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

For information & support, call 13 11 20
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Understanding Head and Neck Cancers is reviewed approximately every two years.
Check the publication date above to ensure this copy is up to date.


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

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

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

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

As the experience for every person with a head and neck cancer is different, you need to discuss your treatment options with your doctor. However, we hope the information in this booklet will answer some of your questions and help you think about other questions to ask your treatment team.

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

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

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

1. **Normal cells**
2. **Abnormal cells**
3. **Abnormal cells multiply**
4. **Malignant or invasive cancer**

Normal cells → Abnormal cells → Abnormal cells multiply → Malignant or invasive cancer

Abnormal cells multiply by travelling through the bloodstream or lymphatic system (Angiogenesis).
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 and can grow its own blood vessels in a process known as 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

---

What is cancer?
What are head and neck cancers?

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

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

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

Other cancers in the head and neck area

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

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

For details about other cancers, call Cancer Council 13 11 20, or download the relevant booklet from your local website.
Types of head and neck cancers
Cancers of the head and neck are categorised by the area of the head or neck where they begin.

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

Cancer can begin in any part of the mouth – the lips, gums, inside lining of the cheeks and lips, front two-thirds of the tongue, floor of the mouth under the tongue, bony roof of the mouth (hard palate), and the small area of gum behind the wisdom teeth.

Oral cavity
**Throat (pharynx)**

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

- **nasopharynx** – the upper part, behind the nose and above the soft palate; cancer starting in this area is called nasopharyngeal cancer

- **oropharynx** – the middle part, the area from the soft palate and tongue base to the back of the mouth, including the tonsils; cancer starting in this area is called oropharyngeal cancer

- **hypopharynx** – the lower part, behind the voice box (larynx); cancer starting in this area is called hypopharyngeal cancer.
**Voice box (larynx)**

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

The larynx contains the vocal cords (glottis), which vibrate when air passes through them to produce the sound of your voice. When you swallow, a small flap of tissue called the epiglottis moves to cover the larynx to prevent food going into the trachea. Below the vocal cords is the subglottis. Under the voice box, in front of the trachea, is the thyroid gland.
Salivary glands

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

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

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

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

The are four pairs of paranasal sinuses:

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

Q: How common are head and neck cancers?
A: About 4400 people in Australia (approximately 3170 men and 1230 women) are diagnosed with a head and neck cancer each year. This includes about 1370 people diagnosed with cancer in the mouth and tongue; 1000 with lip cancer; 890 with pharyngeal cancer; 590 with laryngeal cancer; 320 with salivary gland cancer; and 170 with nasal or paranasal sinus cancer.

Q: What are the risk factors?
A: Head and neck cancers are associated with a number of major risk factors. Two of the main risk factors are alcohol and tobacco, and the combined effect of drinking and smoking is significantly greater than the risk of just drinking or just smoking. Research shows that the risk is 35 times higher for people who are both heavy smokers and heavy drinkers. The main risk factors include:
- **drinking alcohol** – compared to non-drinkers, drinkers have about 6 times the risk
- **smoking tobacco (including cigarettes, cigars and pipes)** – compared to nonsmokers, smokers have about 7 times the risk
- **viruses** – the human papillomavirus (HPV), especially HPV 16, has been linked to cancers of the oropharynx, and may play a role in other head and neck cancers. Exposure to the Epstein-Barr virus (EBV) may also be linked to the development of some head and neck cancers.
Other risk factors include:

- **older age** – head and neck cancers are more common in people aged 40 years and older
- **being male** – men are about three times more likely than women to develop head and neck cancer
- **family history** – people with a parent, brother, sister or child with head and neck cancer have double the risk of developing some types of head and neck cancer
- **being from southern China or South-East Asia** – people from some cultural backgrounds may be more likely to develop some types of head and neck cancers. This is because of cultural practices such as chewing tobacco or eating salty fish (salty fish is high in nitrates that react with protein to form chemicals that damage DNA)
- **chemical exposure at work** – breathing in asbestos fibres, wood dust, dry-cleaning solvents or certain types of paint or chemicals is associated with an increased risk of some types of head and neck cancer
- **low immunity** – people with low immunity conditions, such as those who have had a kidney transplant, have a higher risk of developing oral and oropharyngeal cancers
- **sun exposure** – ultraviolet (UV) radiation may cause skin cancer on the lip
- **areca nut, betel nut, pan or gutka** – chewing or smoking these products may cause oral cancer.

Eating adequate amounts of fruit and vegetables may help decrease the risk of oral and oropharyngeal cancers. Talk to your doctor if you are worried about any of these risk factors.
Q: What are the symptoms?
A: There are many possible symptoms of head and neck cancer. However, these symptoms can also occur with other illnesses, so they don’t necessarily mean you have cancer – only tests

<table>
<thead>
<tr>
<th>Mouth (oral) cancer</th>
<th>Pharyngeal cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>mouth pain or pain when swallowing</td>
<td>throat pain or difficulty swallowing</td>
</tr>
<tr>
<td>a persistent sore or swelling in the mouth</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>
</tr>
<tr>
<td>red or white patches on the gums, tongue or mouth</td>
<td>bad breath</td>
</tr>
<tr>
<td>bad breath</td>
<td>weight loss</td>
</tr>
<tr>
<td>changes in speech or difficulty pronouncing words</td>
<td>voice changes or hoarseness</td>
</tr>
<tr>
<td>difficulty chewing or swallowing food, difficulty moving the tongue or limited chewing</td>
<td>dull pain around the breastbone</td>
</tr>
<tr>
<td>weight loss</td>
<td>a lump in the neck</td>
</tr>
<tr>
<td>a lump in the neck</td>
<td>pain in the ear or frequent ear infections</td>
</tr>
<tr>
<td>loose teeth, or dentures that no longer fit</td>
<td>feeling that your air supply is blocked</td>
</tr>
<tr>
<td>earache, or ringing in the ears</td>
<td>numbness of the face</td>
</tr>
<tr>
<td></td>
<td>nasal congestion</td>
</tr>
<tr>
<td></td>
<td>hearing loss</td>
</tr>
<tr>
<td></td>
<td>headaches</td>
</tr>
</tbody>
</table>
can confirm the diagnosis. If you are concerned about any of these symptoms, make an appointment with your general practitioner (GP) without delay.

