

# UNDERSTANDING CANCER OF UNKNOWN PRIMARY



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## CANCER OF UNKNOWN PRIMARY

### WHAT ARE LYMPH NODES?

Lymph nodes are bean-shaped glands located throughout the body that are part of the immune system's defence against infection. There are hundreds of lymph nodes in the head and neck area and most of these run down the sides of the neck and under the jaw. Lymph nodes are normally difficult to feel because they are soft and small (less than 1 cm). The lymph nodes may become swollen during infection or with cancer.

### WHAT IS CANCER OF UNKNOWN PRIMARY?

Cancer occurs when cells become abnormal and grow uncontrollably. These cells buildup to form a mass (in other words, a lump). Cancer of unknown primary in the head and neck region occurs when the origin of the cancer is not found but has spread to the lymph nodes in the neck. It accounts for 5% of all head and neck cancers.

Most cancers that spread to the lymph nodes of the neck come from flat-shaped cells that line areas such as the inside of the mouth, nose and throat. These cancers are called squamous cell cancers (SCC). Only a few of cancer cases come from the salivary glands, skin or other places.

### WHAT CAUSES CANCER OF THE UNKNOWN PRIMARY?

The main causes of head and neck cancers and cancer of unknown primary are:

- **Alcohol and smoking (cigarettes, cigars or pipes)** or using 'smokeless' tobacco (snuff and chewing tobacco): increases risk of developing of head and neck cancer. Those who smoke and drink a lot of alcohol are at a much higher risk compared with those who only use alcohol alone.
- **Exposure to HPV (human papillomavirus)**: may contribute to the development of head and neck cancer involving the tonsils or back of the tongue (tongue base). The cancers in the tonsil and tongue base are usually small and difficult to detect but can spread to lymph nodes in the neck and account for many head and neck cancers classified as from an unknown primary.

- **Sun exposure:** contributes to skin cancer, the most common type of cancer in Australia. Patients with skin cancer often have had many primary cancers treated making it difficult to know whether a cancer in a lymph node has come from a skin cancer or not.

## WHAT ARE THE SIGNS AND SYMPTOMS?

Patients with cancer of unknown primary usually notice a lump in their neck, which is often painless. Most patients don't have any other symptoms.

Swollen lymph nodes may be due to an infection, such as a cold or flu, but in this situation the swelling should subside after two weeks. Children and young adults may sometimes have persistently enlarged lymph nodes due to viruses such as glandular fever.

However, adults that notice a swollen lymph node that does not go away within three weeks should consult their doctor. Adults presenting with enlarged lymph nodes for longer than three weeks may be recommended to have a needle biopsy to check for cancer.

## HOW IS CANCER OF UNKNOWN PRIMARY DIAGNOSED?

For a diagnosis of cancer of unknown primary, your doctor will need to do the following things:

- Talk with you about your **medical history**. This includes discussing symptoms that might point to the source of the cancer, risk factors (e.g. smoking or drinking), and any previous history of cancer
- Perform a **physical examination** by examining your nose, mouth, throat, thyroid gland and skin for any suspicious areas
- Arrange a referral to a head and neck or ear, nose and throat (ENT) specialist who may perform a nasoendoscopy (a flexible camera that passes through the nose to better examine the back of the nose, throat and voice box), order diagnostic tests such as a biopsy of the lymph node (external needle biopsy under local anaesthetic) and scans for further assessment. An examination under anaesthetic may be required if these tests do not reveal an obvious source of the cancer.

**Common tests used include:**

- **Examination under anaesthesia:** In some patients, the primary cancer may grow slowly and be too small to be seen on examination in the clinic or on scans. Sometimes, a biopsy of the most likely primary site is needed to confirm there is no cancer there, but examining these areas is often difficult when the patient is awake. The doctor may suggest examining the areas under general anaesthesia (with you asleep) if the primary site of cancer hasn't been identified. Whilst under anaesthesia, the doctor can perform a thorough examination of the mouth, throat, voice box and the back of the nose (nasopharynx).

