tubing needs to be replaced. A dietitian will advise you on a feeding plan to ensure your dietary needs are met.

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**Temporary nasogastric tube**

- **Temporary feeding tube** – A tube is inserted through your nasal passageway (nasogastric or NG tube). It will usually be used for a few days or weeks.

- **Long-term or permanent feeding tube** – A tube is inserted into your stomach (gastrostomy) while you are under general anaesthetic. This may be referred to as a PEG (percutaneous endoscopic gastrostomy) or a RIG (radiologically inserted gastrostomy) depending on how it is inserted.
Many people find that having a feeding tube eases the discomfort of eating and the pressure of having to eat meals. If medications can’t be swallowed, these can also be given through the feeding tube. However, having a feeding tube inserted is a significant change, and it is common to feel upset about it. Talking to your family, a counsellor, dietitian or nurse may help you adjust to the change.

**Weight loss and staying nourished**

The side effects on pages 48–53 may cause you to lose weight. Even a small drop in your weight (e.g. 3–4kgs) may put you at risk of malnutrition. You may be malnourished even if you are overweight.

Significant weight loss and malnutrition can lead to reduced energy and strength, and lower quality of life. Your response to treatment may be reduced and side effects can become more severe.

### Staying nourished after treatment

- Eat small meals frequently.
- Choose foods high in protein.
- Eat and drink nourishing meals or snacks.
- Try walking before meals. Light exercise may help to stimulate your appetite.
- Modify foods to make them easier to chew or swallow.
- Add high energy ingredients to recipes, such as whey powder, full-cream milk, other dairy products (sour cream, butter or cheese), oil, eggs, avocado, or honey.
- Ask your dietitian about nutritional supplement drinks, which may help to prevent weight loss.
Breathing changes
If breathing is difficult, the surgeon will perform a tracheostomy. An artificial opening (stoma) through the neck into the windpipe (trachea) will be created, which allows you to breathe.

After most types of surgery, you will have a temporary stoma. If you have a total laryngectomy, you will have a permanent stoma. If you are having another surgical procedure, the tracheostomy is usually done at the same time under general anaesthetic.

Tracheostomy tube
If you have a tracheostomy tube, your trachea is still connected with your upper airway. A plastic outer tube is inserted in the hole to keep it from closing. An inner tube can be removed for cleaning.
Some patients who have a small tube or a tube with a hole (fenestrated tracheostomy tube) will be able to speak straight away. However, in most cases, you will not be able to speak at first, because air will not pass up through the tube into the larynx and mouth. Your speech pathologist will teach you how to speak.

After a recovery period, the tracheostomy tube will probably be removed and the stoma will close up. At first your voice may be weak and breathy, but it should return to normal once the stoma has healed. Your physiotherapist will teach you breathing exercises and airway clearance techniques to make breathing easier.

Occasionally, people need a tracheostomy tube for several weeks during radiotherapy or on a permanent basis. Your health care team will discuss this with you if needed.

The tubes can block without regular cleaning and suctioning. Your health care team will show you how to keep the tubes clean. They will also advise what products to use to keep your airway warm and moist.

**Stoma**

People who have a total laryngectomy breathe through a permanent stoma. During the laryngectomy, the trachea is stitched permanently to an opening at the front of the neck and is no longer connected to the mouth and nose in the upper airway.

You may have a tube inserted into the stoma immediately after the surgery. This ensures the stoma stays the same size and keeps your airway open for breathing while you are healing. Your nurses will
teach you and your carers how to clean the tube. You will probably be able to remove the tube during the day. Eventually, you may not need it at all. Your speech pathologist or nurse will show you products that cover the stoma but still enable you to breathe while providing heat and moisture for the trachea.

Feeling self-conscious about the way the stoma makes you look and speak is not unusual. Addressing your concerns may help you come to terms with the change. See page 69 for ways to get support.

For more information about stomas, see the Laryngectomee Association of NSW’s booklet You Can Say That Again, available from Cancer Council 13 11 20.

**Speech changes**

If you lose your voice or your ability to speak clearly, it is natural to feel distressed, frustrated and angry at times.