<table>
<thead>
<tr>
<th>Laryngeal cancer</th>
<th>Salivary gland cancer</th>
<th>Nasal or paranasal sinus cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>• swelling or a lump in the neck or throat</td>
<td>• swelling or a lump near the ear, jaw, lip, or inside the mouth</td>
<td>• decreased sense of smell</td>
</tr>
<tr>
<td>• a persistent sore throat</td>
<td>• different appearance on each side of the face or neck</td>
<td>• a persistent blocked nose, particularly in one nostril</td>
</tr>
<tr>
<td>• a persistent change in the sound of your voice, including hoarseness</td>
<td>• difficulty swallowing or opening mouth widely</td>
<td>• frequent nosebleeds</td>
</tr>
<tr>
<td>• difficulty swallowing or pain when swallowing</td>
<td>• drooping, numbness or muscle weakness on one side of the face (palsy)</td>
<td>• excess mucus in the throat or back of the nose</td>
</tr>
<tr>
<td>• constant coughing</td>
<td></td>
<td>• frequent headaches or sinus pressure</td>
</tr>
<tr>
<td>• difficulty breathing</td>
<td></td>
<td>• difficulty swallowing</td>
</tr>
<tr>
<td>• weight loss</td>
<td></td>
<td>• loose or painful upper teeth</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• a lump on/in the face, nose or mouth</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• numbness of the face, upper lip, or within the mouth or upper teeth</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• pressure or pain in the ears</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• a bulging or watery eye</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• double vision</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• complete or partial loss of eyesight</td>
</tr>
</tbody>
</table>
Diagnosis

If you notice any symptoms, see your general practitioner (GP). You can also mention any mouth sores, swelling or change of colour in your mouth to your dentist.

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

Physical examination

The doctor will examine your mouth, throat, nose, neck, ears and eyes depending on your symptoms. 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 by gently feeling both sides of your neck.

To see some areas of the head and neck, such as the nasopharynx, tongue base and pharynx, the doctor may use viewing equipment (see below and opposite) and take a tissue sample (see page 18).

Nasendoscopy

A nasendoscopy examines the nose and throat area using a thin flexible tube with a light and camera on the end. This device is called a nasendoscope. Before the nasendoscope is inserted, a local anaesthetic is sprayed into the nostril to numb the nose and throat.
You may find that the spray tastes bitter. The doctor will gently pass the nasendoscope into one of your nostrils and down your throat to look at your nasal cavity, nasopharynx, oropharynx, hypopharynx and larynx. Images from the nasendoscope may be projected onto a screen. This test may feel uncomfortable, but should not hurt.

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

**Laryngoscopy**
A laryngoscopy is a procedure that allows a doctor to look at your larynx and pharynx, and take a tissue sample (biopsy). 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 takes 10–40 minutes. You can go home when you’ve recovered from the anaesthetic. You may have a sore throat for a couple of days.

*A bronchoscope is similar to a laryngoscope, but it allows doctors to examine the airways to see if cancer 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 when doctors remove a sample of cells or tissue from the affected area, and a pathologist examines the sample under a microscope for any cancer cells.

The sample may be taken during a nasendoscopy or laryngoscopy. A biopsy can be taken from hard to reach areas using a fine needle to collect the sample. An ultrasound or CT scan (see *Imaging tests*, pages 20–21) can help the doctor guide the needle. Biopsy results are usually available in about a week. If the cancer can’t be diagnosed from the sample of tissue, the mass may be removed and checked for signs of cancer during surgery.

**Testing lymph nodes**

The lymph nodes in the neck are often the first place cancer cells spread to outside the primary site. To see whether the cancer has spread, some or all of the lymph nodes are removed and checked for cancerous cells.

The first lymph node cancer cells spread to is known as the sentinel node. There can be more than one sentinel node. A small amount of radioactive material is injected near the tumour to find the sentinel node. A scan is taken to show which node the substance flows to first. This node will be removed for testing.

If the sentinel nodes are clear of cancer cells, the cancer has not spread to the lymph nodes. If one or more sentinel nodes contain cancer cells, a neck dissection may be needed (see page 31).
X-rays

You may need 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)** – This type of x-ray is used to examine the jaw and teeth of people with mouth cancer.

**Chest x-ray** – Sometimes used to check the general health of people with mouth, pharyngeal or laryngeal cancer, or to see whether the cancer has spread to the lungs. However, most people have a CT or PET scan to look at these areas (see pages 20–21).

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**Overview of the lymph nodes**

Lymph nodes, also called lymph glands, are small, bean-shaped structures that are part of the lymphatic system. These are a key part of the immune system, which helps protect the body against disease and infection. Lymph nodes are found throughout the body, including in the head and neck area. The majority run down the sides of the neck and under the jaw.
Imaging tests
You will usually have at least one of the tests described below:

CT scan – A CT (computerised tomography) scan uses x-rays to take pictures of the inside of your body and then compiles them into one detailed, cross-sectional picture. Before the scan, you may have an injection of dye (called contrast) into one of your veins, which makes reading the scan more accurate. It may make you feel flushed and hot for a few minutes.

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

The dye used in a CT scan usually contains iodine. If you have had an allergic reaction to iodine or dyes during a previous scan, let your medical team know beforehand. You should also tell them if you are diabetic, have kidney function problems or are pregnant.

MRI scan – An MRI (magnetic resonance imaging) scan uses a powerful magnet and radio waves to build up detailed cross-sectional pictures of the inside of your body. Let your medical team know if you have a pacemaker or any other metal implant, as some types can interfere with an MRI. As with a CT scan, a dye may be injected into your veins before an MRI scan. During the scan, you will lie on a treatment table that slides into a large metal tube that is open at both ends.
The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention this beforehand to your medical team. You may be given medicine to help you relax, and you will usually be offered headphones or earplugs. MRI scans usually take between 30 and 90 minutes.

**PET scan** – A PET (positron emission tomography) scan is usually 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 some major hospitals.

Before the scan, you will be injected with a glucose solution containing 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 cells, including cancer cells, which are using more energy. These show up as “hot spots” during the scan. However, a PET scan can find hot spots that are not cancer. The scan itself takes about 30 minutes.

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

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

The tests described on pages 16–21 help show whether you have a head and neck cancer and whether it has spread. Working out how far the cancer has spread is called staging and it helps your health care team recommend the best treatment for you.

In Australia, the TNM system is the method most commonly used for staging head and neck cancers. In this system, letters are assigned numbers to describe the cancer.

Based on the TNM numbers, the doctor then works out the cancer’s overall stage (I–IV). Stages I–II are considered early head and neck cancer, and stages III–IV are considered advanced. Usually the earlier cancer is diagnosed, the better the outcome, but people with more advanced head and neck cancer may also respond well to treatment.

### TNM staging system

<table>
<thead>
<tr>
<th>T (Tumour) 1–4</th>
<th>Indicates the size of the primary tumour. The higher the number, the larger the cancer.</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (Nodes) 0–3</td>
<td>Shows if the cancer has spread to nearby lymph nodes. N0 means the cancer has not spread to the lymph nodes; the more nodes affected, the higher the number.</td>
</tr>
<tr>
<td>M (Metastasis) 0–1</td>
<td>Shows if the cancer has spread (metastasised) to other parts of the body. M0 means the cancer has not spread; M1 means the cancer has spread.</td>
</tr>
</tbody>
</table>
Prognosis

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

In most cases, the earlier head and neck cancer is diagnosed, the better the chances of successful treatment.