Based on the examination, the doctor may recommend:

- **Needle [biopsy](#) (Fine Needle Aspiration or FNA biopsy):** This is when a thin needle is inserted into the suspicious lymph node to remove a sample. Typically, this is performed using ultrasound guidance with local anaesthetic to reduce your discomfort. The tissue is then examined under a microscope to look for cancer cells by a pathologist. This is the most sure way to know if you have cancer.
  - If a diagnosis cannot be made based on the FNA, it is either repeated or a **core biopsy** (a similar procedure with a larger needle) may be performed. If the diagnosis remains uncertain, then a surgeon may perform an excisional lymph node biopsy to remove the suspicious lump under general anaesthesia and send the sample to the pathologist for review.
- **[Ultrasound scan:](#)** Gel is applied to the neck, and a hand-held device is rolled over the gel to create a picture of the tissues in the neck. It is painless and is a very good way to assess the thyroid gland.
- **[CT \(Computed Tomography\) scan:](#)** This uses X-rays to take 3D pictures inside the body. Depending on the clinical situation, patients may require a CT scan of the head, neck, and possibly the chest. Often dye is injected into a vein during the procedure to give clearer images.
- **[MRI \(Magnetic Resonance Imaging\) scan:](#)** This uses magnetic fields to take pictures inside the body. An MRI scan may be used with, or instead of a CT scan to help with diagnosis. Dye may be injected into a vein during the procedure to make certain structures and blood vessels show up more clearly.

- **PET (Positron Emission Tomography) scan:** Using a radioactive form of sugar, a PET scan can show a cluster of cancer cells and check if the cancer has spread elsewhere in the body. This scan may help identify where the cancer has come from (the primary site). There are some instructions to follow for the next few hours after the scan while the radioactive dye is leaving your system.
- **X-ray of the jaw bones:** This is part of the dental assessment, which may be needed before treatments.

## THE CANCER CARE TEAM

After a diagnosis of cancer has been made, your doctor is likely to talk about your diagnosis with the cancer care team they work with. This is known as a head and neck cancer MDT (multidisciplinary team). You may be asked to attend an appointment where the MDT talks about how best to treat your cancer and coordinate your treatment and care. This team includes experts who will review the diagnosis and tests performed and considers all parts of your treatment and recovery. The purpose of the MDT is to decide on the best treatment for your cancer and to help you regain the best function possible in the long-term.

Healthcare professionals that are a part of your head and neck cancer MDT	
Head and neck surgeons	specialist doctors who surgically remove cancers in the face, mouth, throat and neck. This includes surgeons with a background in otolaryngology (Ear Nose and Throat), general surgery, maxillofacial surgery, and reconstructive surgery. If surgery is required, the head and neck surgeon will carry out the procedure.
Reconstructive (plastic) surgeons	specialist doctors with expertise in reconstructing the head and neck. Some head and neck surgeons also do reconstructive surgery, depending on their training and experience.
Radiation oncologists	specialist doctors trained in the use of carefully directed radiation to treat cancer.

Radiation therapists	healthcare professionals who deliver the radiation treatment prescribed by the radiation oncologist.
Medical oncologists	specialist doctors who are experts in the use of medicines like chemotherapy and immunotherapy to treat cancer.
Speech pathologists	healthcare professionals who work with people who have difficulties speaking or swallowing.
Dietitians	healthcare professionals who give food and dietary advice.
Dentist/oral medicine specialists	healthcare professionals who care for the mouth and teeth. Mouth care is very important in head and neck cancer, especially if radiation therapy is needed.
Pathologists	specialist doctors who are experts in looking at cells under a microscope and determining if they are cancer.
Radiology and nuclear medicine specialists	specialist doctors who interpret scans such as CT, MRI and PET scans.
Palliative care team	specialist doctors and nurses who have expertise in managing symptoms and improving quality of life, often in patients where the cancer can't be cured.
Nurses	healthcare professionals who are experts in the care of people with cancer, and work with all members of the cancer care team. Often, specialist cancer nurses are part of the MDT. They will help to plan and coordinate your care.
Psychologists	are healthcare professionals who assist people with worries about coping and living with cancer (mental health).
Social workers	are healthcare professionals who provide practical and emotional support to people living with cancer.