People around you may need to learn new ways to communicate with you and take time to listen carefully. If your voice or speech has changed, some people might pretend to understand what you’re saying so they don’t upset you, or because they’re embarrassed to say they don’t understand. This can be frustrating and you may feel uncomfortable or alienated.

You will no longer be able to hold your breath if you have a permanent stoma. Water sports are not recommended because water can get into your lungs and cause drowning.
Loss of speech
Some people lose the ability to speak clearly or produce voice due to surgery to their mouth or the removal of their larynx. You may find it helpful to:
- gesture, point, nod, smile, or mouth words
- ring a bell to call people
- write on a pad or whiteboard, or point to pictures on a board
- use a computer, mobile phone or other device to type messages
- use the National Relay Service – relayservice.com.au.

Having speech therapy
Three main methods your speech therapist may try after a total laryngectomy are:

**Oesophageal speech** – You swallow air and force it up through your oesophagus to produce a low-pitched burp. This technique may be difficult and usually requires training.

**Mechanical speech** – A battery-powered device creates a vibrating sound when it is held against the neck or cheek or placed inside the mouth. You press a button attached to the device when you want to speak.

**Tracheoesophageal speech** – Your surgeon may create a puncture between your trachea and oesophagus during the laryngectomy or later on. Your surgeon may insert a voice prosthesis (or valve) to direct air from your trachea into the oesophagus. This creates a low-pitch, ‘throaty’ voice.

Talking will take time and practice. You will need to get used to the way your new voice sounds. If you are feeling self-conscious about the change, counselling may help.
You will work with a speech pathologist to improve your speech and learn strategies for communicating with your family and friends. Although this can be challenging, most people who have had surgery are able to learn techniques to talk again. A counsellor or psychologist can help you address any problems or frustrations.

**Appearance changes**

Many types of surgery will change the way you look – this may be temporary or permanent. Today’s surgical techniques mean that scarring is unlikely to be significant for most people. Scars from surgery are often hidden in the neck or in skin creases on the face. They are barely visible and often fade over time.

**Face** – If part of the jaw, nose or skin is removed, your face will look different. Some people will have a reconstruction with a prosthesis, which is a soft plastic replacement for the tissue that has been removed. A prosthesis is fitted permanently and blends in well with your own features. If you are likely to need a prosthesis, the doctor will discuss this with you before the operation.

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

**Neck** – After head and neck surgery, you will experience scarring and swelling in the head and neck areas. This swelling can be temporary or permanent and may change your appearance. You may have a hole in your lower neck (stoma) and may also have scarring.
Managing appearance changes
You may be distressed or embarrassed about these changes. Give yourself time to adapt. You may be concerned that if you have surgery or reconstruction to your face, or you have a tracheostomy or feeding tube, this will also change your partner’s attraction to you.

Try to see yourself as a whole person (body, mind and personality) instead of focusing on what has changed. Many people find it helps to talk things through with a counsellor, friend or family member. You can also consult a reconstructive surgeon, who may be able to make physical changes (such as scars) look less obvious, or rebuild parts of your face and neck using tissue from other parts of your body.

Talk to your doctors about how surgery and reconstruction will affect your appearance. You may also like to visit Look Good Feel Better at lgfb.org.au or call Cancer Council 13 11 20 for tips and workshop details.

Pain and physical discomfort
**Pain** – Pain following surgery or cancer treatment may lead to distress, low mood, fatigue, reduced appetite and reduced quality of life. Speak to your doctor about pain management options. Your physiotherapist may also give you advice on positioning for comfort, make recommendations on exercises or use of other pain relief options such as transcutaneous electrical nerve stimulation (TENS).

**Stiff neck and shoulder** – If you have lymph nodes removed, you may have stiffness and numbness in your neck, and pain in
your shoulder. Neck movement may be restricted, or your shoulder may be dropped or depressed due to nerve injury. Nerve damage usually heals within 4 months, and sensation should return within 12 months. A physiotherapist can assist with reducing pain, and improving posture, movement and function. Your physiotherapist may also suggest using a postural brace for shoulder support.