To work out your prognosis, your doctor will consider your test results; the type of head and neck cancer and rate of growth; how well you respond to treatment; and other factors such as your age, general fitness and medical history.

Which health professionals will I see?

Your GP will usually arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist. The specialist will arrange further tests.

If head and neck cancer is diagnosed, the specialist will advise you about treatment options. Once your treatment for head and neck cancer begins, you will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is often referred to as a multidisciplinary team (MDT) and it may include some or all of the health professionals listed in the table on the next two pages.
## MDT health professionals

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<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><strong>head and neck surgeon</strong>*</td>
<td>ENT or general surgeon specialising in cancer of the head and neck</td>
</tr>
<tr>
<td><strong>oral (maxillofacial) surgeon</strong>*</td>
<td>specialises in surgery to the face and jaw</td>
</tr>
<tr>
<td><strong>reconstructive surgeon</strong>*</td>
<td>performs surgery that restores, repairs or reconstructs the body’s appearance and function</td>
</tr>
<tr>
<td><strong>radiation oncologist</strong>*</td>
<td>prescribes and coordinates the course of radiotherapy</td>
</tr>
<tr>
<td><strong>medical oncologist</strong>*</td>
<td>prescribes and coordinates chemotherapy, hormone therapy and targeted therapy</td>
</tr>
<tr>
<td><strong>radiation therapist</strong></td>
<td>plans and delivers radiotherapy treatment</td>
</tr>
<tr>
<td><strong>nurses and cancer nurse coordinators</strong></td>
<td>coordinate your care, liaise with other members of the MDT, and support you and your family throughout treatment</td>
</tr>
<tr>
<td><strong>audiologist</strong></td>
<td>diagnoses and treats hearing problems</td>
</tr>
<tr>
<td><strong>dentist or oral medicine specialist</strong></td>
<td>evaluates and treats the mouth and teeth</td>
</tr>
<tr>
<td><strong>prosthodontist</strong></td>
<td>specialises in replacing any missing teeth</td>
</tr>
<tr>
<td><strong>gastroenterologist</strong></td>
<td>specialises in disorders of the digestive system, and inserts a feeding tube if required</td>
</tr>
<tr>
<td><strong>speech pathologist</strong></td>
<td>evaluates and treats communication, voice and swallowing difficulties during and after treatment</td>
</tr>
<tr>
<td><strong>dietitian</strong></td>
<td>recommends an eating plan to follow while you are in treatment and recovery</td>
</tr>
<tr>
<td><strong>social worker</strong></td>
<td>links you to support services and helps you with emotional, practical and financial issues</td>
</tr>
<tr>
<td><strong>counsellor, psychologist</strong></td>
<td>provide emotional support and help manage any feelings of depression and anxiety</td>
</tr>
<tr>
<td><strong>physiotherapist, occupational therapist</strong></td>
<td>assist with physical and practical problems, including restoring range of movement after surgery and managing lymphoedema</td>
</tr>
<tr>
<td><strong>palliative care team</strong></td>
<td>specialise in pain and symptom control to maximise wellbeing and improve quality of life</td>
</tr>
</tbody>
</table>

* Specialist doctor
Key points

- There are many types of tests used to diagnose a head and neck cancer. These tests are arranged by your GP, dentist 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 the end (nasendoscope) 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 tissue sample (biopsy) is taken to examine the cells under a microscope to see whether cancer is present. A biopsy can be done during a physical examination, under guidance of ultrasound or CT scan, or occasionally under general anaesthetic.

- A range of imaging tests may be done. These will show where the cancer is located and whether it has spread (the stage).

- The stage of the cancer shows how far the cancer has spread in the body. Head and neck cancer is assigned a stage using the TNM system. TNM stands for tumour, nodes, metastasis.

- Your prognosis is the expected outcome of the disease. It is based on the cancer’s stage, and factors such as your age, medical history and fitness. Your doctor will discuss your prognosis with you.

- You will be cared for by a team of health professionals who work together as a multidisciplinary team.
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 offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so 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 your doctor questions – see page 77 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 the 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 to get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 and ask for a free copy of Understanding Clinical Trials and Research, or visit australiacancertrials.gov.au.
The main treatments for head and neck cancers are surgery, radiotherapy and chemotherapy. You may have one of these treatments, or a combination. The treatment will depend on:
- the type, size and location of the tumour
- your age, medical history and general health
- whether, and how far, the cancer has spread
- the types of symptoms and side effects you experience.

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

See a dentist or oral medicine specialist – Have a thorough check-up and ask for an oral health care plan. The plan outlines any dental work you need before treatment starts, and also provides guidance on appropriate care before, during and after treatment. The dentist may recommend taking out any unhealthy teeth that might be affected by radiotherapy. These teeth may be removed during cancer surgery or before radiotherapy.

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

Stop smoking before you have surgery – If you continue to smoke, you may not respond to treatment as well as people who don't smoke. Also, smoking may make side effects worse and increase the chance of a second primary cancer. See your doctor or call the Quitline on 13 7848 for support to quit.
# Treatment options by type of head and neck cancer

<table>
<thead>
<tr>
<th>Head and Neck Cancer Type</th>
<th>Treatment Options</th>
</tr>
</thead>
</table>
| **Mouth (oral) cancer**   | • Commonly treated with surgery.  
                           | • May be followed by radiotherapy alone or combined with chemotherapy (chemoradiotherapy). |
| **Pharyngeal cancer**     | • Treatment will depend on the type of pharyngeal cancer you have: nasopharyngeal, oropharyngeal or hypopharyngeal.  
                           | • The options may include surgery, radiotherapy, chemotherapy, or a combination. |
| **Laryngeal cancer**      | • Early laryngeal cancer is treated with surgery or radiotherapy.  
                           | • Advanced laryngeal cancer is sometimes treated with surgery first. Radiotherapy (with or without chemotherapy) is usually given after surgery to reduce the chance of the cancer coming back.  
                           | • Surgery may be offered to people who have had radiotherapy if the cancer comes back or is not all destroyed by radiotherapy. |
| **Salivary gland cancer** | • Surgery is the main treatment. This may include removing some lymph nodes.  
                           | • Surgery may be followed by radiotherapy alone or in combination with chemotherapy (chemoradiotherapy). |
| **Nasal or paranasal sinus cancer** | • Commonly treated with surgery, including removal of some lymph nodes.  
                              | • Surgery may be followed with radiotherapy. |
Surgery

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

The types of surgical procedures used for the different head and neck cancers are described on the following pages. If surgery is minor, recovery is usually fast and there are often few long-term side effects. For more advanced cancer, surgery will be more extensive, lasting 12 hours or more, and often cause longer-lasting or permanent side effects. See the Managing side effects chapter on pages 50–68 for more information.

Call 13 11 20 for a free copy of Understanding Surgery, or download a digital version from your local Cancer Council website.