Visit the [Head and Neck Cancer Australia website](#) for further information on the health professionals who may be part of your **cancer care team**.

## WHAT IS STAGING?

Once your doctor has made a diagnosis of cancer, it is important that they assess the extent (or stage) of the cancer. Staging a cancer is important because it helps doctors to choose the best treatment for you. It also gives information about the chances of cure.

The **TNM (Tumour, Node, Metastases)** system is used to stage cancer. This system is used to summarise information about the size of the cancer and whether it has spread to lymph nodes or other parts of the body.

### THE TNM SYSTEM

- **T** stands for the size of the primary cancer (Tumour). A T value can range from 1 (small cancer) to 4 (large cancer).
- **N** indicates whether the cancer has spread to the lymph nodes. Where there is no cancer in the lymph nodes, the N value is 0. An N value can range from 1 to 3, depending on the size and number of cancerous lymph nodes.
- **M** stands for distant metastases, or whether the cancer has spread to other parts of the body outside the head and neck. An M value can be either 0 (cancer has not spread to other parts of the body) or 1 (cancer has spread to other parts of the body).

Once the values for T, N and M have been worked out, they are combined to give an overall score between 1 and 4. Your doctor may write this in Roman numerals: I, II, III and IV.

The chance of cure depends on both the type of cancer and the stage.

Staging is complicated but in broad terms cancers may be described as:

- **Early-stage cancers (Stage I or II cancers)** which are localised or locoregional cancer ranging from small (less than 4 cm in size) and having not spread to the lymph glands or other parts of the body.
- **Advanced stage cancers (Stage III or IV cancers)** which are more advanced due to their size (more than 4 cm) and having spread to the lymph nodes. **It is important to know that most patients with head and neck cancer of unknown primary can be cured.**

**Metastatic cancer (any M1)** – any cancer that has been confirmed to have spread to other parts of the body outside of the head and neck. This is generally not said to be able to be cured, however there are treatment options that will be discussed to slow the cancer and improve quality of life.

## WHAT IS GRADING?

Grading refers to the growth pattern of the cancer cells. The grade of the cancer is determined by a pathologist who examines a biopsy sample under a microscope. The pathologist determines the grade of the cancer by how the cells look. In general, grading can be used for certain types of cancer to estimate how quickly the cancer is likely to grow and spread. Grading does not generally impact the staging of cancer of unknown primary and may not be discussed for this reason.

## TREATMENT OPTIONS

Your cancer care team will discuss the treatment options available for treating cancer of unknown primary. This is the time to ask any questions you may have and a good time to consider if you would like further information, or a second opinion.

The treatment most suited to each person depends on many factors including:

- the number and size of lymph nodes that are affected
- personal factors (e.g. age, general health and treatment history)
- treatments available (and whether any clinical trials are available)
- your preferences for treatment.

The treatment options for cancer of unknown primary are surgery (often combined with radiation therapy and chemotherapy) or radiation therapy (often combined with chemotherapy).

## SURGERY

Some common types of surgery that can be used for cancer of unknown primary in the head and neck area are:

- **Neck dissection:** This involves removing the enlarged cancerous lymph node(s), together with other lymph nodes in the same region of the neck.

- **Tonsillectomy:** This involves removing the tonsils, if there are signs of cancer in the tonsils or other lymph nodes in the neck. It can also help with diagnosing the type of cancer.

## HOW CAN I PREPARE FOR THE SURGERY?

Your doctor will explain details of the surgery, general risks and side effects of surgery. Ask your doctor if you have questions. They may recommend:

- **stopping blood thinners (e.g. aspirin) before surgery to reduce the risk of bleeding**
- **special stockings to reduce the risk of blood clots**
- **staying active straight after surgery to reduce the risk of blood clots and chest infection**
- **antibiotics to reduce to risk of wound infection.**

Before starting treatment, it is important that you consider stopping smoking to reduce the risk of infection and help you fully recovery after your treatment.

## SIDE EFFECTS OF SURGERY

Treatment for cancer of unknown primary may lead to several side effects. You may not experience all the side effects. Speak with your doctor if you have any questions or concerns about treatment side effects.

