

Head and Neck Cancers

J A S C A P

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS,
MUMBAI, INDIA

JASCAP

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JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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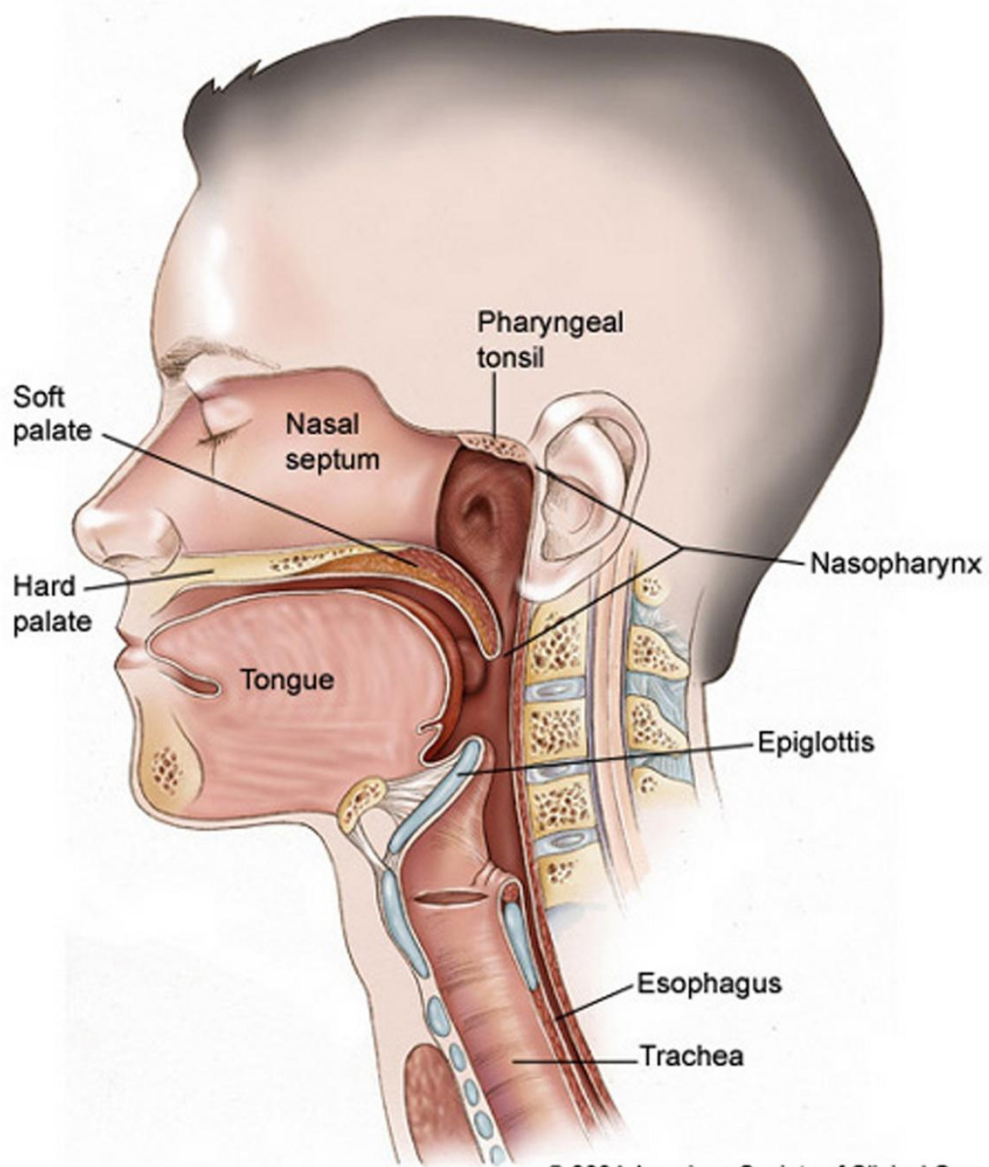
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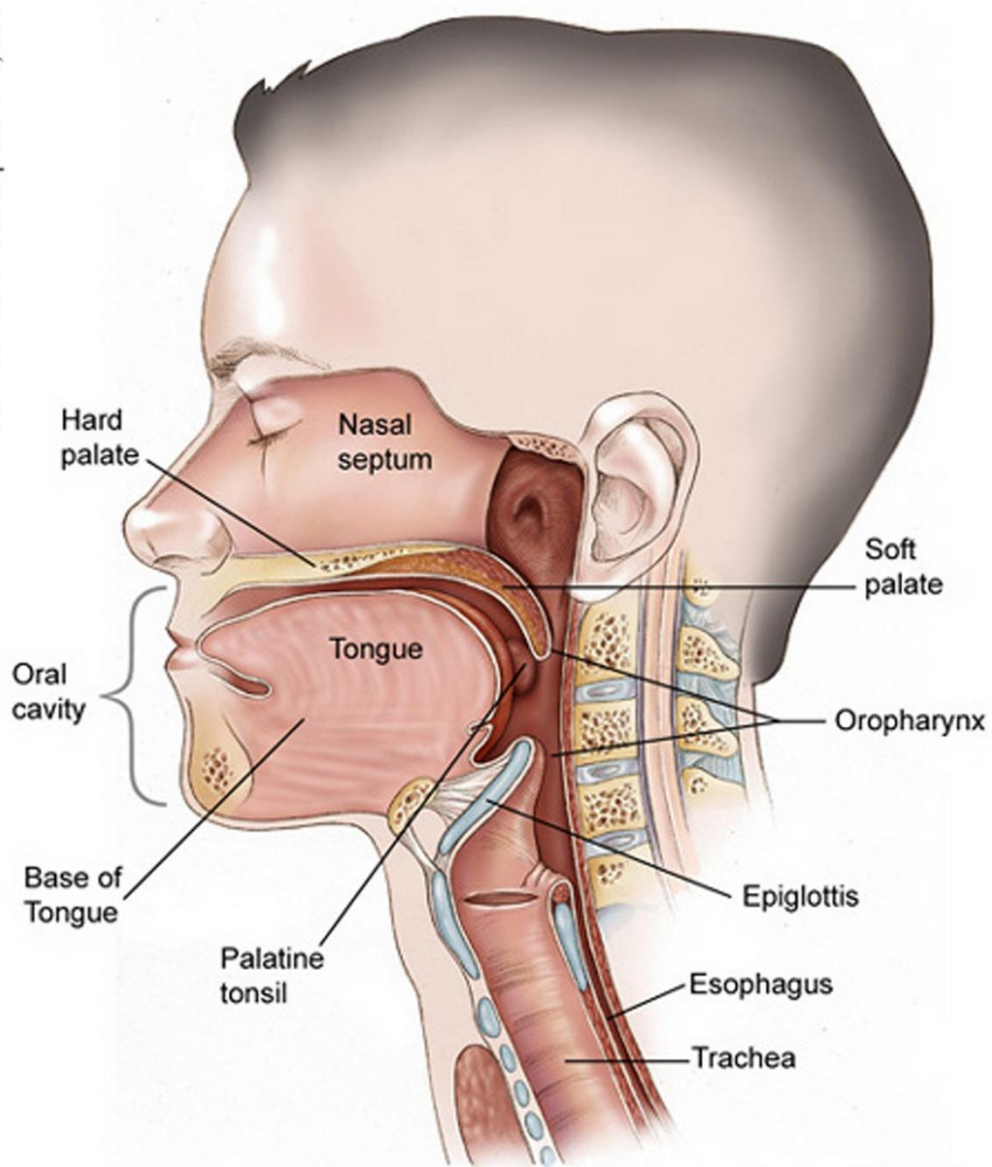
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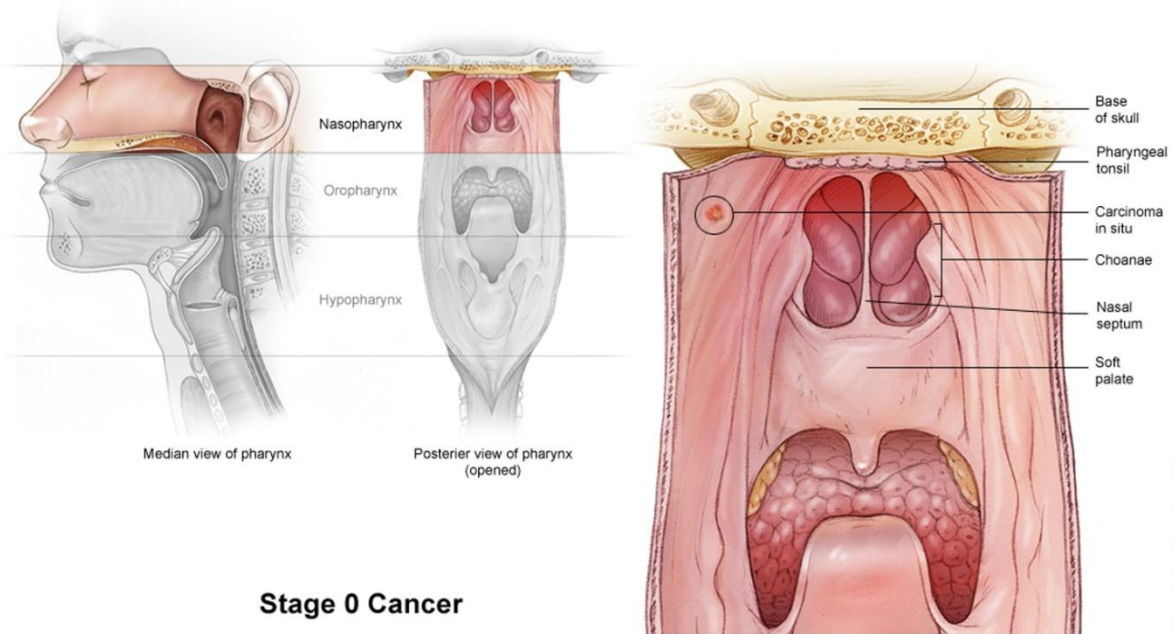
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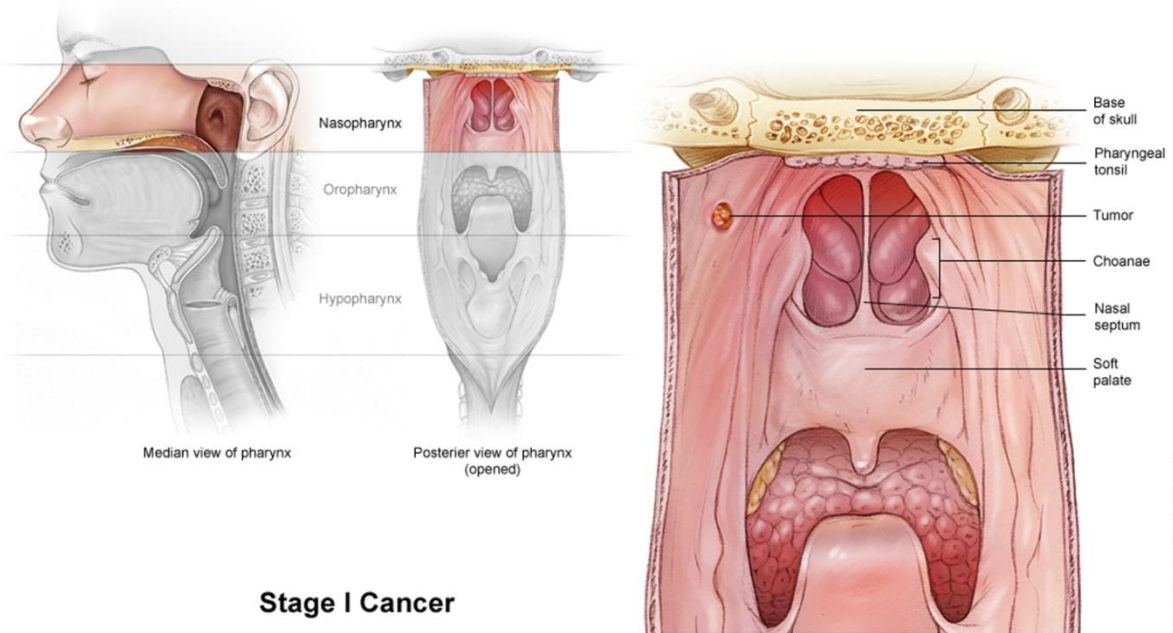