Removing lymph nodes

If a head and neck cancer has spread to the lymph nodes in your neck, or if there is a chance the cancer will spread, your surgeon will probably remove some lymph nodes. This operation is called a neck dissection or lymphadenectomy.

Most often lymph nodes are removed from one side of the neck, but sometimes they need to be removed from both sides. A neck dissection may be the only surgery needed when the primary cancer will be treated with radiotherapy, or a neck dissection may be part of a longer head and neck operation. Removing the lymph nodes may affect the movement and appearance of your neck or shoulder (see Lymphoedema on pages 66–67).
How the surgery is done

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

- **endoscopic surgery** – uses telescopes and microscopes through the nose and mouth to remove cancers
- **trans-oral robotic surgery (TORS)** – uses robotic arms to access areas 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 the upper and lower jaw or skull may need to be partially removed.

Endoscopic and trans-oral robotic surgery usually mean less scarring, a shorter hospital stay and faster recovery. However, open surgery may be a better option in many situations.

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

Reconstructive surgery may involve using skin, bone or tissue from another part of the body to rebuild the area. This is called a free flap. Occasionally synthetic materials such as silicone and titanium are used to re-create bony or structural areas. This is called a prosthetic reconstruction.
Surgery for oral cancer
The type of surgery will depend on the size of the cancer and where it is. Localised cancers can be treated by removing part of the tongue or mouth. There are often few side effects. If the cancer is larger, surgery may be more extensive and require reconstructive surgery to help you chew, swallow or speak.

Different types of oral surgery include:
- **glossectomy** – removes part or all of the tongue
- **mandibulectomy** – removes part or all of the lower jaw
- **maxillectomy** – removes part or all of the upper jaw (maxilla)
- **mandibulotomy** – cuts through the lower jaw to access a cancer in the throat or back of the tongue
- **trans-oral 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.
Surgery for pharyngeal cancer
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 healthy tissue, which is checked by a pathologist to make sure all the cancer cells have been removed.

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

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 larynx and pharynx.

Surgery for laryngeal cancer
Operations for laryngeal cancer may include removing the cancer through the mouth (endoscopic surgery), open surgery to remove the larynx (laryngectomy) and a neck dissection (see page 31).

If the cancer is at an early stage, it may be removed through the mouth using trans-oral surgery with standard surgical equipment or laser or robotic surgery. It may take up to six months for your voice to recover. In some cases, there may be long-term or permanent changes to the pitch, loudness or quality of your voice – see page 59 for more details.
If the cancer has advanced, you may need open laryngeal surgery. This will involve removing all of the larynx (total laryngectomy) or part of the larynx (partial laryngectomy).

**Total laryngectomy** – This operation removes the whole larynx and separates the windpipe (trachea) from the oesophagus. Without your vocal cords, you won’t be able to speak naturally, but you will work with a speech pathologist to learn new ways to communicate (see pages 62).

If you have a total laryngectomy, your thyroid gland may be removed during surgery (thyroidectomy). Once the thyroid is removed, you will no longer produce thyroxine (T4), the hormone that maintains your metabolism, energy levels and weight. You will be prescribed an oral hormone tablet, which you will need to take daily for the rest of your life. Ask your doctor for more details.

**Partial laryngectomy** – This type of operation is used for small laryngeal cancers. A cut is made on your neck and the part of the larynx with the cancer is removed. This surgery is now rare as surgery through the mouth (endoscopic surgery) has become more common for small cancers.

After a partial laryngectomy you will keep parts of your voice box and usually be able to speak and swallow afterwards. However, your voice may be hoarse after surgery and you may have a tracheostomy tube inserted for a short time after the operation. See pages 60–62 for more details. Talk to a speech pathologist about ways to improve your ability to swallow and speak after surgery.
Surgery for salivary gland cancer

Most salivary gland tumours affect the parotid gland. Surgery to remove part or all of the parotid gland is called a parotidectomy. Some people with salivary cancer will also need a neck dissection.

The facial nerve, which controls expressions of the face and movement of the eyelid and lip, runs through the parotid gland. If this nerve is damaged during surgery, you may be unable to smile, frown or close your eyes. This is known as facial palsy, and it can take months to a year for movement to improve. In some cases, it may need to be repaired using a nerve from another part of the body, often from the leg (nerve graft). If the facial nerve is removed (facial nerve sacrifice), several procedures will help improve movement and appearance of the face.

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

Some tumours found in the salivary glands are benign, but these are removed using the same surgical techniques.

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)
Surgery for nasal or paranasal sinus cancer

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

The type of surgery depends on the location of the tumour and, if you have paranasal sinus cancer, the affected sinuses.

Different types of surgery for nasal cancer include:

- **maxillectomy** – removes part or all of the upper jaw (maxilla), possibly including the 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** – requires 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** – removes 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.

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.
What to expect after surgery

The length of your hospital stay will depend on the type of surgery you have and how well you recover. The side effects listed below are often temporary. For more information about ongoing effects, see the Managing side effects chapter, pages 50–68.

**Pain** – At first, you will need some pain relief. You will have patient-controlled analgesia (PCA), which delivers a measured dose of pain relief when you press a button.

**Drips and drains** – You may have tubes at the surgery site to drain excess fluid.

**Sore throat** – This usually lasts for less than 24 hours, but may take longer if you were treated for pharyngeal or laryngeal cancer.

**Breathing difficulties** – If your mouth or tongue is swollen and breathing is difficult, the surgeon will place a breathing tube in your lower neck (tracheostomy). The tracheostomy is usually temporary. See pages 60–62 for more information.

**Speech changes** – Your ability to speak may be affected. Often this is temporary, but see page 59 if this side effect is ongoing.

**Dietary changes** – You will usually start with fluids, move on to pureed 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 pages 56–57 for more information.
Julie’s story

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

The treatment from my multidisciplinary team sent the stage 4 cancer in my tonsils, throat and tongue into remission.

For 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.

I have to be honest, the side effects of treatment were tough. My capacity to swallow was limited to liquid food for some time, so I lost 20 kg in 6–8 weeks. I lost the capacity to talk for quite a few weeks, and used an iPad to communicate.

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

I really recommend asking for help from speech pathologists, nutritionists, psychologists and senior nurses, as well as the medical team. Find a dentist who understands the effects of treatment and get advice for the health of your teeth long-term.

Tell your trusted family members and friends what you need and ask directly for help.
Long-term side effects of treatment

After surgery or radiotherapy, many people have to adjust to significant changes. You may also see a speech pathologist and/or dietitian before surgery or radiotherapy to discuss these issues. Talk to your doctor about what to expect.

Breathing changes
After some types of throat surgery, the surgeon may need to help you breathe using a temporary tube in your neck. If you have a total laryngectomy, you’ll need a permanent hole (stoma).

Taste and smell changes
If you have a craniofacial resection, you may lose the 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.

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

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

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. If you have lost teeth, they may be able to be replaced/reconstructed surgically.