Possible side effects depend on the surgical approach that best suits your individual cancer. This includes whether you need to have lymph nodes removed from the neck and whether you need tissue taken from another part of your body to fix the area where the cancer was taken out. Your treating team will talk about the type of surgery they will do in more detail and the specific risks that apply to you.

Your doctor may recommend that you receive supportive care to help during your recovery. Further information about [supportive care](#) is available on the website.

## RADIATION THERAPY

For cancer of unknown primary, radiation therapy may be used to treat the lymph nodes affected by cancer with or without the primary site(s) that it may likely have come from. The most common approach for cancer of unknown primary is called **external beam radiation**. This is where the radiation is applied from outside of the body and is non-invasive.

- **Definitive radiation therapy:** This is when radiation therapy is used on its own to clear the cancer without surgery. Definitive radiation therapy is targeted to one side of the neck area (unilateral), containing the cancerous lymph nodes, and one side (unilateral) or both sides of the throat (bilateral) to treat all possible areas of primary cancer. Typically, radiation therapy is delivered daily (but not on weekends) over 7 weeks. Chemotherapy may be given at the same time as the radiation therapy (concurrent chemoradiation), sometimes once per week or once every few weeks during the 7 weeks of radiotherapy.
- **Adjuvant radiation therapy:** This is when radiation therapy is given after surgery and is used as an additional treatment to clear any cancer that may not have been removed during surgery. Adjuvant radiation therapy may also be given in combination with chemotherapy (concurrent chemoradiation).
- **Palliative radiation therapy:** In cases where a cure is not possible, a lower dose of radiation therapy is used to relieve symptoms of advanced or metastatic cancer. Symptoms that may require palliative radiation therapy include pain, bleeding, breathing and swallowing difficulties. **This is given over a shorter number of treatments, not 7 weeks.**

## HOW DO I PREPARE FOR RADIATION THERAPY?

You will meet with many members of the cancer care team, who will help you learn how to look after yourself through radiation therapy, recovery and long-term follow-up. They will also talk to you about side effects and how to manage them. It may be helpful to write down questions as they come up, so you can ask anyone in your cancer care team when you see them.

- **Mask-making and simulation:** Radiation therapy is a precise treatment. To make sure, that the cancer is covered by the treatment and to minimise dose to normal structures, you will need to be very still during the treatment, usually for about five minutes. A radiation therapy mask that is

made to fit perfectly to your shape, will be put on you during each treatment to minimise movement while the treatment machine targets where the cancer is.

- You will have a planning **CT scan** (and sometimes other scans) with the mask on. Your radiation oncologist and radiation therapists will use these scans with all your other clinical information to develop a radiation therapy plan just for you (a personalised plan) based on your own internal anatomy and cancer size and location. Your individual plan will go through several quality checks by the radiation therapy and radiation oncology physicist team before it is ready to be used for your treatment. This whole process can take approximately 2-3 weeks.
- **Teeth and mouth care:** You might need to have some of your teeth taken out, this will depend on the area being treated and the dose of radiation therapy. It is important to take out any broken or infected teeth before radiation therapy. Taking out unhealthy teeth after radiation therapy can cause problems with the jawbone.
- **Diet, nutrition and the role of your dietitian:** Your cancer and its treatment can make it hard to eat and drink. Your doctor will recommend you see a dietitian to maximise your nutrition during treatment as well as while you are recovering. Sometimes feeding tubes may be recommended depending on the area being treated and the dose of radiation therapy. **There are two common types of feeding tubes:**
  - **Gastrostomy tube (sometimes called a PEG tube or RIG tube):** this type of tube is inserted through your abdominal wall into your stomach, with part of the tube staying outside the stomach. A syringe can be attached to the tube to give you food and medications this way if needed. The tube is inserted using a camera through the mouth into the stomach (gastroscopy) or using a CT scanner to guide insertion directly through the skin (radiologically inserted gastrostomy, RIG). If a PEG or RIG tube is needed, your doctor will organise this before or close to the start of your radiation therapy.
  - **Nasogastric tube:** this type of tube goes through the nose down into the stomach and is usually used for short periods (days or weeks). A nasogastric tube can be inserted at any time (before, during or after treatment).