Stage 0 Cancer

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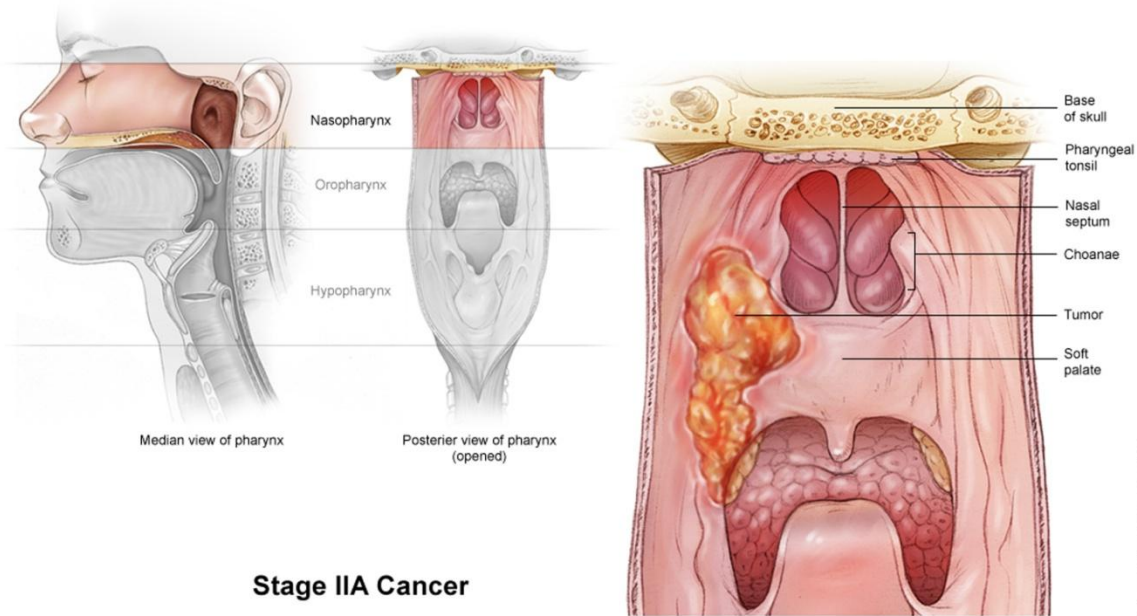
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Stage I Cancer

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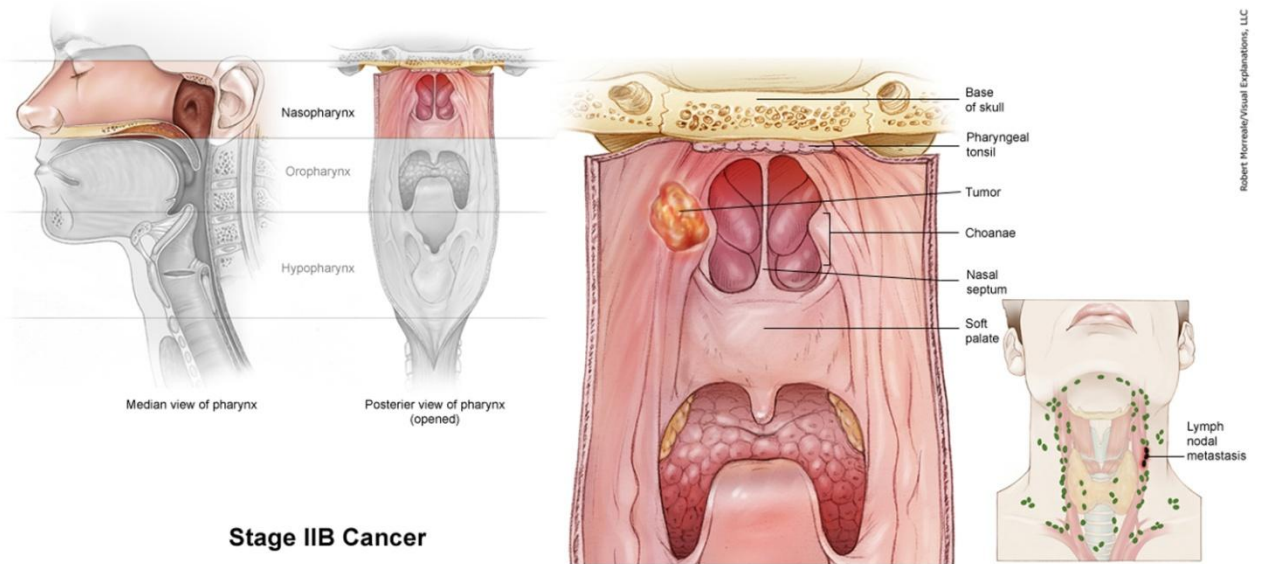
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Stage IIA Cancer

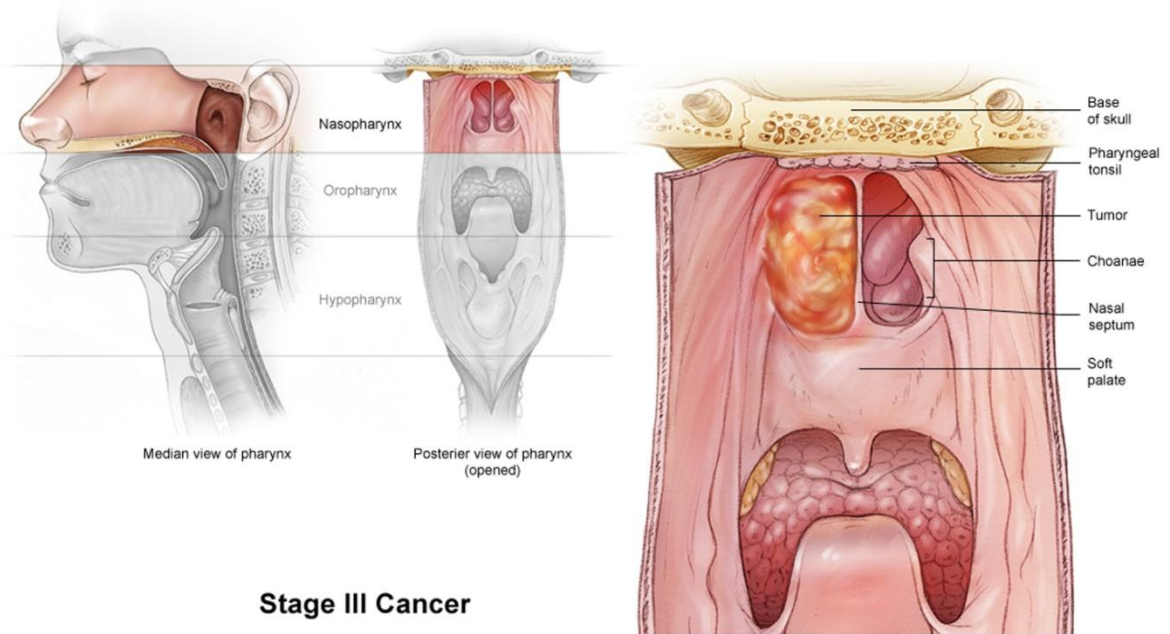
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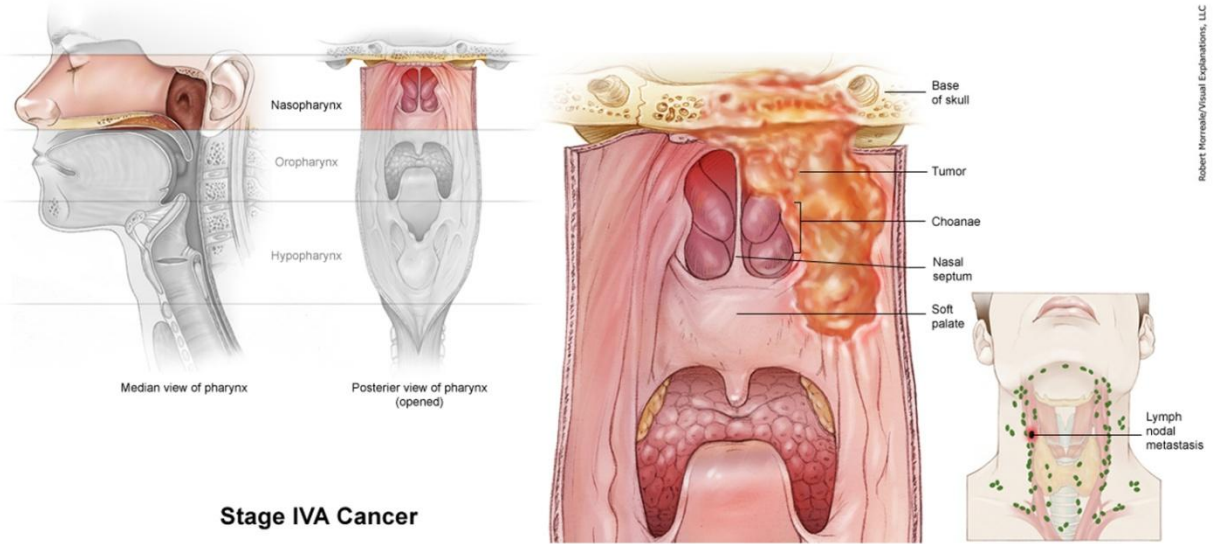
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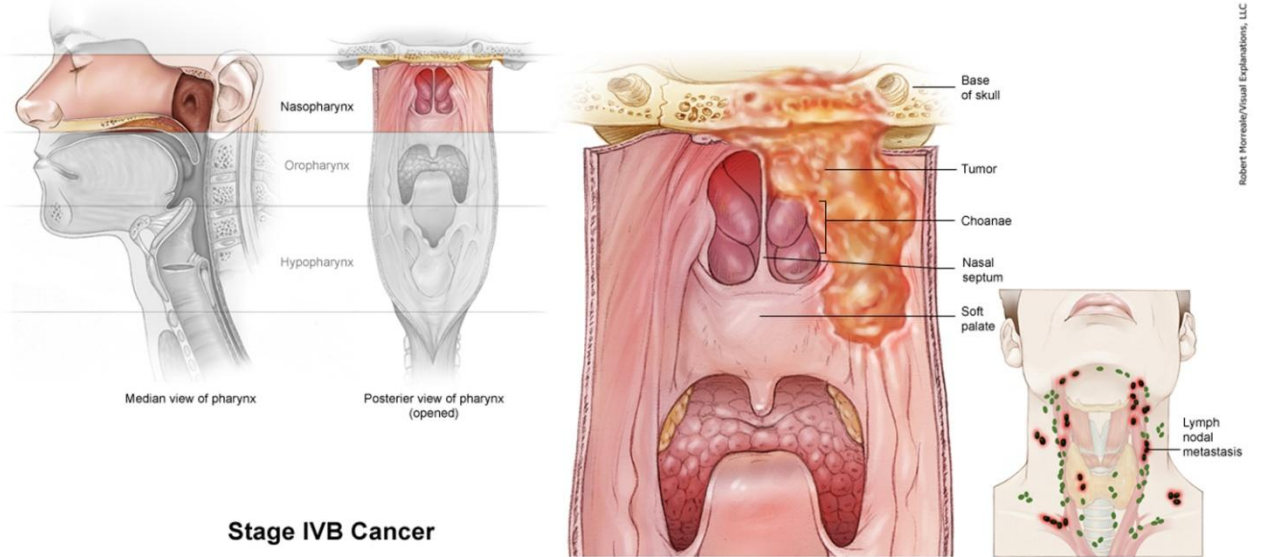
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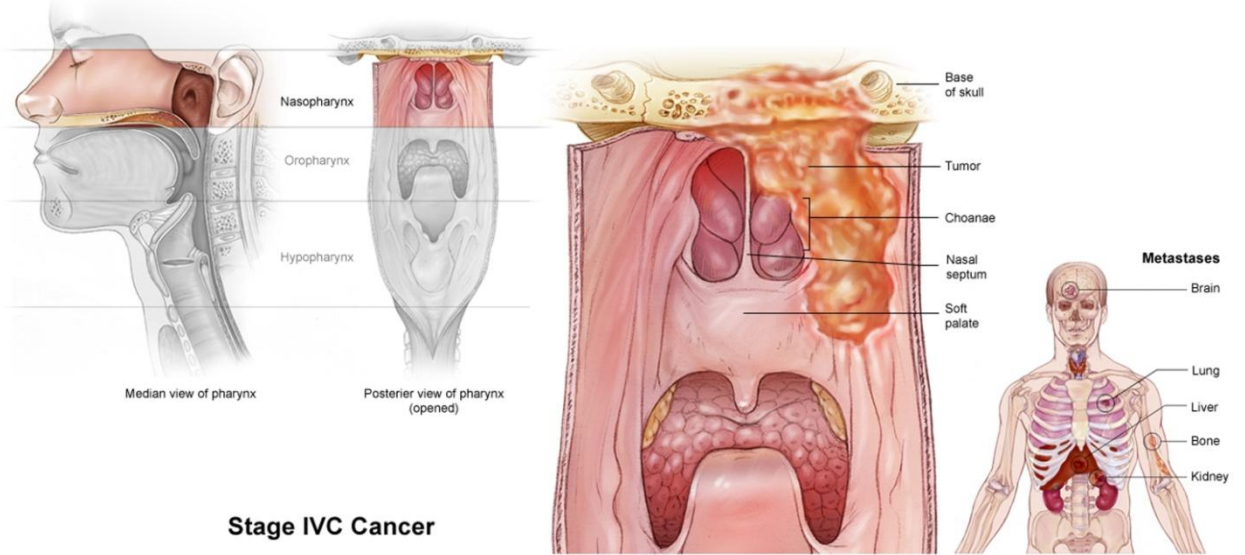
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Stage IVB Cancer

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Stage IVC Cancer

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*** JASCAP has separate booklets / factsheets on these particular categories of head and neck cancers.**

Head and Neck cancers

Introduction

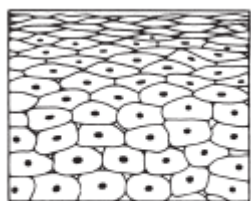
This booklet is for you if you have or someone close to you has cancer of the head and neck.