Lymphoedema
If you have lymph nodes removed, you may experience persistent swelling in the soft tissue of the affected head and neck area.

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.

Further information: See the Managing side effects chapter on pages 50–68.
Radiotherapy

Radiotherapy (also known as radiation therapy) uses radiation such as x-rays to kill or harm cancer cells so they cannot multiply. The radiation is targeted at the cancer, and treatment is carefully planned to do as little harm as possible to healthy body tissue near the cancer. Radiotherapy can be given externally or internally, but for head and neck cancers it is usually given externally.

It can be used on its own or in combination with surgery or chemotherapy:
- before surgery (neoadjuvant), to shrink large tumours so they are easier to remove during surgery
- after surgery (adjuvant), to reduce the chance of the cancer coming back by eliminating any cancer cells that may not have been taken out during surgery. You will probably start radiotherapy as soon as your wounds have healed and you’ve recovered your strength, usually within six weeks. Adjuvant radiotherapy is sometimes given together with chemotherapy (called chemoradiotherapy or chemoradiation).

External beam radiotherapy

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

The treatment can be delivered in different ways, including intensity-modulated radiation therapy (IMRT), volumetric modulated arc therapy (VMAT), and TomoTherapy. These techniques deliver radiation precisely to the affected area, which reduces treatment time and side effects.
Having external beam radiotherapy

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

During treatment, you will lie on a table under a machine called a linear accelerator. You will wear the mask for 5–15 minutes during treatment (longer during the planning session). Treatment itself is painless and is usually given Monday–Friday as outpatient treatment for 6–7 weeks. You will be monitored by the radiation therapist throughout. Let them know if wearing the mask makes you feel uncomfortable.
Side effects of radiotherapy

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

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

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

- **Ongoing or permanent** – dry mouth, thick saliva, difficulties with swallowing and speech, changes in taste, fatigue, muscle weakness, appetite and weight loss, thrush, hoarseness, dental problems, difficulty opening the mouth, hair loss. Some people find that food and fluid goes into the windpipe. This is called aspiration and it causes obstruction and difficulty breathing. People who develop an underactive thyroid (hypothyroidism) may need to take thyroid medication after radiotherapy, see *Total laryngectomy* on page 35.

For information about managing side effects, see pages 50–68. You can also call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*, or download a digital version from your local Cancer Council website.
Chemotherapy

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

Chemotherapy may be given for a range of reasons:
• in combination with radiotherapy (chemoradiotherapy), to increase the effects of radiation
• before surgery or radiotherapy (neoadjuvant chemotherapy), to shrink a tumour
• after surgery (adjuvant chemotherapy), along with radiotherapy, to reduce the risk of the cancer returning
• as palliative treatment to relieve pain and improve quality of life (see page 48).

Osteoradionecrosis

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

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

Treatment for ORN may include long-term antibiotic medicines or hyperbaric oxygen treatment. While you sit or lie in a pressurised chamber, concentrated oxygen is delivered to the bone to help it heal. Other treatment options include certain medicines and sometimes surgery.
**Side effects of chemotherapy**

Chemotherapy can affect the healthy cells in the body and cause side effects. Everyone reacts differently to chemotherapy, and effects will vary according to the drugs you are given.

Often, combined chemoradiotherapy causes more severe side effects than if you have chemotherapy and radiotherapy separately, but the side effects can be managed.

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

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

To find out more, call Cancer Council 13 11 20 for a free copy of *Understanding Chemotherapy*, or download a digital version from your local Cancer Council website.
**Targeted therapy**
New types of drugs known as targeted therapy are designed to attack specific changes within cancer cells.

Targeted therapy drugs work differently from chemotherapy drugs. While chemotherapy affects all rapidly dividing cells and kills cancerous cells (cytotoxic), targeted therapy drugs affect specific molecules within cells to block cell growth (cytostatic).

A number of targeted therapy drugs are being tested for head and neck cancer in clinical trials (see page 28). One targeted therapy drug called cetuximab is available in Australia for head and neck cancers, when people cannot take the standard chemotherapy drug. Cetuximab is a monoclonal antibody that binds to the surface of cancer cells and stops them growing and dividing. When used to treat head and neck cancer, it is used with radiotherapy.

**Immunotherapy**
These drugs can stimulate the body’s own immune system to attack the cancer. Immunotherapy may be effective in treating some forms of head and neck squamous cell cancer.

Some types of immunotherapy drugs work by enabling the immune system to bypass “checkpoints” set up by the cancer that block the immune system. These antibody drugs can block a protein called PD-1 found on immune cells. The drugs release this “brake”, allowing the immune system to better attack the cancer. Several checkpoint immunotherapy drugs for head and neck cancers are currently being tested in clinical trials (see page 28).
Pembrolizumab has been approved for head and neck cancer, but is not yet reimbursed (as of June 2017).

**Side effects of immunotherapy**
The side effects of immunotherapy drugs are different to chemotherapy, and are caused by an overactive immune system attacking the normal parts of the body. Most commonly this includes fatigue, rash and diarrhoea, but as any part of the body can be attacked by the immune system, other side effects can occur. Early side effects can usually be controlled before they become severe, so let your medical team know as soon as they appear.

**Palliative treatment**
Palliative treatment helps to improve people's quality of life by alleviating symptoms of cancer without trying to cure the disease and is best thought of as supportive care. Many people think that palliative treatment is for people at the end of their life, however, it may be beneficial for people at any stage of advanced head and neck cancer.

As well as slowing the spread of cancer, palliative treatment can help manage symptoms such as pain and help you live as long as possible in the most satisfying way you can. Treatment may include radiotherapy, chemotherapy or other drug therapies. For more information, visit your local Cancer Council website or call 13 11 20 for free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*. 
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 treatments, is commonly used for head and neck cancers.

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

- During radiotherapy, you will need to wear a specially-made mask to keep you still during treatment.

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

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

Head and neck cancer, and its treatments, can change your ability to chew, swallow or talk. These side effects can be temporary or permanent, and will require ongoing management and rehabilitation.

This chapter provides information and tips to help you manage side effects, including coping with changes in your eating, breathing and speech, and managing pain. For additional support, information and referral to services, call Cancer Council 13 11 20.

Mouth problems

Dry mouth
Radiotherapy to the head or neck area can cause dry mouth (xerostomia). This can make chewing and swallowing difficult. A dry mouth can also make it harder to keep your teeth and mouth clean, which can increase the risk of developing cavities.

Mouth sores and ulcers
During chemotherapy and radiotherapy, mouth sores are common. The sores can form on any soft tissue in your mouth, making eating, swallowing and talking difficult.