- **Speech, voice and swallowing:** Your cancer and its treatment can make swallowing and speech difficult. Your doctor will recommend you see a speech pathologist, who can help you with ways to manage swallowing and communication difficulties, during and after treatment.
- **Once the treatment machine has turned off, you are not radioactive and can go about your day as normal after leaving the treatment room.**

## **SIDE EFFECTS**

The side-effects of radiation therapy start around two weeks into treatment and progress through treatment to peak in the last week or just after treatment ends. The side effects start to improve 3-4 weeks after the end of treatment.

### **Side effects of radiation therapy depend on:**

- the dose of radiation therapy
- the area being treated
- whether or not chemotherapy is added to the radiation therapy.

Each individual responds to radiation therapy differently. Some people may experience a few side effects while others may not experience many at all. The following are some common side effects of radiation therapy.

### **Common side effects of radiation therapy include:**

- tiredness
- skin irritation in the treated area (e.g. redness, dryness and itching, peeling skin and some areas of skin breakdown (sores))
- dry mouth and throat due to loss of saliva (called xerostomia)
- changed taste (usually a loss of taste or sometimes an unpleasant taste in the mouth)
- pain on swallowing or difficulty with swallowing, managed with pain relief
- hair loss directly in the treatment area (for example, beard or sideburns, but not the top of the head)
- losing weight

Most side effects are short lived and may go away within 4–6 weeks of finishing radiation therapy. Some side effects may last for months after you finish radiation therapy, and some may be permanent.

Once your radiation therapy ends, you will have regular follow-up appointments so your cancer care team can check your recovery and monitor any side effects that you may have. Your doctor will usually order a PET scan, timed for you to have done about 12 weeks after your last radiation therapy session, to make sure the cancer has completely gone. If the cancer has not gone away after radiation therapy, or comes back in the future, you may still be able to have surgery to try to remove the cancer.

Your doctor may recommend some specific supportive care options to help you during your treatment and recovery. Further information about [supportive care](#) is available on the website.

## CHEMOTHERAPY

Chemotherapy works by destroying or damaging cancer cells. For head and neck cancers, chemotherapy is usually given into a vein through a needle with a catheter (tube) attached.

Usually, chemotherapy is used in combination with radiation therapy to make the radiation therapy more effective. It is usually given once a week or once every 3 weeks throughout the duration of radiation therapy. Unlike chemotherapy for many other cancers, most patients do not lose their hair or have severe nausea and vomiting.

## SIDE EFFECTS

The side effects of chemotherapy depend on the medication used and how much you are given by your doctor (the dose). The most common medications used are called cisplatin, carboplatin and cetuximab.

Each individual responds to chemotherapy differently. Some people may experience a few side effects while others may not experience any at all. The following are some common side effects of chemotherapy.

- **a feeling of wanting to vomit (nausea) or vomiting**

- increased [side effects of radiation](#), if you have chemotherapy at the same time as radiation
- loss of feeling in the fingers and toes
- kidney damage (caused by some medications)
- hearing loss/thinning
- ringing in the ears
- rash
- higher risk of infection (if the chemotherapy reduces the number of white cells in the blood).

Most of these side effects are short lived and may go away once you finish chemotherapy. Some side effects can take months or years to improve or may be permanent.

Once your treatment ends, you will have regular follow-up appointments so that your doctor can check your recovery, make sure the cancer has not returned and monitor and treat any side effects that you may have.

Your doctor may recommend that you receive supportive care to help during your recovery. Further information about [supportive care](#) is available on the website.

## FOLLOW-UP CARE

For cancers of unknown primary, in addition to making sure the cancer does not return in the lymph nodes, your doctor will also check the likely sites of primary cancer as part of your monitoring. This will include a physical exam and checking your nose and throat using a thin, flexible tube with a light and camera ([nasoscopy](#)) in the clinic every few months. The timing of your follow up appointments may extend to twice a year or once a year after a suitable period without evidence of the cancer on examination in the clinic.

Some people may also need imaging studies such as [CT, MRI or PET](#) scans during follow-up. It is important to keep up with follow-up to ensure that if the cancer comes back, it may be caught as early as possible and can be treated. If you have any concerns between visits, you should contact your doctor or cancer care team.