If you are a patient your doctor or nurse may wish to go through the booklet with you and mark sections that are particularly important for you. You can make a note below of the main contacts and information that you may need quickly.

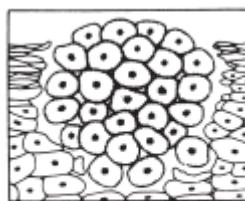
What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a **tumour**.



Normal cells



Cells forming a tumour

Tumours can be either **benign** or **malignant**. Cancer is the name given to a malignant tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a **biopsy**.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. However, if they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

The lymphatic system is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs, such as

bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a **secondary cancer** or **metastasis**. Even when the cancer spreads somewhere else in the body, it is still referred to as the site where it was originated, and is still named after the part of the body where it started. For example, if lung cancer spreads to bones, it is still termed as lung cancer and not bone cancer. In that case, it may be said that the person has "*lung cancer with bone metastases*".

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

Types of cancers

Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

- squamous cells - that line different parts of the body, such as the mouth, gullet (oesophagus), and the airways
- adeno cells - form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
- transitional cells - are only found in the lining of the bladder and parts of the urinary system
- basal cells - that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

- bone sarcomas - that are found in the bones
- soft tissue sarcomas - that develop in the other supportive tissues of the body.

Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

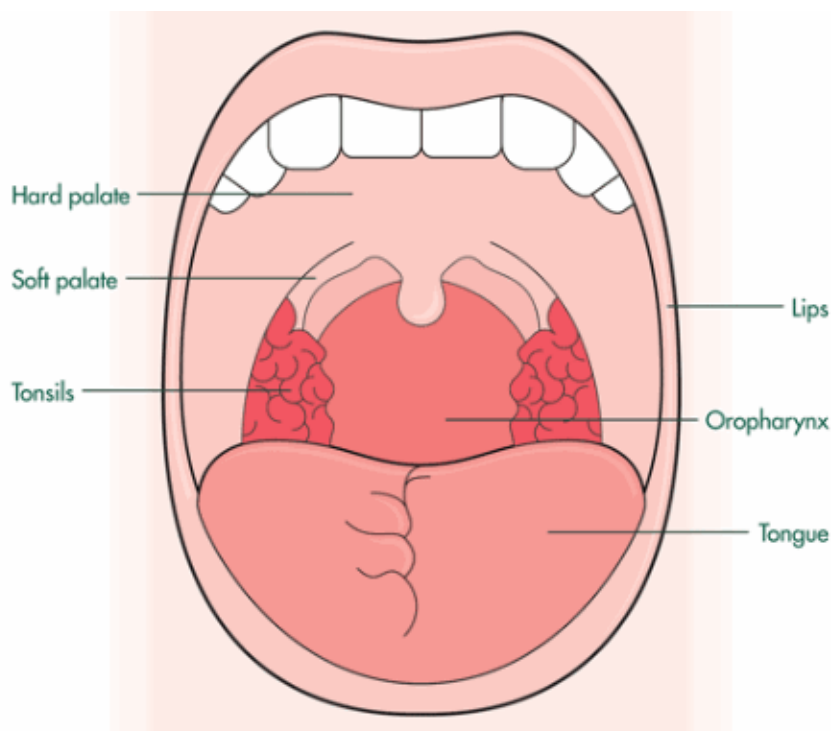
Categories of Head and neck cancers

Cancer can occur in any of the tissues or organs in the head and neck. There are over 30 different places that cancer can develop in the head and neck area.

- Cancers of the oral cavity
- Oropharyngeal cancer
- Cancer of the nose, paranasal sinus and nasopharynx
- Cancer of the ear
- Cancer of the salivary gland
- Cancer of the eye
- Cancer of the voice box (larynx), cancer of the thyroid gland

Cancers of the oral cavity (mouth)*

The oral cavity (see diagram below) includes the lips and the mouth. Cancer can occur in the tongue, the roof of the mouth (the hard palate), the floor of the mouth (under the tongue), the gums, and the inner lining of the lips and cheeks (sometimes referred to as the buccal mucosa).



The oral cavity: Looking into the mouth

Oropharyngeal cancer*

This develops in the oropharynx, the part of the throat that is directly behind the mouth (see diagram below). It includes the soft part of the roof of the mouth (the soft palate), the base of the tongue (the part you can't see), the side walls of the throat (where the tonsils are found) and the back wall of the throat (also called the posterior pharyngeal wall).

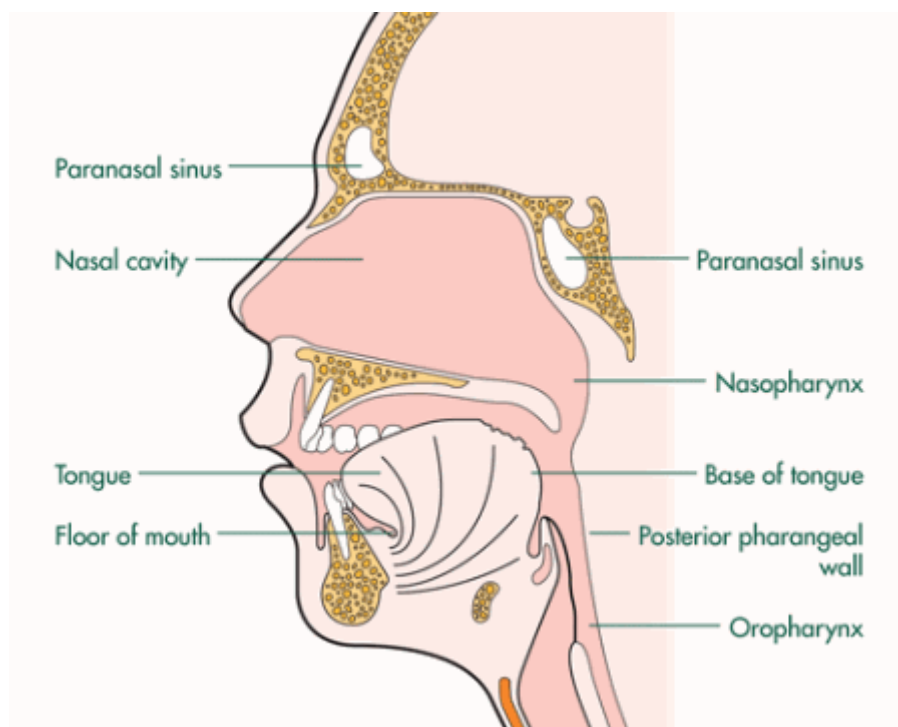


Diagram showing a cross-section of the head

Cancer of the nose, paranasal sinus* and nasopharynx*

Cancers can develop in the skin of the nostril and the lining of the nose.

The highest part of the throat, which lies behind the nose, is called the nasopharynx (see diagram below). Cancers that occur here are known as nasopharyngeal cancer.

Alongside the nose, in the bones of the face, lie air spaces known as the sinuses (or paranasal sinuses). Cancers can develop in the linings of these areas too.

Cancer of the ear

Cancer can develop in the structures deep inside the ear, but this is very rare. Most develop in the skin of the ear.

Cancer of the salivary gland*

Cancers affecting the salivary glands are also rare. There are different types of salivary gland cancer, depending on the type of cell that has become cancerous. We have more factsheet on salivary gland cancers.

Cancer of the eye*

Cancers can develop in the skin of the eyelids. Cancers are very unusual in the eye itself. When they do occur, they are usually a type called ocular melanoma. Occasionally a cancer of the white blood cells, called lymphoma, can develop behind the eye. In very rare cases, cancer may spread into the eye from a cancer elsewhere in the body: for example, the breast.

Cancer of the voice box (larynx), cancer of the thyroid gland*

Cancer can also develop in the voice box (larynx) or in the thyroid gland, which are both in the neck.

*** JASCAP has separate booklets / factsheets on these particular categories of head and neck cancers.**

Types of head and neck cancers

Head and neck cancers are uncommon and only about 7800 people in the UK are diagnosed with them each year.

About 90% of head and neck cancers are of a type called **squamous cell carcinoma**. These start in the cells that form the lining of the mouth, nose, throat or ear, or the surface layer covering the tongue.

Head and neck cancers can also develop from other types of cells:

- **Lymphomas** develop from the cells of the lymphatic system.
- **Adenocarcinomas** develop from cells that form the lining of glands in the body.
- **Sarcomas** develop from the cells which make up muscles, cartilage or blood vessels.
- **Melanomas** start from cells called melanocytes, which give colour to the eyes and skin.

Risk Factors and causes of head and neck cancers

The causes of head and neck cancers in most people are still unknown, but research is going on all the time to learn more.

There are a number of risk factors that can increase your chance of developing head and neck cancer. These are:

Age and sex

Like most types of cancer, head and neck cancers are more common in older people. They are also more common in men than women.

Smoking and drinking alcohol

Squamous cell carcinomas are much more common in smokers and people who drink a lot of alcohol, particularly spirits, and even more common in people who do both.

Pipe smokers and people who hold cigarettes between their lips for long periods have a higher risk of cancers in the lip area.

Chewing tobacco or paan

People who chew tobacco or betel nuts and those who use paan have a higher risk of cancers in the oral cavity.

Sunlight

People who have long periods of exposure to the sun in their daily life have an increased risk of developing cancers of the lip and the skin of the head and neck area, especially the ear.

Diet

A poor diet that contains very little fresh fruit and vegetables may increase your risk of certain types of mouth cancer.

Exposure to chemicals

Breathing in certain chemicals and hardwood dusts (for example, in workplaces) increases the risk of cancers of the nose and sinuses.

Human papilloma virus

In recent years it has been discovered that some head and neck cancers, particularly those of the tonsil and tongue, are linked to infection with the human papilloma virus (HPV). This is often related to oral sex, which transmits the virus.

Pre-cancerous conditions

There are a number of pre-cancerous conditions that can affect the head and neck, such as leukoplakia and erythroplakia which can increase the risk of a cancer developing.

Inherited faulty genes

Most head and neck cancers are not caused by an inherited faulty gene, so members of your family are not likely to be at higher risk of developing head and neck cancer because you have it. If someone with head and neck cancer has a relative who also has cancer, this is more likely to be due to similar lifestyles and habits (such as smoking) than an inherited cancer risk.

How common is the Head and Neck Cancer in India?

Head and Neck cancer is the most common cancer among men from the Indian subcontinent. For women from India, Head and Neck cancer ranks third after Cervical and Breast cancers¹.

In India, between the years 2001-2003, across five urban centers - Mumbai, Delhi, Chennai, Bhopal and Bangalore, – and one rural center - Barshi, a total of 10,344 cases of Head and Neck Cancers were registered (23.5% of all cancers) for males across all age groups; while a total of 3,470 cases of Head and Neck Cancers were registered (7.8% of all cancers) for females across all age groups. Considering all men, women and children with all types of cancers together, a grand total of 13,814 cases of Head and Neck Cancers (15.6% of all cancers) were registered at the six centers mentioned above, between the year 2001-2003²

The TATA Memorial Hospital (T.M.H.) in Mumbai, India registered a grand-total of 19,127 cases of all types of cancer patients in the year 2006, for men, women and children combined, out of which 4,522 (close to 25% of the total cases) were diagnosed with the Head and Neck cancers. Out of the total 4,522 patients diagnosed with Head and Neck cancers, mentioned above at the T.M.H., 3,572 (79%) were males and 950 (21%) were females³.

Symptoms and diagnosis

Symptoms of head and neck cancers

The symptoms of head and neck cancers will depend upon where it is – for example, cancer of the tongue may cause some slurring of speech.