Your doctor can give you medicines to reduce the pain when you eat, drink or speak. Some pain relief medicines can be applied directly to the mouth sores to numb them. Your dietitian can suggest foods to reduce discomfort. You may need to choose softer foods and nourishing fluids. If you are unable to eat and drink enough to meet your nutritional needs, you may need a feeding tube to support you during recovery.
# How to relieve mouth problems

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

## Mouth sores and ulcers
- Talk to your doctor about mouthwashes or medicines to relieve ulcers and to keep your mouth fresh.
- Use a soft-bristled toothbrush and replace it often to reduce infections. Brush gently.
- Suck on ice cubes.
- Avoid rough, crunchy or dry foods (e.g. chips, nuts, toast, crackers). Also avoid vinegar, spices, salty foods, alcohol, very hot or very cold foods and drinks, citrus or tomato-based food and juice.
- Gargle with ½ tsp salt plus ½ tsp baking soda in a glass of warm water. Use frequently as a mouthwash.
- Tell your doctor or dietitian if you have ongoing or severe difficulty swallowing.
- Download the *Mouth Health and Cancer Treatment* fact sheet from your local Cancer Council website.
**Difficulty kissing**

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

Some people 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 to a counsellor.

**Taste, smell and appetite changes**

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

It can take several months for taste changes to return to normal, and this may affect your appetite. See the tips box on the opposite page for ways to manage changes to taste and smell. If you do not regain your full sense of smell, a speech pathologist may be able to teach you a new technique.

For further information, call Cancer Council 13 11 20 to request a copy of *Nutrition and Cancer*, or download a digital version from your local Cancer Council website.
# How to manage taste and smell changes

<table>
<thead>
<tr>
<th>Taste</th>
<th>Smell</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Add extra flavour to food if it tastes bland, e.g. use fresh herbs.</td>
<td>• If you lose your sense of smell, take precautions such as checking the use-by dates of foods and installing smoke detectors in your home.</td>
</tr>
<tr>
<td>• Freshen your mouth with sugar-free mints or gum, and brush your teeth after meals.</td>
<td>• If loss of smell stops you eating enough, you may lose weight. Use nutritional supplement drinks to increase nutritional intake, e.g. Ensure or Resource. These are available from most pharmacies.</td>
</tr>
<tr>
<td>• If you smoke, try to quit. As well as damaging your health, smoking reduces appetite and changes the taste of food. Call the Quitline on 13 7848 or visit quitnow.gov.au.</td>
<td>• Find ways to enjoy food more. Choose foods that are fresh and full-flavoured for a sensation on your tongue.</td>
</tr>
<tr>
<td>• Use a straw so the taste of drinks isn’t as strong.</td>
<td>• Download a copy of the fact sheet on <em>Understanding Taste and Smell Changes</em> from your local Cancer Council website for more information.</td>
</tr>
<tr>
<td>• Stimulate your appetite with aromatic foods and ingredients.</td>
<td>• Avoid bitter or metallic-tasting foods such as coffee and chocolate.</td>
</tr>
<tr>
<td>• If food tastes “off”, rinse your mouth by drinking tea, or eating ice-cream and soft fruits such as watermelon.</td>
<td>• See a dietitian for additional suggestions.</td>
</tr>
</tbody>
</table>

Find ways to enjoy food more. Choose foods that are fresh and full-flavoured for a sensation on your tongue.
Swallowing difficulties
Chewing and swallowing involve your lips, teeth, tongue and the muscles in your mouth, jaw and throat working together. Many people with a head and neck cancer have difficulty swallowing (dysphagia) before, during or after treatment. This may be because of the tumour or the treatments, and difficulty swallowing may be short-term or long-term. Being able to swallow is important for adequate nutrition.

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

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

Removing part of the larynx (partial laryngectomy) – Surgery may cause food to go down the wrong way into the lungs (aspiration). This is because the larynx and epiglottis act like valves and shut off the airway when swallowing so liquid or food don't go into the lungs. Signs of aspiration include coughing during or after swallowing.

Radiotherapy – This can cause dry mouth, pain, and changes to the strength of the muscles and nerves used in swallowing. These effects could be worse if you also have chemotherapy at the same time as radiotherapy (chemoradiotherapy).
Swallowing test
You may have a test before and after treatment to look at what happens when you swallow. A speech pathologist uses a movie-type x-ray known as a videofluoroscopic swallowing study (VFSS) or modified barium swallow (MBS) to check that foods and liquids are going down the correct way. If more detail is needed, you may have a fibre-optic endoscopic evaluation of swallowing (FEES) test during a nasendoscopy (see pages 16–17). The test results will help plan your treatment.

How to manage swallowing difficulties
- See a speech pathologist for ways to change your swallowing action to help reduce discomfort or food going down the wrong way (aspiration). They can also show you swallowing exercises to complete during treatment. To find a speech pathologist, speak with the health care team at your treating centre or visit speechpathologyaustralia.org.au.
- Continue to eat and drink whenever possible during treatment to keep your swallowing muscles moving and working. This will reduce the likelihood of long-term swallowing problems.
- Ask your doctor for medicines to relieve discomfort when swallowing. Some medicines come as mouth rinses.
- Talk to a dietitian or speech pathologist about ways to adjust the consistency of food to make it easier to swallow.
- See the Laryngectomee Association of NSW’s cookbook for recipes, stilltalking.org/#cookbook.
Feeding tube

After surgery or during radiotherapy treatment, you may find eating and swallowing uncomfortable and need to have food through a feeding tube (also called enteral feeding) to help you get the nutrition you need while your throat heals. This tube is usually temporary, but is sometimes permanent.

A feeding tube can help ensure you stay well nourished and hydrated. It can also help you maintain or gain weight. If you can’t swallow medicines, check with your doctor or nurse whether these

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Types of feeding tubes

Temporary feeding tube

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

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

The NG tube is usually put in and removed by a doctor or nurse. Specially prepared food will be put down the tube.
can also be given through the feeding tube. Your health care team will show you how to care for the tube to prevent leakages and blockages. They’ll also let you know when the tube needs to be replaced. If the tube falls out, let your doctor know immediately. Washing your hands before using the tube and keeping the tube and your skin dry will help prevent infections.

Having a feeding tube inserted is a significant change, and it is common to have a lot of questions. Adjusting to a feeding tube takes time, but talking to a dietitian or nurse may help.
Malnutrition
The side effects discussed on pages 50–57 may make eating difficult, which can cause you to lose weight. Even a small drop in your weight (e.g. 3–4 kg), particularly over a short period of time, may put you at risk of malnutrition. You may be malnourished even if you are overweight.

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

How to prevent unplanned weight loss
• Eat small meals frequently.
• Include high-energy and high-protein foods at every meal or snack. For example, drink milk rather than water and choose cheese and biscuits over lollies.
• Try ready-to-use nutritional supplement drinks. Examples include Sustagen, Ensure and Resource Fruit Flavoured Beverage. Many pharmacies and supermarkets sell these specially formulated drinks. You don’t need a prescription.
• If you are having trouble swallowing, talk to a speech pathologist for advice on thickening the supplement.
• For more information, call 13 11 20 for a copy of Nutrition and Cancer, or download a digital version from your local Cancer Council website.
Changes to speech

The ability to talk can be affected following surgery and radiotherapy, either by the treatment itself or by side effects such as a tracheostomy or swelling after surgery. You may lose the ability to speak clearly (dysarthria) or the ability to produce sound (dysphonia). The degree and duration of any change will vary depending on the location of the tumour and treatment.