Quitting smoking and drinking alcohol can help reduce the risk of a new head and neck cancer

occurring. Ask your cancer care team for advice if this applies to you. Maintaining your overall health and fitness with the aid of your general practitioner can help reduce the risk of separate new cancers or other health impacts developing.

## **SUPPORTIVE CARE DURING TREATMENT**

It is important to have appropriate supportive care before, during and after treatment for head and neck cancer. Here are some things you should consider before/during treatment.

- In the first week or two after surgery, you may need to be fed by a tube while your body is healing, and the swelling is reducing
- You may find it difficult to swallow after radiation therapy because it may make your mouth dry and your throat sore. You may notice changes in your taste, or you may enjoy your food less. Radiation therapy may also affect your teeth (e.g. cause tooth decay).
- Chemotherapy may cause changes in how you taste food, give you a feeling of wanting to vomit (nauseous) or vomit. These side effects may also reduce your appetite.

## **DIET AND NUTRITION AND ROLE OF YOUR DIETITIAN**

It is important for people with head and neck cancer to stay well-nourished and to avoid weight loss. If you can't eat or drink enough, you may become malnourished or begin to lose weight. To help you get enough nutrition, you may need a feeding tube for a short period of time.

Having a good diet can help you:

- get through treatment
- reduce the chance you will get an infection
- recover more quickly
- keep your strength and energy levels up.

## WHAT CAN I DO TO KEEP MY FOOD INTAKE UP?

- Eat a diet high in protein and calories (energy).
- Eat small meals or snacks more often if you have trouble eating a full meal.
- Drink calorie-rich fluids such as milk, milkshakes, smoothies or juice. Your dietitian may recommend supplement drinks that are high in protein and calories.
- If you have a sore throat, avoid foods that scratch or burn it such as citrus, vinegar, chips or toast.

## WHERE CAN I FIND SUPPORT?

Your dietitian is an expert in food and nutrition who will help you with your diet. Your dietitian will help you work out a plan to get all the energy you need. They may give you some tips to help make eating and drinking easier and to help you enjoy your food to help you keep weight on.

You may have trouble eating and drinking because of your treatment, but you may find that this gets better over time. Some people need a feeding tube to make sure they are eating enough and getting enough energy. If this is the case for you, your doctor, dietitian and nurse will talk with you about what this involves. Feeding tubes are usually only needed for a short time, until you recover enough and can eat more. Some people may need feeding tubes for a longer period.

More information about diet and nutrition is available [here](#).

## SPEECH, VOICE AND SWALLOWING, AND THE ROLE OF YOUR SPEECH PATHOLOGIST

Treatment for head and neck cancer may cause changes to parts of your mouth (lips, teeth, tongue, palate) and/or throat (pharynx, larynx), which can affect your ability to speak and/or swallow. These changes may only last for a short time or they may be permanent.

Speech and voice problems can affect your daily life. This may leave you feeling frustrated, distressed or embarrassed, particularly if people have trouble understanding your speech.

**If you find it difficult to swallow (known as dysphagia), you may notice:**

- you need to swallow many times to clear food from your mouth or throat
- you need to clear your throat or cough while eating

- it hurts to swallow
- your voice gurgles after swallowing.

Make sure to drink plenty of water when eating and include gravy or sauces with foods to help you swallow them more easily.

If your treatment has caused changes to your speech, voice or swallowing, you can get help from a speech pathologist. A speech pathologist is an expert in difficulties with communication and swallowing. Your doctor may recommend that you see a speech pathologist before, during and after your treatment.

Your speech pathologist can:

- give you exercises or tips to help your speech and voice
- help you plan other ways of communicating such as writing or using a computerised voice to speak for you
- show you how to use devices or aids if you need them
- show you safe swallowing tricks such as changing your head position or changing the thickness of food/liquids to make it easier to swallow them.

You may also get help from a doctor or a dietitian, and, in some cases, they may recommend a [feeding tube](#).