**Lock jaw** – Radiotherapy can result in significant reduced opening of the jaws (trismus). Trismus can be temporary or permanent, and may be distressing and painful, and limit or prevent medical examination or treatments requiring access to the oral cavity. Ask for a referral to see a speech pathologist or physiotherapist if you have been diagnosed with trismus by your doctor.

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**Managing fatigue**

Fatigue, or feeling exhausted and lacking energy for daily activities, is a common physical side effect of cancer treatment. Fatigue can continue for months or, in some cases, years after treatment ends. Call Cancer Council 13 11 20, or ask your GP or occupational therapist for suggestions on how to manage and reduce fatigue.

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**Vision changes**

If the cancer is in your eye socket, the surgeon may have to remove your eye (orbital exenteration). The empty eye socket will be replaced by a sphere of tissue from another part of your body. This keeps the structure of the eye socket. Later you can be fitted for an artificial eye, which is painted to look like your remaining eye. The eye is like
a large contact lens that fits over the new tissue in the eye socket. You will still be able to see with your remaining eye, but your depth perception and peripheral vision will be poorer. Your changed vision should not prevent you from continuing activities such as driving or playing sport, but it may take time to get used to these changes.

**Lymphoedema**

Lymphoedema is swelling that occurs in soft tissue. Swelling usually occurs in a limb such as the arm or leg, but can also occur in the neck after lymph nodes are removed during surgery, or if they are damaged by infection, injury, or other treatment such as radiotherapy. Lymphoedema may be permanent, but it can usually be managed, especially if treated early.

Signs of lymphoedema include persistent swelling, which may be associated with new feelings of throat congestion, heaviness, tightness, aches or pins and needles.

Some hospitals have physiotherapists or occupational therapists specialising in lymphoedema care. They can provide education on prevention and provide a personalised treatment program. This may include lymphatic drainage massage, exercises, skin care and the provision of compression garments if needed.

Key points

- Many people with a head and neck cancer will experience side effects. Some go away following treatment; others need ongoing management and/or rehabilitation.

- A dry mouth is common due to the salivary glands being damaged or removed. Mouth sores often occur during chemotherapy and radiotherapy. This can make it difficult to eat, drink or speak.

- You may experience temporary changes in taste, smell and appetite. Some people may lose their sense of smell permanently.

- Tube feeding may be useful if you have difficulties eating. This may be for a few weeks or it may be long-term.

- You may have a tracheostomy or stoma to help you breathe. This can be a major change but support is available.

- You may need speech therapy after surgery. Most people relearn how to speak or communicate in other ways.

- Surgery may change the way you look. If you find this distressing or embarrassing, seek advice from a counsellor or psychologist.

- Lymph node removal may cause temporary or permanent loss of nerve function or lymphoedema. This may result in facial droop, depressed shoulder posture or ongoing swelling of the head and neck.

- Removal of an eye may be required if the cancer is in the eye socket. Changed vision should not prevent you partaking in activities like sport or driving, but it may take some time to get used to the change.
Looking after yourself

Cancer can cause physical and emotional strain. It’s important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor’s advice. Cancer Council’s *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to 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.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.
Relationships with others

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what’s happening, and do the same for others. People may deal with the cancer in different ways, for example by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

Sexuality, intimacy and fertility

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.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.
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 if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to ‘normal life’, but they don’t want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

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

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Go to beyondblue.org.au or call 1300 224 636 to order a fact sheet.
After treatment: follow-up

After treatment, you will need regular check-ups to monitor your health and confirm that the cancer hasn’t come back. You will also receive continued support by your allied health team as you need it, or you may be referred to local services.

Tests will include occasional scans, as well as physical and visual examinations of your head and neck. Over time, if there are no further problems, your check-ups will become less frequent. If you notice any new symptoms in-between check-ups, you should let your GP or specialist know as soon as possible.

What if the cancer returns?

For some people, head and neck cancer does come back after treatment, which is known as a relapse or a recurrence. This is why it is important to have regular check-ups so that any recurring cancer can be found as soon as possible.

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

Some friends and family stepped up and were a great support, while others just disappeared. Understanding why some disappeared was one of my challenges.  