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

How to manage changes to speech

- Try non-verbal ways to communicate – gesture, point, nod, smile, mouth words or ring a bell to call people.
- Use a notepad or technology (computer, tablet, mobile phone) to write notes.
- Ask people to speak louder or confirm the message to check what you heard was correct.
- Encourage family and friends to be honest if they don’t understand you and to learn new ways to communicate with you.
- Work with a speech pathologist to improve your speech and learn strategies for communicating with your family and friends (see Restoring speech after a laryngectomy on page 62).
- Speak to a counsellor or psychologist about any problems or frustrations.
Breathing changes
If breathing is difficult or swelling of the airway is expected after surgery, the surgeon will make a hole in the front of your neck under general anaesthetic. This is known as a tracheostomy. A tracheostomy tube is placed through the hole into the windpipe (trachea), and this allows you to breathe.

You will have a temporary tracheostomy after most types of surgery, and it will usually be done at the same time. With a temporary tracheostomy, the tube will usually be removed after a recovery period, and the hole will close up within a few days or weeks with a simple dressing. At first your voice may be weak and breathy, but it should return to normal once the stoma has healed. Your speech pathologist will teach you to speak and assess your swallowing, and your physiotherapist will show 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. If you have a total laryngectomy, a permanent stoma or breathing hole will be created at the time of the surgery. A laryngectomy tube may be used to keep the stoma from becoming smaller. If you need a permanent stoma, your health care team will discuss this with you and teach you how to look after it.

Some states have support groups for people with head and neck cancers. Call Cancer Council 13 11 20 for details.
Living with a tracheostomy or stoma

Having a stoma or tracheostomy is a big change in a person’s life and takes some adjustment. 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 73 for ways to get support.

Caring for the tube – Your health care team will show you how to clean and change the tracheostomy or laryngectomy tube.

Coping with dry air – The air you breathe will be much drier since it no longer passes through your nose and throat, which
normally moistens and warms the air. This can cause irritation, coughing and excess mucus coming out of the tracheostomy/stoma. Your speech pathologist or nurse will show you products that cover the stoma or to attach to the tracheostomy tube. This will provide heat and moisture for the trachea.

Swimming and other water sports – You will need to use special equipment to avoid water getting into the windpipe.

Restoring speech after a laryngectomy

If changes to your voice are long-term, such as after a total laryngectomy, a speech pathologist may use a variety of methods to help you use your voice again.

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

**Tracheoesophageal puncture (TEP) speech** – Your surgeon creates a puncture between your trachea and oesophagus. A small voice prosthesis (or valve) is inserted to direct air from your trachea into the oesophagus. This creates a low-pitch, “throaty” voice. TEP is usually done during the laryngectomy or later.

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

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

Your physiotherapist may also give you advice on positioning for comfort, suggest exercises, or recommend other pain relief options such as transcutaneous electrical nerve stimulation (TENS). For more information, call 13 11 20 for a copy of *Overcoming Cancer Pain*, or download a copy from your local Cancer Council website.

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

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

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

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

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

**Face** – If 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 it is likely you will need a prosthesis, the doctor will discuss this with you before the operation.

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

**Swelling** – During surgery or radiotherapy lymph nodes can be damaged and this can cause swelling in the head and neck areas. Sometimes the swelling develops internally and is difficult to see. Lymphoedema can be temporary or permanent and may change your appearance. This usually improves with time but some people find lymphoedema therapy helps (see page 66–67).
**Tips for adjusting to appearance changes**

You may be distressed or embarrassed about significant changes to your appearance. You may feel that any visible changes make you less attractive and worry that others will reject you. Try to give yourself time to get used to any physical changes.

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

Talk to your doctors about how surgery and reconstruction will affect your appearance and the possibility of having plastic surgery or a facial prosthesis to rebuild parts of your face and neck.

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

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**Managing fatigue**

Fatigue, or feeling exhausted and lacking energy for daily activities, is a common 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 fatigue.
**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. If lymph nodes have been damaged during surgery or removed in a lymphadenectomy, it may prevent lymph fluid from draining properly. This causes fluid build-up and swelling.

Swelling usually occurs in a limb such as the arm or leg, but can also occur in the neck. People who have had surgery followed by radiotherapy to the neck are more at risk, especially if both sides are treated. The likelihood of developing lymphoedema will also depend on the number of lymph nodes removed during surgery.
Symptoms of lymphoedema are easier to manage if the condition is treated early. The main signs of lymphoedema include swelling, redness and skin warmth, which may come and go.

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

In many hospitals, a lymphoedema practitioner will assess you before you have surgery. Some hospitals have specialist physiotherapists who can teach you simple exercises to reduce your risk of developing lymphoedema.

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

Key points

- People with a head and neck cancer often experience side effects. Some effects go away after treatment; others need ongoing management and/or rehabilitation.

- A dry mouth is common if the salivary glands have been damaged or removed and no longer produce saliva. Mouth sores often occur during chemotherapy and radiotherapy. This can make it difficult to eat, drink or speak.

- You may experience changes in taste, smell and appetite. These changes are usually temporary, but some people may lose their sense of smell permanently.

- Difficulty swallowing is common and can be managed using exercises, medicines and diet.

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

- You may need therapy after surgery to learn how to speak or communicate in other ways.

- You may have a tracheostomy or stoma to help you breathe. Support is available.

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

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

- Removing lymph nodes may cause loss of nerve function. It can also cause swelling in the neck or a limb (lymphoedema). A lymphoedema practitioner can help improve swelling.
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 whether 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.

Call 13 11 20 for free copies of Sexuality, Intimacy and Cancer, Fertility and Cancer and Emotions and Cancer, or download the booklets from your local Cancer Council website.
Life after treatment

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

Some people say that they feel pressure to return to “normal life”, 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.

The organisation beyondblue has information about coping with depression and anxiety. Go to beyondblue.org.au or call 1300 22 4636 to order a fact sheet.
Follow-up appointments
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 from a speech pathologist and dietitian as you need it, or you may be referred to local services.

Tests will include imaging 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 recurrence. This is why it is important to have regular check-ups.

If the cancer is only in the head and neck, you may have surgery to remove the cancer, or you may be able to have 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
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.
In a support setting, 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 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. These include:

- **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 Cancer Council Online Community at cancercouncil.com.au/OC.

Talk to your nurse, social worker or Cancer Council 13 11 20 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 programs can offer valuable opportunities to share experiences and ways of coping.

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

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. Visit carersaustralia.com.au or call 1800 242 636 for more information and resources.