## TEETH AND MOUTH CARE AND ROLE OF YOUR DENTIST

Treatments for head and neck cancer, especially radiation therapy, can cause side effects that affect your teeth and mouth such as:

- dry mouth
- an increase in ulcers or inflammation in your mouth (mucositis)
- altered taste
- being unable to fully open your mouth (trismus)
- tooth decay
- infected or bleeding gums

- breakdown of tissue or bone in some areas of the mouth.

These side effects may be painful and may make it difficult to eat, talk or swallow. It is important to take care of your teeth and mouth during treatment because infections can be harmful and slow down your treatment. Some side effects can last for a long time after treatment ([late effects](#)).

## WHAT CAN I DO TO KEEP MY TEETH AND MOUTH HEALTHY?

There are a few things that you can do to keep your teeth and mouth healthy.

- Drink plenty of water and chew sugar-free chewing gum to keep your mouth moist.
- Gently brush your teeth, gums and tongue with a soft toothbrush after every meal and at bedtime.
- Gently floss your teeth every day.
- Use high-strength fluoride toothpaste.
- Use an alcohol-free mouthwash.

Your dentist is an important member of your healthcare team before, during and after treatment because side effects that affect the teeth and mouth can often be prevented or reduced through regular dental check-ups.

- It is a good idea to have a dental check-up before you start treatment. Your dentist will check the health of your teeth and mouth and will give you a plan to keep your mouth healthy. Sometimes teeth that are decayed and unhealthy need to be removed before radiation therapy to reduce the risk of problems after treatment.
- During your treatment, your dentist will look out for any teeth or mouth side effects.
- After your treatment, you should visit your dentist every 6 months for a check-up because the side effects of radiation therapy on your teeth can be long lasting.

## MENTAL HEALTH FOR PEOPLE WITH CANCER

Sometimes this is referred to as psychosocial aspects or survivorship.

Being diagnosed with cancer and having treatment can lead to extra worries or concerns for you and the people caring for you. Depending on the treatment, you may experience any of the following:

- low mood or depression
- anxiety
- disfigurement
- difficulties with eating
- difficulties with speaking
- changes in sexual activity.

You may have got through the diagnosis and treatment for head and neck cancer, but you may be finding it difficult to deal with some of the side effects of treatment. Speak with your doctor about any difficulties you may be experiencing. Your doctor may give you a referral to a psychologist or another healthcare professional who can help you. Speak with your family and friends too about any concerns you may have.

You may find it helps to join a patient support group and speak with others who are having treatment for head and neck cancer. You can contact the Head and Neck Cancer Helpline ([Head and Neck Cancer Helpline | Head and Neck Cancer Australia](#)) and find help and advice in online self-help resources such as [Beyond Blue](#).

## QUESTIONS TO ASK YOUR DOCTOR

- What type of cancer do I have? Where is it located?
- What are the risk factors?
- What lifestyle changes (diet, exercise) do you recommend I make?
- What are the chances that the treatment (surgery or radiotherapy or both, with or without chemotherapy) will cure the cancer?

- How long will it take before I can eat again and what sort of food?
- Will I need a feeding tube? How long will I need the feeding tube for?
- What will happen if I don't have the treatment?
- How much will the treatment cost? Will my health insurance cover it?
- What are the possible side effects of treatment? How can they be prevented or controlled?
- Will I have a scar?
- Will I be able to lead a normal life?
- Will I need follow-up treatment? What follow-up tests will I need after the operation?
- What are the chances that the cancer will return?
- Am I suitable for any clinical trials?

You may want to write specific questions here to ask your doctor or cancer care team

#### **About Head and Neck Cancer Australia**

Head and Neck Cancer Australia is the only national charity dedicated to providing free, trusted and easy to understand information, education and support to people affected by Head and Neck Cancer.

We represent over 5,300 people who are newly diagnosed each year and more than 17,000 people who are living with Head and Neck Cancer across Australia.

We also lead the national effort to advocate for government support to encourage prevention, increase early diagnosis and improve the quality of life of people living with Head and Neck Cancer in Australia.

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E: [contact@headandneckcancer.org.au](mailto:contact@headandneckcancer.org.au)

W: [www.headandneckcancer.org.au](http://www.headandneckcancer.org.au)

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