The most common symptoms of a cancer of the head and neck include:

- an ulcer in the mouth that doesn't heal within a few weeks
- difficulty in swallowing, or pain when chewing or swallowing
- trouble with speaking or breathing, such as a hoarse voice or persistent noisy breathing
- a constant sore throat and earache affecting one side
- a swelling or lump in the mouth or neck.

Less common symptoms include:

- a numb feeling in the mouth or on the lips
- an unexplained loose tooth

¹ Globocan 2008: Cancer incidence and mortality rates worldwide

² Population based cancer registry 2001-2003 Mumbai, Delhi, Chennai, Bhopal, Barshi and Bangalore, Indian Cancer Society.

³ TATA Memorial Hospital Registry Data for 2006

- a persistent blocked nose or nosebleeds
- ringing in the ear or difficulty hearing
- pain in the face or upper jaw
- pre-cancerous changes in the lining of the mouth or on the tongue, which can appear as persistent white patches (**leukoplakia**) or red patches (**erythroplakia**) – they are usually painless but can sometimes be sore and may bleed.

Although these symptoms can be caused by conditions other than cancer, it's important that they are always checked out by your doctor or dentist, particularly if they persist.

Lymph nodes

An important common symptom of head and neck cancer is swelling of one or more of the **lymph nodes** in the neck.

The lymph nodes (also known as lymph glands) form part of the lymphatic system, which is the body's natural defence against infection. They contain white blood cells that help to fight infection and disease. Lymph nodes occur throughout the body but can sometimes be felt as tiny pea-sized lumps in the neck, under the armpits and in the groin.

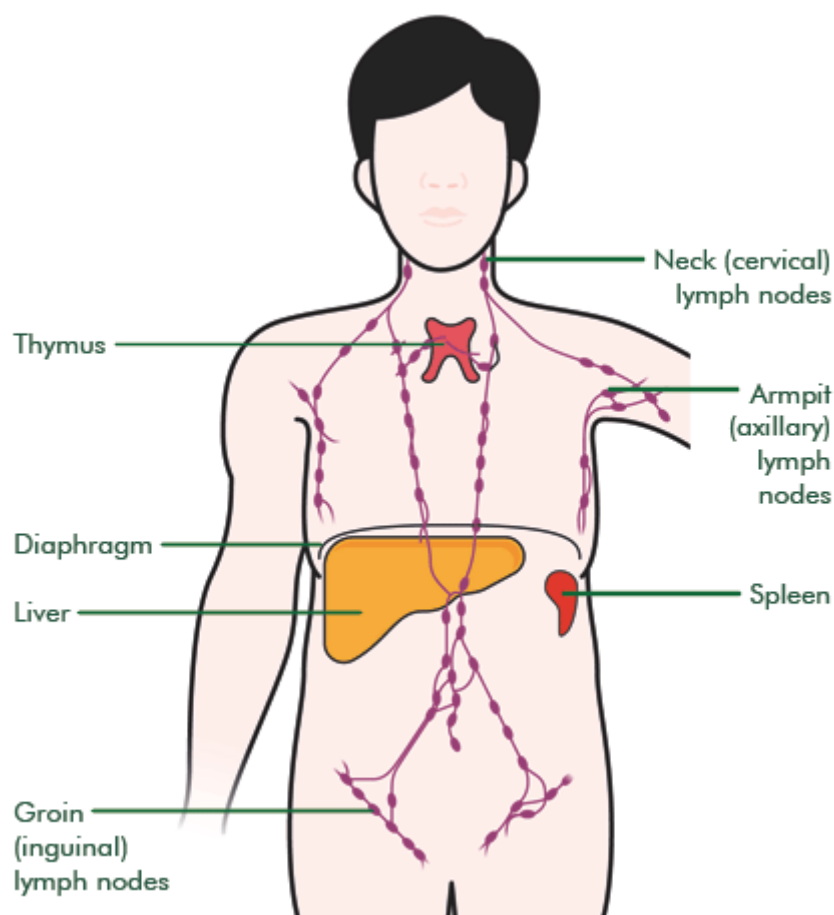


Diagram of the lymphatic system in the upper body

Cancers in any part of the body can spread into nearby lymph nodes. This is particularly common with head and neck cancers, where the lymph nodes in the neck can become enlarged. Sometimes the first symptom of a head and neck cancer will be a painless enlargement of one of these lymph nodes.

Enlarged lymph nodes are much more likely to be due to a harmless infection than to cancer. However, if a lump stays for more than 3–4 weeks, despite a course of antibiotics, it should be examined by a specialist.

How head and neck cancers are diagnosed

Your GP or dentist will refer you to hospital for specialist advice, tests and treatment. You are likely to see an oral and maxillofacial surgeon (who is qualified as a dentist and a doctor) or an ear, nose and throat (ENT) specialist.

At the hospital

At the hospital, the specialist will ask you about your current symptoms as well as your medical history, and will want to know if you are taking any medicines. The doctor will then examine your mouth, throat and neck.

Nasendoscopy

In order to examine your throat and neck, the doctor may use a small mirror held at the back of your mouth. The doctor may also pass a **nasendoscope** (a very thin flexible tube with a light at the end) into your nose to get a better view of the back of the mouth and throat.

These tests can be uncomfortable, but will only last a few minutes. You may be given a lozenge to suck which contains a local anaesthetic that numbs the mouth, or the area may be sprayed with an anaesthetic spray which numbs the back of your throat. If you do have a local anaesthetic, you shouldn't eat or drink anything for about an hour afterwards, until your throat has lost the numb feeling. This is because there's a risk of things going into your windpipe when you swallow. You could also burn your mouth or throat with hot drinks.

Biopsy

The doctor can only make a definite diagnosis by taking a sample of cells from the abnormal area to examine under a microscope. This procedure is called a **biopsy**.

Sometimes the biopsy can be taken in the clinic. The affected area is first numbed with some local anaesthetic. A small piece of the suspected cancer is then removed using a very fine needle or a special pair of tweezers (**biopsy forceps**).

However, it is more likely that a biopsy will be taken while you are asleep under a general anaesthetic. This allows the specialist to examine the mouth and throat area closely and take biopsies from any other suspicious areas. Usually this is done during a day visit, but you may need to spend a night in hospital.

A specialist doctor, known as a pathologist, will look at the sample of cells under the microscope. They will be able to tell if cancer cells are present and find out what type of cancer it is.

Fine needle aspiration cytology (FNAC)

This is a quick, simple procedure that is done in the outpatient clinic. Using a fine needle and syringe, the doctor takes a sample of cells from a lump and sends it to the laboratory to see if any cancer cells are present. An FNAC may be quite uncomfortable and the area may be bruised for a week or so afterwards.

Microcytology

This is a new test that is still being evaluated in research. It is sometimes used for people with pre-cancerous conditions who need to have regular biopsies. Instead of having biopsies, a small amount of blue dye is painted onto the abnormal area, which is then looked at very closely using a microscope. Microcytology should not be painful although it may be a little uncomfortable.

Staging of head and neck cancers

The stage of a cancer is a term used to describe its size and whether it has spread beyond its original site. Knowing the extent of the cancer helps the doctors to decide on the most appropriate treatment.

A common way of staging head and neck cancers is the **TNM staging system**.

T describes the size of the **t**umour and whether it has begun to spread to nearby structures, such as the skin or muscle.

N describes whether the cancer has spread to the lymph **n**odes.

M describes whether the cancer has spread to another part of the body (secondary or **m**etastatic cancer).

The staging of the different types of head and neck cancers are all slightly different. Your doctor or nurse can give you more details about the stage of your cancer.

Grading

Grading refers to the appearance of the cancer cells under the microscope. The grade gives an idea of how quickly the cancer may develop. Squamous cell cancers of the head and neck are graded from 1–3.

Low-grade or grade 1 means that the cancer cells look very like normal cells in the head and neck area.

In **high-grade** or grade 3 cancers the cells look very abnormal and are more likely to spread.

Moderate-grade or grade 2 cancers fall between these two grades and have a level of activity somewhere between.

Further tests for head and neck cancers

If the biopsy result shows that you have cancer, your doctor may want to do some further tests to find out more about your cancer. These tests help the doctor gather as much information as possible, so they can decide which is the best type of treatment for you.

Your doctor will decide which particular tests are necessary in your case. These may include some of the following:

X-ray

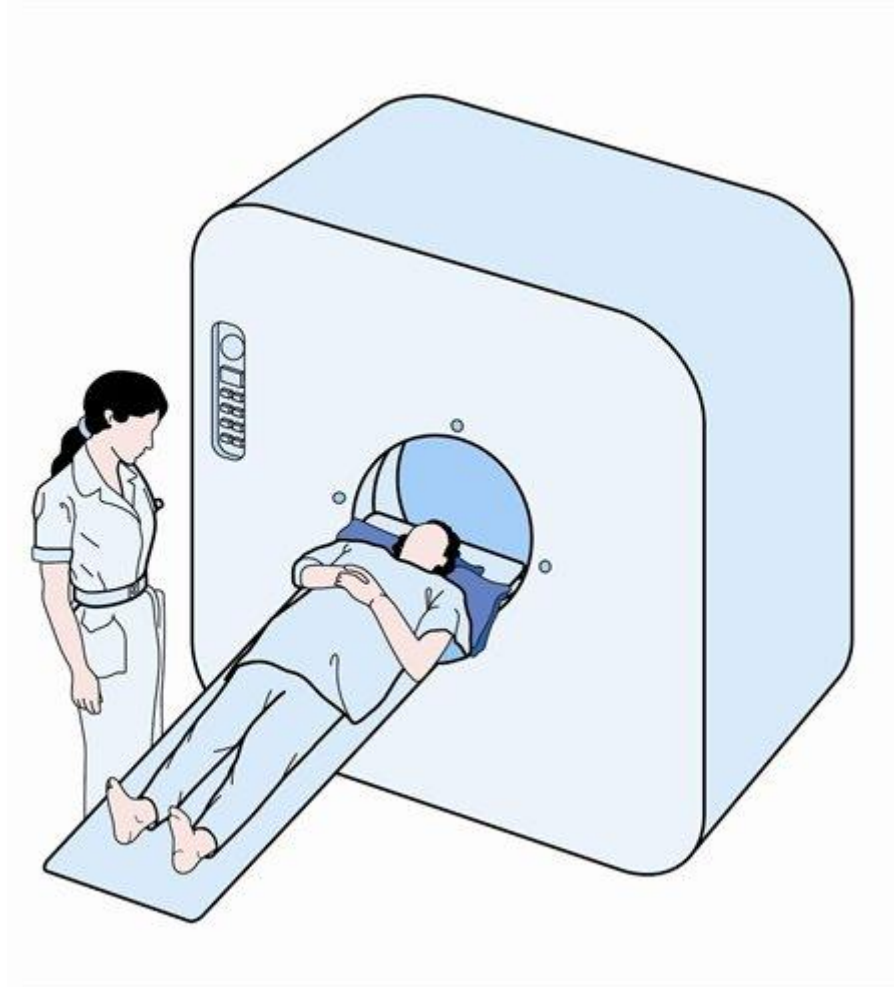
The doctor may want to take x-rays of your face or neck to see whether any bones have been affected. An x-ray known as an **orthopantomogram** (OPG) may be taken to look at your jaw and teeth.

You may have a chest x-ray to check your general health and to see whether the cancer has spread to the lungs. It is very rare for head and neck cancers to spread beyond the head and neck area, but if they do it's usually to the lungs.

CT (computerised tomography) scan

A CT scan is a series of x-rays, which builds up a three-dimensional picture of the inside of the body. The scan is painless but takes from 10–30 minutes. CT scans use a small amount of radiation, which will be very unlikely to harm you and will not harm anyone you come into contact with.

You will be asked not to eat or drink for at least four hours before the scan.



Having a CT scan

You may be given a drink or injection of a dye which allows particular areas to be seen more clearly. For a few minutes, this may make you feel hot all over. If you are allergic to iodine or have asthma you could have a more serious reaction to the injection, so it's important to let your doctor know beforehand.

You will probably be able to go home as soon as the scan is over.

MRI (magnetic resonance imaging) scan

This test is similar to a CT scan but uses magnetism instead of x-rays to build up a detailed picture of areas of your body. Before the scan you may be asked to complete and sign a checklist. This is to make sure that it's safe for you to have an MRI scan because the scanner is a powerful magnet. The checklist asks about any metal implants you may have, for example a pacemaker, surgical clips or bone pins.

You should also tell your doctor if you have ever worked with metal or in the metal industry, as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body it's likely that you won't be able to have an MRI scan. In this situation another type of scan can be used.