Marty
Brien’s story

After recurring laryngitis, my GP referred me to an ENT specialist. A CT scan revealed a tumour on my left vocal cord. I had a biopsy done under a general anaesthetic. This showed that it was a squamous cell carcinoma.

I had radiotherapy to my left vocal cord. In most cases this is successful, but a month later, a CT scan showed that the tumour had spread to my right vocal cord. My only treatment option now was surgery. I had a total laryngectomy to remove my voice box and had a new airway made in the front of my neck (stoma).

I had to learn to talk, swallow and keep my airways healthy. I use daily steam inhalations to help clear my chest secretions. It now takes me longer to eat as my food has to be chewed well and I’ve lost my sense of smell.

It’s a lot of effort to communicate now but I picked it up in about a week. I use a voice prosthesis in my throat or alternatively what’s known as a handheld electrolarynx.
Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

**Practical and financial help**

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can’t afford to pay – call 13 11 20 to ask if you are eligible.

**Talk to someone who’s been there**

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.
You may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren’t trying to protect their loved ones.

**Types of support**

There are many ways to connect with others for mutual support and to share information. This includes:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **peer support programs** – match you with someone who has had a similar cancer experience, e.g. Cancer Connect.
- **online forums** – such as cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council about what is available in your area.

> 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*
You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and some types of programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers’ services and get a copy of the Caring for Someone with Cancer booklet.
The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of information.

**Australian**

Cancer Council Australia ........................................... cancer.org.au
Cancer Australia .................................................. canceraustralia.gov.au
Carers Australia .................................................. carersaustralia.com.au
Department of Health .............................................. health.gov.au
HealthInsite .......................................................... healthinsite.gov.au
beyondblue ............................................................ beyondblue.org.au
Look Good Feel Better ................................................ lgfb.org.au
Australasian Lymphology Association ..................... lymphoedema.org.au
Speech Pathology Australia ..................................... speechpathologyaustralia.org.au
Dietitians Association of Australia (DAA) ..................... daa.asn.au

**International**

Macmillan Cancer Support ......................................... macmillan.org.uk
Cancer Research UK ............................................... cancerresearch.org.uk
American Cancer Society .......................................... cancer.org
US National Cancer Institute ..................................... cancer.gov
Support for People with Oral and Head and Neck Cancer .................................................. spohnc.org
Head and Neck Cancer Foundation ............................. headandneck.org
Mouth Cancer Foundation (UK) .................................. mouthcancerfoundation.org
The Oral Cancer Foundation ..................................... oralcancerfoundation.org
Web Whispers ........................................................ webwhispers.org
You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don’t understand, ask for clarification.

- What type of head and neck cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- Who will be my primary specialist that coordinates my care?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- What kind of rehabilitation will be available to me afterwards?
- When can I return to work or my usual activities?
- Will my face or neck have significant scarring or will I look different? What can be done to minimise this?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- Should I change my diet during or after treatment?
- If the cancer comes back, how will I know?
advanced cancer
Cancer that has spread deeply into the surrounding tissues or away from the original location (metastasised) and is less likely to be cured.

anaesthetic
A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes a person to lose consciousness for a period of time.

benign
Not cancerous or malignant. Benign lumps are not able to spread to other parts of the body.

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

bone scan
A technique to create images of bones on a computer screen. A small amount of radioactive dye is injected into a vein. It collects in the bones and is detected by a scanning machine.

brachytherapy
A type of radiotherapy treatment that implants radioactive material sealed in needles or seeds into or near cancerous cells. Also called internal radiotherapy.

bronchoscopy
An internal examination of the airways using a tube called a bronchoscope that is inserted into the mouth, throat and lungs.

cancer of unknown primary
Cancer is found in the body but the location where the cancer first started growing (the primary site) cannot be determined. Also called cancer of occult primary.

cells
The basic organisational unit of all living things. A human is made of billions of cells, which are adapted for different functions.

chemoradiation
Treatment that combines chemotherapy with radiotherapy.

chemotherapy
The use of drugs to treat cancer by killing cancer cells or slowing their growth.

cordectomy
Surgery to remove a vocal cord.

craniofacial resection
Surgical removal of a tumour involving a cut through the face.