You may also call Cancer Council 13 11 20 to find out more about carers’ services and to get a free copy of the Caring for Someone with Cancer booklet, or download it from your local Cancer Council website.
Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

**Australian**

- Cancer Council Australia ........................................... cancer.org.au
- Cancer Australia ........................................................ canceraustralia.gov.au
- Department of Health ................................................... health.gov.au
- healthdirect ................................................................. healthdirect.gov.au
- beyondblue .............................................................. beyondblue.org.au
- Look Good Feel Better .................................................. lgfb.org.au
- Beyond Five ............................................................... beyondfive.org.au
- Australian and New Zealand
  - Head & Neck Cancer Society ......................................... anzhnacs.org
  - Radiation Oncology: Targeting Cancer .................. targetingcancer.com.au
  - Australasian Lymphology Association .................... lymphoedema.org.au
  - Speech Pathology Australia ................................ speechpathologyaustralia.org.au
  - Dietitians Association of Australia .......................... daa.asn.au

**International**

- American Cancer Society ............................................. cancer.org
- Cancer Research UK ................................................. cancerresearchuk.org
- Macmillan Cancer Support (UK) ................................. macmillan.org.uk
- National Cancer Institute (US) .................................. cancer.gov
- Head and Neck Cancer Alliance (US) ......................... headandneck.org
- Mouth Cancer Foundation (UK) ................................. mouthcancerfoundation.org
- The Oral Cancer Foundation (US) ......................... oralcancerfoundation.org
- The Swallows Head & Neck Support Group ........... theswallows.org.uk
- Web Whispers (US) .................................................. 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?
- Has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Do I have a choice of treatments?
- 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 coordinating my care?
- How much will treatment cost?
- 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?
- Will I need to have a stoma?
- Will my speech be affected?
- 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 is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

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

benign
Not cancerous or malignant.

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

cancer of unknown primary (CUP)
A secondary cancer that is found in the body, but the place where the cancer first started growing (the primary site) cannot be determined.

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

chemoradiotherapy
Treatment that combines chemotherapy with radiotherapy. Also called chemoradiation.

chemotherapy
A cancer treatment that uses drugs to kill cancer cells or slow their growth.

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

CT scan
Computerised tomography scan. This scan uses x-rays to create a detailed, cross-sectional picture of the body.

dysarthria
Difficulty speaking clearly.

dysphagia
Difficulty swallowing.

dysphasia
Difficulty speaking.

dysphonia
Difficulty producing voice.

endoscopic sinus surgery
A type of surgery for cancers that can be accessed through the nasal cavity. Tissue is removed using a flexible tube with a camera on the end (endoscope) and no surgical cuts need to be made.

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

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

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

external beam radiotherapy
A type of radiotherapy delivered to the cancer from outside the body.

facial nerve
A major nerve in the skull that controls muscle movement in the face. It runs through the parotid salivary gland.
feeding tube
A flexible tube used to provide nutrition to people unable to swallow.

frontal sinuses
Sinuses located behind the forehead.

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

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

Glottis
See vocal cords.

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 is a risk factor for some cancers. Also called the wart virus.

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

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

immobilisation mask
A device that helps keep a person in a fixed position during radiotherapy.

immunotherapy
Treatment that stimulates the body’s immune system to fight cancer.

intensity-modulated radiation therapy (IMRT)
A type of external radiotherapy in which the radiation beams are aimed from several directions, while the intensity (strength) is controlled by computers.

intravenous (IV)
Injected into a vein.

laryngectomy
The surgical removal of the larynx. In partial laryngectomy, part of the larynx is removed. In total laryngectomy, the whole 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 back of the throat, including the larynx and pharynx, using a laryngoscope (a tube with a light on it) or a mirror.

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

laser surgery
The use of a laser beam to remove tissue.

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

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. Includes the bone marrow, spleen, thymus and lymph nodes.
lymph nodes
Small, bean-shaped glands that collect and destroy bacteria and viruses. Also called lymph glands.

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

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

mandible
The lower jawbone.

mandibulectomy
Removal of part or all of the lower jaw.

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

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

maxilla
The upper jawbone.

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

maxillectomy
Removal of part or all of the upper jaw.

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

metastasis (plural: metastases)
Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

metastatic neck cancer with unknown primary
Cancer that is found in the lymph nodes of the neck but the primary location cannot be located.

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

MRI scan
Magnetic resonance imaging scan. It uses magnetism and radio waves to take detailed cross-sectional pictures of the body.

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

nasendoscope
A flexible tube with a light and camera on the end.

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

nasogastric (NG) tube
A plastic feeding tube that is passed through the nose into the stomach.

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

neck dissection
Surgery to remove lymph nodes in one or both sides of the neck. Also called lymphadenectomy.
oesophageal speech
Forcing air into the top of the oesophagus and then out again to produce a voice.

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

open surgery
A surgical method that involves one large cut in the body to view and access the organs.

oral cavity
Refers to the mouth and includes the lips, gums, cheeks, the roof and floor of the mouth, front two-thirds of the tongue, and the area behind the wisdom teeth.

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

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

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

osteoradionecrosis (ORN)
A condition in which bone tissue of the jaw breaks down, causing pain.

palliative treatment
Medical treatment to help people with advanced cancer manage pain and other physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy or other therapies.

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

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

parotidectomy
Surgery to remove the parotid gland.

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

PET scan
Positron emission tomography scan. Uses a low dose of radioactive glucose solution to find cancerous areas.

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

pharynx
The throat. The muscular tube at the back of the nose that connects the mouth and nose with the oesophagus.

prognosis
The likely outcome of a person’s disease.

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

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

radiotherapy
The use of radiation to kill or injure cancer cells so they cannot grow and multiply. Also called radiation therapy.

reconstructive surgery
Surgery to rebuild an area of the body that has been damaged.
**rhinectomy**
The surgical removal of part or all of the nose.

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

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

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

**sentinel node**
The first lymph node that cancer cells may spread to.

**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.

**sublingual gland**
One of the major salivary glands. It is found under the tongue.

**submandibular gland**
One of the major salivary glands. It is found under the jawbone.

**targeted therapy**
Type of treatment that uses drugs or other substances to selectively target proteins or other molecules involved in cancer cell growth.

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

**Tomotherapy**
A type of 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 puncture (TEP)**
A surgically created valve between the trachea and oesophagus to create a low-pitched voice.

**tracheostomy**
Surgery to make a hole at the base of the neck into the trachea (windpipe), which allows you to breathe.

**trans-oral robotic surgery (TORS)**
Surgery to remove a tumour with robotic surgical equipment.

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

**tumour**
A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).
ultrasound
A scan that uses soundwaves to create a picture of an internal part of the body.

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

volumetric modulated arc therapy (VMAT)
A type of radiotherapy that rotates around the treatment area to deliver radiation to the body.

xerostomia
Dry mouth.

References
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).

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

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

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