Before having the scan, you'll be asked to remove any metal belongings including jewellery. Some people are given an injection of dye into a vein in the arm, which doesn't usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

During the test you'll be asked to lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It's painless but can be slightly uncomfortable, and some people feel a bit claustrophobic during the scan. It's also noisy, but you'll be given earplugs or headphones. You will be able to hear, and speak to, the person operating the scanner.

PET (positron emission tomography) scan

PET scans are a newer type of scan and you may have to travel to a specialist centre to have one. They are not always necessary but you can discuss with your doctor whether one would be useful in your case. PET scans can be used to find out whether a head and neck cancer has spread beyond the original site, or to examine any lumps that remain after treatment to see whether they are scar tissue or whether cancer cells are still present.

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and show up on the scan.

PET/CT scan

The scan is a combination of a CT scan which takes a series of x-rays to build up a three-dimensional picture (see above) with a PET scan which uses low dose radiation to measure the activity of cells in different parts of the body (see above). This gives more detailed information about the part of the body being scanned. PET/CT scans are a new type of scan and you may have to travel to a specialist centre to have one.

You will be asked not to eat for six hours before the scan, although you may be able to drink. You will be given an injection of a mildly radioactive substance into a vein, usually in your arm. You may be asked to avoid talking and moving your head and neck area after the injection. The radiation dose used is very small. The scan is then taken after at least an hour. It usually takes 30–90 minutes.

You should be able to go home after the scan is over.

Other tests

Occasionally it is necessary to do other tests to give further information about the extent of your cancer. These may include a barium swallow or ultrasound scanning. Your doctor or nurse will explain these tests to you.

Waiting for your test results

It will probably take 7-10 days for the results of your tests to be ready, and this waiting period can be an anxious time. It may be helpful to talk to a relative or close friend.

Treating head and neck cancers

Treatment Overview

There are three main types of treatment for head and neck cancers:

- surgery
- radiotherapy
- chemotherapy.

Two other treatments may sometimes be used:

- biological therapies
- photodynamic therapy (PDT).

You may have two or more different treatments. These may be combined together, such as chemotherapy and radiotherapy – this is known as chemoradiation.

For most people, the treatment is aimed at:

- removing the cancer
- reducing the chances of the cancer coming back.

Cancers affecting the head and neck are uncommon so people with this type of cancer are usually treated in specialist hospitals. This may mean that you have to travel for your treatment.

How treatment is planned

In most hospitals a team of specialists will decide the treatment that's best for you. This **multidisciplinary team (MDT)** includes:

- an oral and maxillofacial surgeon – a doctor or dentist who specialises in surgery to the mouth and jaws, or an ear, nose and throat (ENT) surgeon
- an oncologist – a doctor who specialises in cancer treatments such as radiotherapy, chemotherapy and biological therapy
- a radiologist – a doctor who helps to analyse scans and x-rays
- a pathologist – a doctor who advises on the type and extent of the cancer
- a nurse specialist who gives information and support
- a speech and language therapist
- a dietitian.

The team will often include a number of other healthcare professionals such as:

- a dentist or oral hygienist
- a physiotherapist
- an occupational therapist
- a psychologist or counsellor.

Together they will be able to advise you on the best course of action and plan your treatment, taking into account a number of factors. These include your age, general health, and the type and stage of your cancer.

If two treatments are equally effective for the type and stage of cancer – for example, surgery or radiotherapy – your doctors may offer you a choice of treatments. Some people find it very hard to make a decision. If you're asked to make a choice, make sure that you have enough information about the different treatment options, what is involved and the side effects you might have, so that you can decide what the right treatment is for you.

Remember to ask questions about any aspects that you don't understand or feel worried about. You may find it helpful to discuss the benefits and disadvantages of each option with your doctor, specialist nurse, or with our cancer support specialists.

Giving your consent

Before you have any treatment, your doctor will explain the aims of it to you. They will usually ask you to sign a form saying that you give your permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent, and before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages
- any other treatments that may be available
- any significant risks or side effects

If you don't understand what you've been told, let the staff know straight away so that they can explain again. Some cancer treatments are complex, so it's not unusual for people to need repeated explanations.

It's often a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write down a list of questions before you go to your appointment.

Patients often feel that hospital staff are too busy to answer their questions, but it's important for you to be aware of how the treatment is likely to affect you. The staff should be willing to make time for you to ask questions.

You can always ask for more time to decide about the treatment if you feel that you can't make a decision when it's first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor, or the nurse in charge, so that they can record your decision in your medical notes. You don't have to give a

reason for not wanting to have treatment, but it can help to let the staff know your concerns so that they can give you the best advice.

Benefits and disadvantages of treatment

Many people are frightened at the thought of having cancer treatments, particularly because of the potential side effects. Some people ask what would happen if they did not have any treatment.

Although many of the treatments can cause side effects, these can usually be controlled with medicines.

Treatment can be given for different reasons and the potential benefits will vary depending upon the individual situation. In people with early-stage head and neck cancer, surgery or radiotherapy is often done with the aim of curing the cancer. Occasionally additional treatments are given to reduce the risk of it coming back.

If the cancer is at a more advanced stage, treatment may aim to cure the cancer, or it may only be able to control it, leading to an improvement in symptoms and a better quality of life. For some people the treatment will have no effect upon the cancer and they will get the side effects with little benefit.

If you've been offered treatment that aims to cure your cancer, deciding whether to accept the treatment may not be difficult. However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to make a decision.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss in detail with your doctor or nurse specialist whether you wish to have treatment. If you choose not to, you can still be given supportive (palliative) care, with medicines to control any symptoms.

Second opinion

Usually a number of cancer specialists work together as a team and they use national treatment guidelines to decide on the most suitable treatment for a patient. Even so, you may want to have another medical opinion. Either your specialist, or your GP, will be willing to refer you to another specialist for a second opinion, if you feel it will be helpful. Getting a second opinion may cause a delay in the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Before treatment for head and neck cancer starts

Dental care

You will usually be advised to have a complete dental check-up and any necessary dental work done before your treatment begins. Your cancer doctor may recommend that you see a dentist with experience in treating people who have head and neck cancers, rather than your own dentist.

The dentist or hygienist will give you advice on how to care for your teeth and gums, and check that your teeth are healthy. This is very important because cancer treatment may make your mouth more sensitive and prone to infection, particularly if you have radiotherapy.

Smoking

If you have a head and neck cancer, your treatment is more likely to be successful if you don't smoke. Continuing to smoke can increase the side effects of treatment. It can also increase the risk of a second cancer growing in the same area, or in other parts of the body, such as the lung, or of the original cancer coming back. Smoking can be a difficult habit to break, especially at times of stress, but if you're able to stop smoking it will help your recovery. There are organisations that can help you. Your GP can also give advice and provide nicotine replacement therapies such as nicotine patches, gums and inhalers on prescription.

Alcohol

Avoiding alcohol, particularly spirits, will also help make your treatment more effective and reduce the risk of uncomfortable side effects.

Surgery for head and neck cancers

Surgery is an important part of treatment and usually aims to remove head and neck cancers completely.

The part of your mouth or throat that the doctor may remove depends on where the tumour is. Very small cancers can often be treated with a simple surgical operation under local or general anaesthetic, or with laser surgery, with no need to stay in hospital overnight.

If the cancer is larger, surgery will often involve a hospital stay and an operation under general anaesthetic.

Sometimes the surgery may involve more than one part of your head and neck, and may cause scarring on your face or neck. Some people may need to have reconstructive surgery to the face.

What to expect from the operation

If you need to have surgery, your doctor will discuss the best type of operation for you, depending on the size and position of your cancer, and whether it has spread. It's important to make sure that you have discussed your operation fully with your surgical team. This will help you to understand exactly what is going to be removed and how this will affect you after the operation – in both the short and the long term.

It's likely that during the operation the surgeon will also remove some of the lymph nodes on one or both sides of the neck, even if they are not swollen. This is called a **neck dissection**. Sometimes this is done because the nodes may contain a small number of cancer cells that did not show up in the earlier scans.

Flaps and grafts

The surgeon may need to remove part of the mouth, tongue or throat lining and occasionally some facial skin. This can be replaced using a piece of skin taken from another part of the body – usually the forearm or chest. This is known as a **skin flap**.

If the cancer is affecting part of your jawbone, the affected bone may be removed with the tumour. In this case, you may need to have part of a bone taken from elsewhere in your body to replace the missing jawbone. Usually the bone is taken from the leg. This is known as a **bone graft**. Your doctor and specialist nurse will be able to give you specific information about this type of operation.

Modern techniques usually enable you to move your jaw again as soon as the operation is over.

Prosthetics

Occasionally, in order to remove the cancer, the doctor may also need to remove some of the facial bones such as the cheekbone or palate. Depending on the extent of the operation, you may be offered an artificial replacement called a **prosthesis** (false part). This is a specially designed soft plastic replacement for the part of your face that has been removed. The most common prosthesis is an **obturator** – a denture with an extension that is used to replace the upper jaw.

Modern prostheses can be designed to suit your needs. They will never feel like your own tissue but they can look very realistic and work very well. If you're likely to need a prosthesis, your doctor and specialist nurse will discuss this with you fully before your operation. You will also talk to a prosthetics technician, who will be involved in designing and making your prosthesis.

It's important to discuss your operation fully with your surgical team so that you know what to expect and how it will affect you.

Some people can have surgery as a day patient, particularly when this involves just an examination under anaesthetic or a biopsy. If your surgery is more complicated, you will need to stay in hospital for several days or up to a few weeks. Your stay in hospital will depend on the extent of the surgery and whether or not you have had a skin flap or tissue graft.

After your operation you'll be encouraged to start moving around as soon as possible. This is an essential part of your recovery and, even if you have to stay in bed, it's important to do regular leg movements and deep breathing exercises.

A physiotherapist will explain these to you.

If you have extensive surgery, you may spend some time in intensive care immediately after the operation. This is a ward where you will be closely checked and given intensive nursing care for as long as necessary to help you recover.

Drips, drains and tubes

After the operation, it's likely that you will wake up with a number of drips, drains and tubes attached to you. These will gradually be removed as you recover.

Drips

Most operations to the mouth and throat area can make eating and drinking uncomfortable for a time. Because of this, you'll probably wake up from the operation with an intravenous drip (a tube inserted into a vein in your arm or your neck). This will give fluids and essential nutrients directly into your bloodstream for a few days. It will be removed once you are able to eat and drink again.

Drains

Depending on the extent of your surgery you may have one or two thin plastic drainage tubes leading from the operation site, with bottles attached to them to collect any fluid from the wound site. This helps the wound to heal properly.

Feeding tube

If eating is likely to be difficult for longer than a few days, the surgeon will do one of two things during the operation, while you are still under the anaesthetic.

You may have a thin tube passed through your nose and throat into your stomach. This is called a nasogastric (NG) tube.

The nurses on the ward will put special high-protein, high-calorie liquid food down the tube at regular times. This will help you to keep your strength up and help your body recover from the operation. The NG tube may need to stay in place for a couple of weeks, until you can eat properly again, and will be removed when you are able to eat by yourself.

You may have a tube that passes directly through the wall of your abdomen into your stomach, near your waist. Liquid food can be passed into the stomach directly through this. This is called a **gastrostomy** tube. There are two types of gastrostomy feeding tubes: **percutaneous endoscopic gastrostomy** (PEG) tubes and **radiologically inserted gastrostomy** (RIG) tubes. For a few people these may be permanent.

We have a factsheet on nutritional support which includes nasogastric, PEG and RIG feeding tubes.

A dietitian will visit you to discuss how much food you need to help with your recovery. They will decide the exact amount and type of food you should be given to replace your normal diet.

Catheter tube

Often a small tube (catheter) is put into your bladder, and your urine is drained through this into a collecting bag. This will save you having to get up to pass urine and it is usually removed after a couple of days.

Tracheostomy tube

Sometimes surgery to the mouth or throat can cause some swelling or bruising to the surrounding tissue, which may make it difficult for you to breathe. In this case the surgeon will create an opening into your windpipe (in the lower part of the neck) called a tracheostomy (or stoma) for you to breathe through.

The tracheostomy will be held open by a small plastic tube a few centimetres long. It will usually be removed when the swelling from your operation goes down and the airway is clear again. This will be explained to you by the specialist nurse or speech and language therapist before you have your surgery.

If you have a tracheostomy you may not be able to talk, because air will not be able to pass through your larynx to produce your voice. Your medical team will make sure that you have a way to communicate during this time.

Pain

You may have some pain or discomfort for a few days after your operation. For example, a neck dissection can often cause shoulder stiffness. It's also possible that the surgery may affect the sensation in your mouth, face, neck or shoulders so that some areas feel numb. This can happen even with a very small operation if some of the small nerves in the area need to be cut.