CT scan
A computerised tomography scan. This type of scan uses x-rays to create a picture of the body.

dysphagia
Difficulty swallowing.

dysphasia
Difficulty speaking.

endoscope
A tube with a camera and a light on it that can be inserted into different cavities in the body for a close examination. They are often named after the part of the body they are designed to examine, such as a laryngoscope for the larynx.
endoscopic surgery
A type of surgery for cancers that can be accessed through the nasal cavity. Tissue is removed using an endoscope and no surgical cuts need to be made.

epiglottis
The small cartilage flap in your throat that prevents food or fluid from going down the wrong way.

Epstein-Barr virus (EBV)
A common virus in the herpes family that may increase a person’s risk of developing some types of cancer.

erythroplakia
A red velvety spot or patch in the mouth that may be precancerous.

ethmoid sinuses
Sinuses located behind the ethmoid bone in the skull.

external beam radiotherapy
The use of high-energy radioactive beams to kill cancer cells or injure them so they cannot multiply. The beams of radiation are directed at the cancer from a machine.

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

fenestrated tracheostomy
A tracheostomy tube with an opening to allow air to flow through the voice box.

frontal sinuses
Sinuses located behind the forehead.

gastrostomy
An opening through the abdomen into the stomach. It is usually created to place a feeding tube.

glossectomy
The surgical removal of part or all of the tongue.

hemilaryngectomy
Surgery to remove the left or right half of the larynx.

human papillomavirus (HPV)
A group of viruses that can cause infection in the skin surface of different areas of the body, including the genital area. HPV may be a risk factor for some types of cancer. Also called the wart virus.

hypopharynx
The lowest part of the back of the throat. Also called the laryngopharynx.

hyperbaric treatment
Involves breathing pure oxygen in a pressurised room or tube.

intravenous
Inserted into a vein.

intensity modulated radiation therapy (IMRT)
A type of radiation therapy that allows the beams of radiation to be shaped around the tumour, resulting in less damage to surrounding healthy tissue.

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

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

laryngopharynx
See hypopharynx.
**laryngoscopy**
A procedure that allows the doctor to closely examine the larynx and pharynx using a tube inserted into your mouth and throat (laryngoscope).

**larynx**
The voice box. The larynx houses the vocal cords and connects the pharynx with the trachea.

**laser surgery**
The use of an intense light beam (a laser) that works like a knife to cut or remove tissue.

**lateral rhinotomy**
A cut along the edge of the nose to gain access to the nasal cavity and sinuses.

**leukoplakia**
A white spot or patch in the mouth that may be precancerous.

**lymph nodes**
Small, bean-shaped structures that form part of the lymphatic system. Also called lymph glands.

**lymphatic system**
A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells.

**lymphoedema**
Persistent swelling in tissues as a result of obstruction or damage of lymphatic vessels or lymph nodes from infection, cancer or cancer treatment.

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

**mandibulectomy**
Removal of part of the lower jaw.

**mandibulotomy**
Cutting the lower jaw to give access to the mouth or throat.

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

**maxillectomy**
Removal of part of the upper jaw.

**mechanical speech**
The use of a battery-powered device (such as an electrolarynx) to create vocal sounds.

**metastasis**
A cancer that has spread from another part of the body. Also known as secondary cancer.

**metastatic neck cancer with unknown primary**
Cancer that is found in the lymph nodes of the neck but the primary location cannot be located. It may have started as a head and neck cancer, and is often treated as such.

**midface degloving**
Surgical access to the nasal cavity or sinuses using a cut under the upper lip.

**MRI scan**
A magnetic resonance imaging scan that uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

**mucositis**
Inflammation in the digestive tract.

**nasal cavity**
The large, air-filled space located behind the nose and in the middle of the face.
**nasendoscopy**
An internal examination of the nose and upper airways using a long, flexible tube called an endoscope.

**nasogastric (NG) tube**
A plastic feeding tube that passes in through the nasal passageway and directly into the stomach.