There are several different types of effective painkillers. If you're unable to eat properly you may be given painkillers by injection or as a liquid that can be injected through your NG or gastrostomy tube. Once you are able to eat and drink properly again, you can be given your painkillers as tablets or a liquid that you drink. It's very important to let your doctor or the nurses on the ward know as soon as possible if you have any pain. If your drugs don't completely relieve your pain, the dose can be increased, or the painkillers changed.

Speech

Some operations to the mouth and throat can affect the way that you speak. Speaking is a very complicated process, as the throat (pharynx), nose, mouth, tongue, teeth, lips and soft palate are all involved in producing speech. Any operation that changes one of these parts of the head and neck may affect your speech. For some people this is hardly noticeable, but for others, speech may be temporarily or permanently altered.

A speech and language therapist will be able to help you with your speech and to adapt to any changes.

Stiff jaw

Some operations to the back of the mouth and throat can lead to a stiff jaw. You will be given exercises to prevent this from becoming a permanent problem.

Specialist types of surgery

Laser surgery may sometimes be used to remove small tumours in the mouth and the pharynx. This may be combined with a light-sensitive drug (sometimes called a photosensitising agent) in treatment known as photodynamic therapy (PDT).

A type of surgery called **micrographic surgery** or **Mohs surgery** is sometimes used for cancers of the lip. The surgeon removes the cancer in thin layers, and the tissue that has been removed is examined under a microscope during the surgery. The surgeon will continue to remove more layers until no cancer cells are seen in the tissue. This technique makes sure that all the cancer cells are removed and only minimal healthy tissue is removed.

Preparing to go home

Before you leave hospital you'll be given an appointment to attend an outpatient clinic for check-ups or to plan further treatment, such as radiotherapy. If you need to see

any of the other members of the team, such as the speech and language therapist, specialist nurse or the dietitian, you'll also be given appointments to see them. This is a good time to discuss with your doctor any problems you may have after your operation.

If you have a gastrostomy tube you may go home with it. This is likely to happen if you need radiotherapy treatment after your surgery because the treatment can cause soreness in the mouth and throat area, making it difficult to eat. Before you go home the nurses will be able to teach you or your carers how to look after the gastrostomy tube. They can also arrange for a district nurse to visit you at home.

Radiotherapy for head and neck cancers

Radiotherapy for head and neck cancers is usually given in combination with chemotherapy. This is known as chemoradiation. This may be used instead of or after surgery.

There is good evidence that this combined treatment is more effective than using either chemotherapy or radiotherapy alone. However, radiotherapy may sometimes be used alone if a person is not fit or well enough to have chemoradiation.

You might find it helpful to read our booklet about radiotherapy, which gives information about the treatment and how to cope with side effects.

Radiotherapy can be given in two ways:

- From outside the body as external beam radiotherapy (a beam of x-rays or electrons from a large machine called a linear accelerator). This is the most common way of giving radiotherapy to the head and neck area.
- By implanting radioactive material into the tumour and leaving it there for a few days. This is known as internal radiotherapy, interstitial radiotherapy or brachytherapy.

External radiotherapy for head and neck cancer

External radiotherapy treats cancer by using doses of high-energy x-rays to destroy the cancer cells while doing as little harm as possible to normal cells.

How treatment is given

The treatment is usually given every weekday in the hospital radiotherapy department, with a rest at the weekend. You may sometimes have treatment more than once a day, and occasionally you may also have treatment at the weekend.

It's important to follow the scheduled treatment plan and avoid any unnecessary gaps in your course of treatment. The treatment will usually last 3–7 weeks, depending on the type and size of the cancer. Your radiotherapy doctor (clinical oncologist) will discuss the treatment with you.

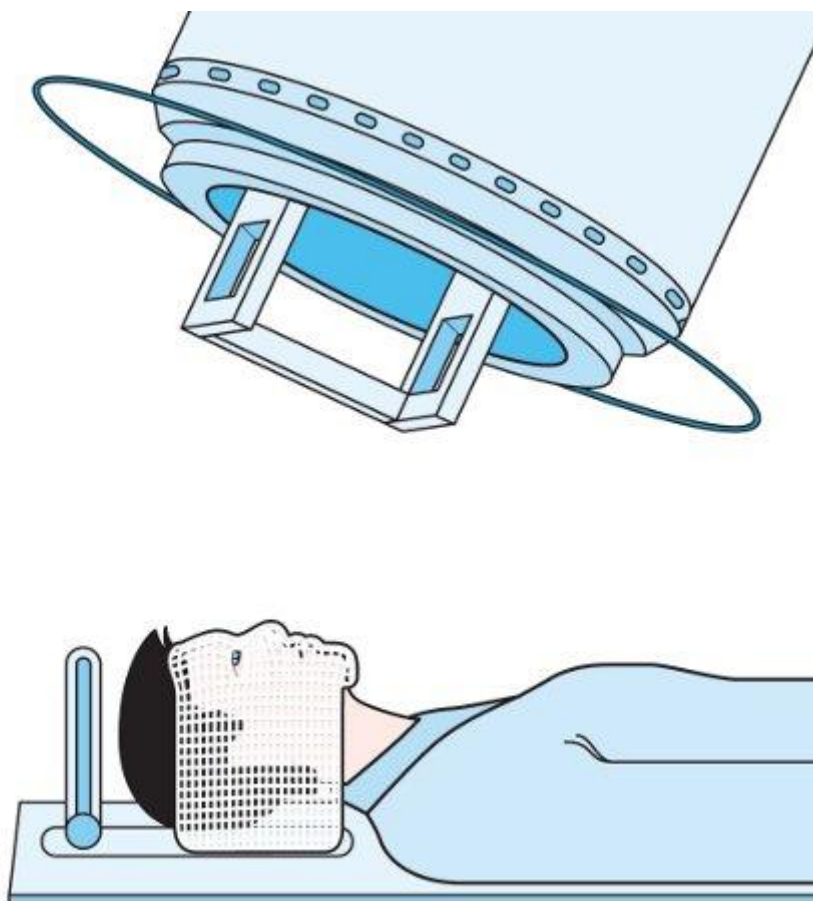
Conformal radiotherapy (CRT) is the most common type of external radiotherapy used for the treatment of head and neck cancers. A special attachment to the

radiotherapy machine carefully arranges the radiation beams to match the shape of the cancer. Shaping the radiotherapy beams reduces the radiation received by surrounding healthy cells. This can reduce the side effects of the radiotherapy treatment (such as a dry mouth) and may allow higher doses to be given, which could be more effective. Another type of radiotherapy known as **intensity-modulated radiotherapy (IMRT)**, which is similar to conformal radiotherapy, may be used in some hospitals.

Planning your treatment

To ensure that the radiotherapy is as effective as possible, it has to be carefully planned by a clinical oncologist. It's a very precise treatment and it's important that you are able to lie still, in exactly the same position, for each treatment.

To help you do this, you may need to wear a see-through Perspex® or plastic device called a '**mould**', '**shell**' or '**mask**' that helps to keep your head and shoulders as still as possible. The mould allows you to see and breathe normally, but it may make some people feel claustrophobic. It's important to let the doctor or nurse know if you suffer from claustrophobia. You will only have the mould in place for a few minutes at a time, and most people soon get used to wearing it.



Patient getting Radiotherapy treatment

You may need to wear a clear, plastic mask for a few minutes at a time, to hold your head still during treatment.

Your mould will be made on one of your first visits to the radiotherapy department. The radiographer (the person who gives the treatment) will explain the whole process to you before starting.

Treatment planning is a very important part of radiotherapy and several visits may be needed.

You will have a **CT (computerised tomography)** scan taken of the area to be treated. A CT scan takes lots of images from different angles to build up a three-dimensional picture of the area. At the same time radiographers will take measurements from you which are needed for treatment planning. This session will usually take about 45–60 minutes and you will need to wear your radiotherapy mould.

Sometimes you may also need to go to the hospital's scanning department to have an **MRI scan**. This uses powerful magnetic fields to give a detailed picture of part of your body, which can give additional useful information.

The radiographer's measurements and the information from the scans are fed into the radiotherapy planning computer to help your doctors plan your treatment more precisely.

Marks are drawn on the mould (or sometimes on your skin) to help the radiographer position you accurately, and show where the rays are to be directed. If the marks are on your skin they must stay there throughout your treatment, but they can be washed off once your course of treatment is finished. Sometimes a few small, permanent marks (tattoos) may be made on your skin. The marks are tiny and will only be done with your permission.

At the beginning of your treatment you'll be given instructions on how to look after the skin in the area being treated. You will be told whether you can wash the marked areas of skin.

Tracheostomy tube

Very occasionally, radiotherapy to the mouth or throat can cause swelling to the surrounding tissue which may make it difficult for you to breathe during the treatment.

If this is likely to happen, your doctors will arrange for you to have a tracheostomy before your radiotherapy treatment starts. The tracheostomy is usually temporary.

During the treatment

Before each session of radiotherapy, the radiographers will position you carefully on the couch, with the mould fitted, and make sure you are comfortable. During your treatment, which only takes a few minutes, you will be left alone in the room, but you'll be able to signal to the radiographers who will be watching you from the next room.

You will have to lie still while the treatment is given, but you will not feel the radiotherapy; it's similar to having an x-ray.

External radiotherapy does not make you radioactive, and it's perfectly safe for you to be with other people, including children, throughout your treatment.

Side effects of radiotherapy

Radiotherapy can cause some temporary side effects. Although these may be worse if you have your treatment combined with chemotherapy, they will usually gradually disappear after the treatment has finished.

If you continue to smoke during your treatment these side effects are likely to be worse, so if you can stop smoking this will help your recovery.

You may have some of the side effects listed below:

Sore skin

The skin over your face and neck is very likely to gradually redden or darken and become sore (like sunburn). This starts after about two weeks of treatment and may last for 2–4 weeks after the treatment has finished. Sometimes the skin will peel or break. The radiotherapy team will tell you how to look after your skin as some chemicals can make the skin more sensitive to radiation. It's very important to use only soaps, creams and lotions that are recommended by the radiotherapy staff.

Rarely, the skin in the treated area may break down and become moist. The radiotherapy team can give you advice if this happens.

Sore mouth and throat

Your mouth and throat will probably become sore and inflamed after a couple of weeks of treatment and you may develop some mouth ulcers. Your voice may also become hoarse. You may become sensitive to very strong flavours and possibly to extreme heat and cold. Eating food may become difficult and swallowing painful.

You will be given advice on how to look after your mouth during your treatment. It's important to follow this advice. Your doctor can prescribe mouthwashes and protective gels that coat the lining of the mouth, and painkillers to help ease any discomfort.

Your specialist nurse or dietitian will advise you on how to change your diet to make eating more comfortable. For example, you'll be encouraged to eat soft food and to avoid smoking, drinking spirits and eating hot or spicy foods. Drinking plenty of bland, cool fluids like milk and water, or sucking ice cubes, will help to keep your mouth moist. You'll be able to discuss any problems with eating and drinking with a specialist nurse or dietitian.

Once the course of radiotherapy has finished, your mouth will gradually heal and most people get back to eating normally a few weeks after the treatment has finished. However, the effects of the radiotherapy occasionally make the throat too uncomfortable for a person to eat or drink and they may need to be fed by a nasogastric or a gastrostomy tube during the treatment and for a period of time after treatment has finished.

Loss of taste

If part, or all, of your mouth is treated, your sense of taste will quickly change during the radiotherapy. Some people either lose their sense of taste completely or find that everything tastes the same (usually rather metallic or salty, or like cardboard). Although your sense of taste should recover, it may take many months for it to return to normal after the treatment.

Loss of appetite

Some people lose their appetite as a general effect of radiotherapy. A sore, dry mouth can also make eating difficult. If you are eating less, it's a good idea to supplement meals with nutritious high-calorie drinks such as Complan® and Build-up® (these are available on prescription or can be bought from a pharmacy or some larger supermarkets). You could also try baby foods, which are soft but also high in protein and calories.

If you're unable to eat solids your doctor or nurse may prescribe supplement drinks, such as Ensure® or Fortisip®, which are complete meals in liquid form.

You will be able to discuss any problems with your diet with the dietitian or specialist nurse at the hospital.

We can provide you with more information and helpful tips on how to eat well when you have lost your appetite.

Dry mouth

You may notice that you can't produce as much saliva as before the treatment. The lining of your mouth and throat may become dry and this can make eating and speech difficult. You may also notice a feeling of sticky mucus in the throat, as sometimes radiotherapy makes the saliva thick and stringy, which can be very distressing. To reduce the dry feeling, you may find it helpful to drink fluids regularly and to use an artificial saliva spray. Wiping small amounts of vegetable or olive oil on the inside of your cheeks may also help.

Although you may start to produce some saliva again within a few months of treatment, it's important to be aware that the problem might continue for some time. If your mouth, throat or the upper part of your neck is being treated, your mouth may become permanently dry.

We have more information about coping with a dry mouth.

Dental care

During your treatment you will need to see your dentist regularly, because your mouth may become drier, more sensitive and easily irritated. You may also be more prone to tooth decay. You should follow the dental hygiene advice that you are given, such as brushing regularly with a soft toothbrush or gauze. You will usually be asked to apply fluoride gel to your teeth every day, either as a mouthwash or in special gum shields, to help protect your teeth from decay.

If your dentist recommends that one of your teeth needs to be removed, you should be referred to a specialist oral and maxillofacial surgeon for advice and treatment.

Hair loss

For most people, radiotherapy for cancers of the head and neck will not make their hair fall out, or the amount of hair loss will be very slight. It's unusual to lose any hair from the scalp during radiotherapy for head and neck cancers, as hair only falls out where the x-ray beam enters and leaves your body. For most people this will be limited to parts of the face and neck. Only the hair very close to the tumour is likely to be permanently lost, so men will lose their beard permanently in those areas of skin that become red or dark and sore during treatment. Hair loss can occur when tumours around the eyes and ears are treated.

Your doctor will advise you if permanent hair loss is likely in your case, and can tell you where it is likely to occur.

Tiredness

You may find that the treatment makes you feel very tired. During your treatment it's important to get as much rest as you can, especially if you have to travel a long way each day for your treatment.

Feeling sick (nausea)

Sickness is more likely to affect people who have combined chemotherapy and radiotherapy treatment. If it's a problem your doctor can prescribe anti-sickness medicines (anti-emetics).

Stiff jaw

If you have radiotherapy to the back of your throat (nasopharynx), the muscles used to open and close your mouth can become stiff.

You will be shown mouth-opening exercises that you should do at least twice a day. There are also specialist aids available to help you exercise your jaw. Your doctor, specialist dentist, or speech and language therapist can give you advice about exercises and where to buy an exercise aid.

Bad breath

This is usually caused by changes to your saliva and it can be reduced by regular mouth care and mouthwashes. It may also be caused by an infection in your mouth, which is common during radiotherapy treatment. If you have bad breath let your doctor or specialist nurse know. They can look inside your mouth to see if you have an infection, which can then be treated with antibiotic or antifungal medicine.

All these side effects can be upsetting and difficult at times. However, it's helpful to remember that many are temporary and will gradually disappear.

Most side effects occur towards the middle and end of the course of treatment and continue during the first couple of weeks after your treatment has finished. The effects can be mild or more troublesome, depending on the dose of radiotherapy and the length of your treatment. Your doctor or specialist nurse will be able to advise you on what to expect, and can offer treatment and support to help relieve any side effects.

Internal radiotherapy for head and neck cancers

In some people, such as those who have small cancers of the tongue, internal radiotherapy may sometimes be used instead of surgery.

Internal radiotherapy (also called interstitial radiotherapy, implant therapy or brachytherapy) involves putting radioactive material directly into the cancer. In this treatment radioactive needles or wires are inserted into the cancer while you are under a general anaesthetic. Over a few days, the needles or wires give a high dose of radiotherapy directly to the tumour from the inside.

You will need to stay, and be cared for, in a single room in hospital for a few days, until the doctor has removed the radioactive needles or wires from your body. Visitors will be restricted and although it will be safe for your family and close friends to visit

you for short periods, children and pregnant women will not be allowed to visit. This is to avoid any chance of them being exposed to even tiny amounts of radiation.

The doctors and nurses caring for you will also only be able to stay in your room for short periods at a time. This is because they may be looking after several people having internal radiotherapy treatment and they need to keep their exposure to the low level of radioactivity to a minimum.

The safety measures and visiting restrictions might make you feel isolated, frightened and depressed at a time when you might want people around you. If you have these feelings it's important that you let the staff looking after you know. It can help to have plenty of reading material and things to keep you occupied while you are in isolation. The isolation only lasts while the radioactive needles or wires are in place (usually 1–8 days). Once they are removed, the radioactivity disappears and it's perfectly safe to be with other people.

Side effects

While the needles or wires are in place, the tissues around them will become swollen. This usually settles by the time they are removed.

The treated area will become sore about 5–10 days after the needles or wires have been removed and this may last for several weeks. During this time, you may find it easier to eat soft foods.

While your mouth is sore it will help to avoid:

- smoking
- drinking spirits
- eating hot or spicy foods.

Drinks like milk and water will help to keep your mouth moist. Your doctor can prescribe special mouthwashes and medicines to help to relieve any discomfort.

Chemotherapy for head and neck cancers

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells.

Chemotherapy drugs work by disrupting the growth of cancer cells. The chemotherapy drugs are usually given by injection into a vein (intravenously). As the drugs circulate in the bloodstream, they can reach cancer cells all over the body. Our booklet on chemotherapy discusses the treatment and its side effects in more detail. We also have factsheets about individual drugs and their particular side effects.

For the treatment of head and neck cancers, chemotherapy is normally given at the same time as radiotherapy. This is known as **chemoradiation**.

Chemotherapy may also be given before chemoradiation treatment, which is known as induction chemotherapy.

Very occasionally chemotherapy is given before surgery to shrink the tumour and make it easier to remove.

Side effects of chemotherapy

Chemotherapy can cause some temporary side effects, which are described below. Although these may be worse with combined radiotherapy treatment, they will usually gradually disappear after the treatment has finished.

Lowered resistance to infection (neutropenia)

Chemotherapy can temporarily reduce the production of white blood cells in your bone marrow, making you more prone to infection.

This effect can begin about seven days after treatment has been given and your resistance to infection usually reaches its lowest point about 10–14 days after chemotherapy. Your blood cells will then increase steadily and will usually have returned to normal before your next cycle of chemotherapy is due.

- You should contact your doctor or the hospital straight away if:
- your temperature goes above 38°C (100.4°F)
- you suddenly feel unwell (even with a normal temperature).

You will have a blood test before having more chemotherapy to make sure that your cells have recovered. Occasionally it may be necessary to delay your treatment if your blood count is still low.

Bruising or bleeding

The chemotherapy can reduce the production of platelets, which help the blood to clot. Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, blood spots or rashes on the skin, and bleeding gums.

Anaemia (low number of red blood cells)

While having chemotherapy you may become anaemic. This may make you feel tired and breathless. Blood transfusions may be given if you become anaemic due to chemotherapy.

Feeling sick (nausea) and vomiting

Your doctor can prescribe very effective anti-sickness (anti-emetic) drugs to prevent or greatly reduce nausea and vomiting. If the sickness is not controlled, or continues, tell your doctor, who can prescribe other anti-sickness drugs which may be more effective.

Hair loss

Not all chemotherapy drugs cause hair loss. Hair may be lost completely or may just thin. You can ask your doctor if the drugs you are having are likely to cause hair loss. If you do lose your hair, you may want to wear a wig – you can ask your doctor or nurse to arrange for you see a wig specialist.

You may prefer to wear a bandana, hat or scarf.

If your hair does fall out, it will almost always grow back over a period of 3-6 months once the chemotherapy has finished.

We have a booklet on coping with hair loss, which has useful tips on wigs and head coverings, and dealing with the emotional effects of hair loss.

Sore mouth and small mouth ulcers

Some chemotherapy drugs cause your mouth to become sore and you may also develop mouth ulcers. Regular mouthwashes are important and your nurse will show you how to use these properly.

If you don't feel like eating meals, you can supplement your diet with nutritious drinks or soups. A wide range of drinks is available and you can buy them at most chemists. You can ask your doctor to refer you to a dietitian for advice about diet.

Tiredness

Chemotherapy affects different people in different ways. Some are able to lead a normal life during their treatment, while many find they become very tired and have to take things more slowly. Just do as much as you feel like doing and try not to overdo it.

Although they may seem hard to bear at the time remember that these side effects are temporary and will usually disappear, in time, once your treatment is over.

Photodynamic therapy for head and neck cancers

Photodynamic therapy (PDT) uses a combination of laser light of a specific wavelength and a light-sensitive drug to destroy cancer cells.

The light-sensitive drug (the **photosensitising agent**) is injected into a vein. It circulates in the bloodstream and is taken up by cells throughout the body. The drug is taken up by cancer cells more than by healthy cells. It doesn't do anything until it is exposed to laser light of a particular wavelength. When a laser is shone onto the cancer, the drug is triggered to interact with oxygen, which then destroys the cancer cells.

There is a delay of four days between the injection and the activation of the drug using laser light. The laser light used in PDT is focused through a fibre-optic tube, and is shone for only a few minutes. The doctor holds the fibre-optic tube very close to the cancer so that the correct amount of light is delivered and the PDT causes the minimum amount of damage to normal, healthy cells.

In early-stage cancer of the head and neck, PDT may be used to try to cure the cancer and is usually given as part of research trials. PDT can sometimes be used to shrink an advanced cancer to reduce symptoms, but it cannot cure an advanced cancer.

Your doctor can advise you whether PDT may be an appropriate treatment in your situation.

Side effects of PDT

After injection of the photosensitising drug, people are highly sensitive to light. They need to take precautions to avoid exposure of their skin and eyes to direct sunlight or bright indoor lighting for a set period (usually about two weeks). Appropriate clothing and eyewear must be worn to prevent reactions to light.

Other temporary side effects may include pain (which can be controlled with painkillers), swelling of the treated area, difficulty in swallowing and bleeding.

We have a separate factsheet about PDT which you may find useful.

Biological therapies for head and neck cancers

Biological therapies use substances that are produced naturally in the body to destroy cancer cells.

There are several types of biological therapy that may be used to treat head and neck cancers. These include monoclonal antibodies and cancer growth inhibitors. Biological therapies are mainly given as part of cancer research trials.

Monoclonal antibodies

Monoclonal antibodies are drugs that recognise and attach to specific proteins (receptors) that are found in particular cancer cells or in the bloodstream.

Some cancer cells have receptors known as **epidermal growth factor receptors (EGFR)**. When growth factors attach to the receptor, the cancer cell is stimulated to grow and divide. The monoclonal antibody cetuximab (Erbix®) locks onto the EGFR and may prevent the cancer cell from growing and dividing. It may also make the cancer cells more sensitive to the effects of radiotherapy.

Cetuximab is sometimes used, in combination with radiotherapy, to treat squamous-cell head and neck cancers that have begun to spread into surrounding tissues (locally-advanced cancer). It's given as a drip (infusion) into a vein.

We have a factsheet about cetuximab.

Other monoclonal antibodies are also being used in trials.

Your doctor or nurse will be able to tell you more about any drugs that are being used in trials and if you are suitable for a trial.

Cancer growth inhibitors

In order to grow and divide, cancer cells 'communicate' with each other using chemical signals. Cancer growth inhibitors interfere with this process and so affect the cancer's ability to develop. Cancer growth inhibitors, such as gefitinib (Iressa®), have been used in trials to treat some types of head and neck cancer that have come back after initial treatment. It's still not known how effective these drugs are because trial results are not yet available.

Research - clinical trials for head and neck cancers

Cancer research trials are carried out to try to find new and better treatments for cancer. Trials that are carried out on patients are known as clinical trials.

Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs and biological therapies (such as gene therapies or cancer vaccines)
- look at new combinations of existing treatments, or change the way they are given, to make them more effective or to reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- see which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different operation, type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will also be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments, or to have side effects that outweigh the benefits.

If you decide not to take part in a trial your decision will be respected and you do not have to give a reason. There will be no change in the way that you are treated by the hospital staff and you will be offered the standard treatment for your situation.

This process is described in more detail in our booklet on understanding cancer research trials.

Blood and tumour samples

Blood samples and tumour biopsies may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you're taking part in a trial you may also be asked to give other samples which may be frozen and stored for future use, when new research techniques become available. These samples will have your name removed from them so you can't be identified.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. This type of research takes a long time, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will, hopefully, improve the outlook for future patients.

Living with head and neck cancers

Quality of Life

Recovery is different for everyone and it depends on the treatment one has. It will usually take some time to recover from treatment.

There may be physical changes in the way one looks, and possibly changes in some of the most basic activities of daily life such as the way one speaks, or what one can eat.

There will also be emotional changes to deal with so it's important to give oneself time to adjust.

How you will look after treatment for head and neck cancer

It can be distressing if you need surgery to part of your head or neck. When surgery affects your looks, it can alter the way that you think of yourself as a person and can be very difficult to deal with.