**nasopharynx**
The open cavity that lies behind the nose and above the soft palate.

**neck dissection**
Surgery to remove lymph nodes and some surrounding structures in the neck, such as muscle, fat or nerves.

**obturator**
A special prosthesis or plate that is used to close a gap in the palate, to form a new roof of the mouth.

**oesophageal speech**
Inhaling or injecting air into the top of your oesophagus and then out again to produce a voice after a total laryngectomy.

**oesophagus**
The tube that carries food from the throat into the stomach.

**oral**
Refers to the mouth, including the lips, gums, cheeks, floor of the mouth, front of the tongue, and inside area of the jaws.

**orbital exenteration**
The surgical removal of the eye and other contents of the orbit.

**oropharynx**
The part of your throat that includes the soft palate and tongue base.

**osteoradionecrosis (ORN)**
A breakdown of bone tissue due to radiotherapy treatment.

**orthopantomogram (OPG)**
Special x-ray used to examine the jaw and teeth of people with mouth cancer.

**palliative treatment**
Medical treatment for people with cancer to help them manage pain and other physical and emotional symptoms.

**paranasal sinuses**
Air-filled spaces within the head that lighten the weight of the skull.

**parathyroidectomy**
The removal of the parathyroid glands, which regulate calcium in the body.

**parotid gland**
one of the major salivary glands. It is found just in front of the ears.

**percutaneous endoscopic gastrostomy (PEG) tube**
A feeding tube inserted directly into the stomach through the abdomen. A gastroenterologist does the procedure.

**PET scan**
A positron emission tomography scan. A specialised imaging test that uses a radioactive glucose solution to identify groups of cancer cells in the body.

**pharyngectomy**
The surgical removal of part or all of the pharynx.

**pharynx**
The throat. This is a muscular tube about 10cm long that extends from the back of the nose to the top of the larynx and oesophagus.
prognosis
The likely outcome of a person’s disease.

prosthesis
An artificial replacement for a lost or damaged body part.

radiotherapy
The use of radiation, usually x-rays or gamma rays to kill or injure cancer cells so they cannot grow and multiply.

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

rhinectomy
The surgical removal of part or all of the nose.

radiologically inserted gastrostomy (RIG) tube
A feeding tube inserted directly into the stomach through the abdomen using x-rays or other scans. A radiologist does the procedure.

saliva
Also called spit. The watery substance released into the mouth from salivary glands.

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

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

salivary gland cancer
Cancer that affects the salivary glands, most commonly the parotid gland.

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

staging
Performing tests to determine how far the cancer has spread.

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

supracricoid laryngectomy
Surgery to remove the upper part of the larynx, including vocal cords.

supraglottic laryngectomy
Surgery to remove the upper part of the larynx above the vocal cords (supraglottis).

targeted therapies
Types of treatments that use drugs or other substances to selectively target proteins or other molecules involved in cancer cell growth.

thyroid
A butterfly-shaped endocrine gland located at the base of the neck. The thyroid releases hormones to control the body’s metabolism and calcium levels.

tomotherapy
A type of three-dimensional radiotherapy that allows the radiation beams to be shaped around a tumour more precisely.

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

trachea
The windpipe. The airway that brings air inhaled from the nose and mouth into the lungs.
**tracheoesophageal speech**
When a person forces air through a surgically created valve between the trachea and oesophagus to create a low-pitched, throaty voice.

**tracheostomy**
An operation in which a hole is made at the base of the neck into the trachea (windpipe), in order to create a clear airway.

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

**tumour**
A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

**ultrasound**
A non-invasive scan that uses soundwaves to create a picture of part of the body. An ultrasound scan can be used to measure the size and location of a tumour.

**vocal folds**
The part of the larynx that vibrates to produce the sounds required for speech. Also called vocal cords or the glottis.

**volumetric modulated arc therapy (VMAT)**
A type of radiation therapy whereby single or multiple beams of radiation sweep around the body, greatly reducing treatment time.

**xerostomia**
Dry mouth.

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**References**


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**Can’t find what you’re looking for?**
For more cancer-related words, visit:
- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary
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 Pink Ribbon Day, 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.
Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn’t just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

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

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

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

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

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
 cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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.