Body image

It's now much less common for people to be disfigured by their surgery, even if they need very extensive treatment. Scars from surgery often lie either in the neck or in skin creases on the face and are barely visible. The underlying bone structures can be built up to a near-normal shape using bone grafts from other places in the body. However, if the operation affects delicate structures such as the nose or lips, your appearance will be altered.

It takes time to adjust to a sudden change in appearance, even when it's only small. Although we live in a society that puts a lot of emphasis on appearance, we all know that the relationships that are important to us, with family and friends, are not just based on the way we look. Nevertheless, it's true that how you feel about the way you look is an important part of self-esteem.

How we look is one of the ways that we define ourselves. Because of this, changes to your appearance as a result of surgery may affect, in some ways, your sense of who you are.

With any change in appearance, it's quite normal to worry about feeling rejected, both socially and possibly even by your partner. There are many reasons for this concern. Our faces play a big part in communication. Watching facial expression, eye contact and nodding, for example, are all ways of gathering information about what is being said. Because of this we look intently at each other when we are speaking. Usually, we accept this without thinking about it, but when your appearance has changed, it can be unsettling to be aware of how much people are looking at your face.

The more you are at ease with the changes yourself, the easier you will find it to deal with the reactions of others. Your family and friends may feel unsure about what to say and how to behave. They may also worry about saying the wrong thing.

The medical professionals looking after you will be able to give them advice about what to expect and how to support you. They may also find it helpful to read our booklet on talking to someone with cancer, which has tips on how to talk to and support a person with cancer.

Ways of coping with your changed appearance

It's very important to have a good idea of what to expect before you have your operation. Ask your doctor to be honest about the physical effects of the surgery, and try to discuss them openly with people who are close to you. If you have a partner, it may help for them to see the doctor or nurse with you, so that you can both be fully aware of what to expect afterwards.

It may help to talk to someone who has had a similar experience. Your doctor may be able to put you in touch with other people who can talk to you about how the surgery has affected them, and give you some idea about how it might affect your life. You may also pick up good tips on how to cope with the changes.

When you come round from the operation you may be anxious to know what you look like, but at the same time frightened of what you might see. Once you have recovered physically from the operation, perhaps after 7–8 days, it's a good idea to look at your face for the first time with a doctor or nurse. They will be able to explain the healing process. Even if you had a good idea of what to expect, you may still feel shocked and upset when you first see your face. If your face feels different – for example, numb or swollen – this can add to the shock.

You may be extremely upset and perhaps wish that you had never agreed to the operation. You may also feel angry. Give yourself some time. These are very strong emotions and part of you needs to grieve for your previous appearance even as you look ahead to the future.

Remember that the changes to your face will be at their worst in the days and weeks immediately after the operation. Any swelling or bruising will disappear as you heal, and scars will gradually fade over time. The hospital staff will help you, and you can get advice and support from support organizations which help people to cope with a changed appearance. Even if it's difficult, it's best not to avoid looking at your face. Some people find that it helps to change their own dressings at this stage.

Camouflage make-up

If parts of the skin from your face or neck have to be removed completely, they can be replaced, but the skin colour will not match the surrounding skin and the scars may be visible. However, there is a way to reduce the differences of skin colour and disguise the appearance of scar tissue. Camouflage make-up consists of specially designed creams, and is available to suit all skin types and colours in both men and women.

Some types of camouflage make-up can be applied to facial prostheses to improve the colour match of the skin. This can be useful in the summer when skin tone changes. If the prosthesis needs colouring it should be taken back to the person or organisation that supplied it.

Meeting other people

As you and the people close to you become more familiar with your changed appearance, you may want to think about seeing other people and going back to work. If you avoid social situations, you may find yourself wanting to go out less and

less. The longer you leave it, the harder it may be. It's best to start by going somewhere familiar with someone else to give you support.

Be prepared for mixed reactions. You may find that people take far less notice of you than you expected. But if people are staring, don't assume that they are making judgements about you. We all look at each other, and hiding your face will often draw attention to you. On the other hand, some people may seem intrusive and may make remarks. Small children are often openly curious and may ask why you look different. Decide in advance how you will answer. A simple sentence saying that you have had an operation will be enough. You don't have to go into the details.

Dealing effectively with other people often involves taking the first step by putting them at ease. They will soon respond to you and not to your appearance. Coping successfully with these sorts of social situations will help to build your self-confidence, and this will increase as you gradually take up your normal activities. These skills are not difficult to learn, but simply need practice. In time you will gain the confidence to manage social situations in an effective way.

Focus on things that make you feel good about yourself or that help you to accept the change in how you look. Remember that personality, interests and a sense of humour are more important than appearance to the people who know you.

These are the qualities that your friends and family value, and these things haven't changed. People who are close to you are likely to be less concerned about what you look like and more about how the change is affecting you. Being open about your fears of rejection can help to overcome any initial awkwardness with others. Given the chance, most people will welcome the opportunity to reassure you of their continuing love for you.

Intimate relationships

Treatment for head and neck cancers can also affect the way that you feel about yourself in a sexual way. This may leave you feeling isolated. Your partner may also need time to adjust. Again, keeping communication open and talking about how you both feel is essential to overcoming any fears or worries that you may have.

Help and support

Cancers of the head and neck may bring with them not only the shock of having cancer, but the added trial of coping with major changes to the way you look, speak and feel about yourself as a result of treatment. It's only natural to feel sad and upset and sometimes these emotions can be overwhelming.

There are many organisations that can help you. Your doctor can refer you to a counsellor, who can listen to your problems and give information about how other people have managed in a similar situation. Some support organisations provide counselling.

We have a booklet on the emotional effects of cancer, which you may find helpful.

Joining a group especially for people with facial disfigurements may help take away your feeling of having to cope alone, and will put you in touch with people who really understand what you are going through.

Changes to eating after treatment for head and neck cancer

Surgery and radiotherapy to the head and neck area may interfere with some of the actions or movements of the mouth, tongue or throat, making it more difficult to eat or drink.

Eating is an everyday activity that we rarely stop to think about. In fact, it's a very complex process with a precise sequence of actions, each needing a high level of muscular control.

After treatment, your doctor will want to make sure that food is going down into the gullet and not into your lungs, which would make you cough or choke.

Assessing your swallowing

If your doctor is concerned that food may be going down the wrong way, they will arrange for your swallowing to be assessed by a speech and language therapist. The therapist may arrange a special x-ray examination of your swallowing called a **videofluoroscopy**. This is completely painless. You will be asked to swallow different types of food, from liquid to semi-solid (like yoghurt), to solid (like a biscuit). A special substance is added to the food to make it show up on the x-ray film.

This test is carried out in a special room by a radiologist and the speech therapist, and is recorded on video.

If the results of the videofluoroscopy show that food or liquid is getting into the lungs, you may need to be fed directly into the stomach through a tube. Sometimes this may need to be permanent, but for most people it is only temporary until they re-learn to swallow with the help of exercises taught by the speech and language therapist. You will also be given advice on the type of food to eat – for example, drinks can be thickened to allow them to be swallowed safely.

The tissue will heal once your treatment is over and any swelling will go down gradually. Your swallowing will slowly improve, although this may take a long time and may never be quite the same as before. Your speech and language therapist will help you. They will assess your eating and swallowing at every stage and advise you on what to do.

It may be that you lose interest in food because your treatment has affected the way that things smell and taste. However, it's important to eat well during and after your cancer treatment. This means getting enough calories and protein to prevent weight loss, increase your strength and rebuild normal tissues. Your dietitian will help you choose the right kinds of foods.

Some people find that after their treatment they can only eat slowly and they experience drooling (saliva drips outside the mouth). These changes may make you feel embarrassed and frustrated and you may find it hard to eat with others. It's important to talk with your family and friends about how you are feeling so that they can help. You can also talk to your specialist nurse - they will understand what you are going through and may be able to put you in touch with other people who have experienced similar difficulties.

Ideas for food and eating

Some suggestions about food are offered below, and our booklet on diet and cancer has helpful tips on how to eat well when you have a sore or dry mouth.

- Try different types of food or ways of preparing food.
- Choose foods that look and smell good to you.
- Try to choose high-calorie foods that contain a lot of protein (such as meat, fish or cheese).
- Cook with butter or oil.
- Help to increase the flavour of food by marinating, or using strongly flavoured seasonings or herbs.
- If your mouth is sore, or swallowing is difficult, try soft foods such as milkshakes, custards, scrambled eggs or mashed vegetables. Avoid foods that may irritate, such as spicy/salty foods, citrus fruit or drinks (orange, lemon and lime), and tomato sauces.
- Mix food with sauces to ease swallowing.
- Try to eat several small meals or snacks during the day – this may work better for you than having three large meals.

Changes to speech after treatment for head and neck cancer

Any change to your lips, teeth, tongue or soft palate is likely to make your speech sound different.

For some people, a change in voice will only be a temporary problem and their speech will return to near normal as tissues heal. For others it will be a greater problem and will cause permanent changes to the way they speak.

This may mean that you have difficulty making one or two specific sounds or saying some words. It may sometimes be more severe, so people can't easily understand what you are trying to say.

Losing the ability to talk, even temporarily, can be frightening and frustrating. However, a speech and language therapist will be involved in your recovery from an early stage and will be able to give support and helpful advice.

Speech therapy

Speech therapy can help you learn to communicate in the clearest and most effective way. Therapy usually begins as soon as possible after surgery and normally continues after you go home. It's likely to involve exercises to improve the range and strength of mouth and tongue movements, or to find new ways to produce speech sounds. If you wear dentures, these may need to be changed. Sometimes, an individually designed prosthesis needs to be made to improve your speech.

There are also special aids that your speech and language therapist will discuss with you if necessary.

Adjusting to your changed speech or voice will take time for you, and your family and friends. The reactions of strangers may be harder to get used to, but will get easier. It often helps if you can put your listener at ease by simply explaining that you have had an operation that has made it difficult for you to talk.

Changes to hearing after treatment for head and neck cancer

Computer technology has made great advances in this area. If you have a problem with hearing after your cancer and treatment, there are **cochlear implants** (digital hearing aids that can recognise speech) and miniature hearing aids that can help.

Sometimes the small tube between the ear and the throat (the **Eustachian tube**) can become blocked after treatment.

The Eustachian tube helps to regulate air pressure in the ear, and if blocked it can affect hearing. If this happens a simple operation to put in a tiny tube (**grommet**) can help the ear to drain and improve hearing. This is usually done under a local anaesthetic.

Follow-up after treatment for head and neck cancers

After your treatment is completed, you will have regular check-ups. These are very important for your surgeon or oncologist to monitor your progress.

You may have scans from time to time but the most important part of your follow-up will be your specialist's examination of your head and neck.

If you have any problems or notice any new symptoms in between these times, you should let your GP, specialist or specialist nurse know as soon as possible.

The check-ups will often continue for several years, frequently at first, then less so. This can make it difficult to put the experience of cancer behind you.

It's important to have a nutritious and well-balanced diet with plenty of fresh fruit and vegetables, even if your appetite and interest in food have been reduced. Your dietitian will be able to advise you on ways to eat well and can help with any problems you may have.

Our booklet on adjusting to life after cancer gives useful advice on how to keep healthy and deal with these changes.

Smoking and alcohol

If you are a smoker, it's important to try to give up. Smoking is the main cause of head and neck cancers and continuing to smoke puts you at greater risk of developing a second cancer. It may also significantly reduce the effectiveness of your current treatment, worsen the side effects and increase the risk of your cancer coming back. Giving up smoking can be very difficult, especially at times of stress.

Cutting back on alcohol can also help. If you can't stop drinking alcohol completely, it's best to avoid spirits if you can.

If your head and neck cancer comes back

For many people with head and neck cancer, their cancer may be cured. However, for some people the cancer will come back some time after the initial treatment.

If this happens, your doctor will explain the treatments available and what these are likely to achieve. In some cases it may be possible to remove the cancer. Radiotherapy may be given if it has not been used before. In other situations, chemotherapy may be offered to try to control the cancer for as long as possible.

Learning that your cancer has come back can feel devastating. Our booklet on coping with advanced cancer may be helpful.

Living with and after cancer

Cancer can affect many areas of your life such as your finances, work, your emotions and relationships. Find information and advice about what the effects might be, how to deal with them and how we can help.

Emotional effects

Information on the emotions you might experience as a result of your cancer diagnosis, ways that you might manage them and other sources of support.

Relationships and communication

Advice on how to talk to other people, talking to children, relationships and sexuality.

NOTE: JASCAP has booklets on the above subjects.

Questions you might like to ask your doctor or surgeon

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. _____

Answer _____

2. _____

Answer _____

3. _____

Answer _____

4. _____

Answer _____

5. _____

Answer _____

JASCAP : We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of "JASCAP".

Note for Reader

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

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