MACMILLAN
CANCER SUPPORT

Understanding head and neck cancer

> "If there is anything you're not sure about, they want you to ask. So if you have any questions, please ask a member of staff. They're so helpful."

Jerry, diagnosed with mouth cancer

About this booklet

This booklet is about head and neck cancer. This includes cancers of the mouth and throat, as well as rarer cancers that start inside the nose, sinuses or salivary glands.

It is for anyone who has head and neck cancer. There is also information for carers, family members and friends.

The booklet explains:

- the different types of head and neck cancer
- the signs and symptoms
- treatment options
- coping with head and neck cancer treatment.

We hope it helps you deal with some of the questions or feelings you may have.

This booklet does not have information about cancer of the larynx. We have another booklet about this called **Understanding cancer of the larynx (voicebox)** – page 134.

Our booklet **Managing the late effects of head and neck cancer treatment** has more detailed information about coping with the long-term side effects of treatment (page 134).

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 140 to 150, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (pages 151 and 152).

Quotes

In this booklet, we have included quotes from people who have had head and neck cancer, which you may find helpful. These are from people who have chosen to share their story with us. Some are from Jerry, who is also on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out (page 150).

Jerry, diagnosed with mouth cancer, and his nurse Sandra

Contents

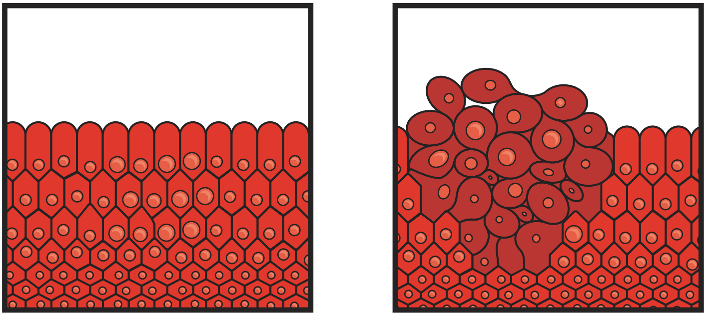
About head and neck cancer

What is cancer?

Cells are tiny building blocks that make up the body's organs and tissues. Cells receive signals from the body, telling them when to grow and when to divide to make new cells. This is how our bodies grow and heal. These cells can become old, damaged or no longer needed. When this happens, the cell gets a signal from the body to stop working and die.

Sometimes these signals can go wrong, and the cell becomes abnormal. The abnormal cell may keep dividing to make more and more abnormal cells. These can form a lump, called a tumour.

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy (pages 30 to 34). The doctors examine the sample under a microscope to look for cancer cells.

A tumour that is not cancer (a benign tumour) may grow, but it cannot spread to anywhere else in the body. It usually only causes problems if it grows and presses on nearby organs.

A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another tumour. This is called a secondary cancer or a metastasis.

Some types of cancer start from blood cells. Abnormal cells can build up in the blood, and sometimes the bone marrow. This is where blood cells are made. These types of cancer are sometimes called blood cancers.

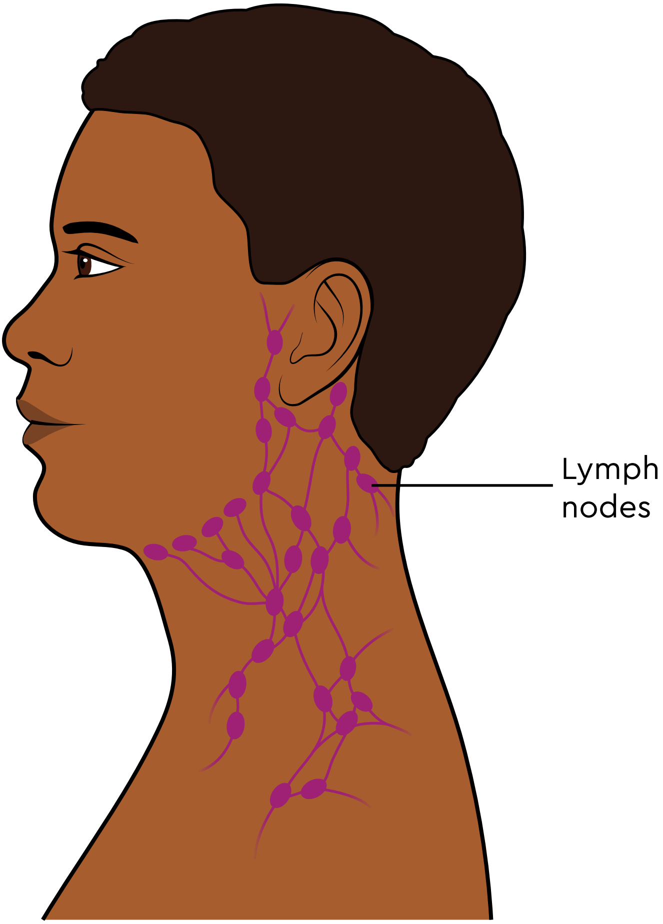
The lymphatic system

The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

Lymph nodes are sometimes called lymph glands. They filter bacteria (germs) and disease from the lymph fluid. When you have an infection, some lymph nodes may swell as they fight the infection.

The most common place for head and neck cancer to spread to is the lymph nodes in the neck. This may cause a swollen lymph node in the neck.

Lymph nodes in the head and neck



Head and neck cancer

Head and neck cancer is a general term to describe different cancers in this area. These cancers start in the tissues in the head and neck area. For example, it could start in the:

- mouth (includes the tongue, palate, gums and lips)
- throat (the pharynx)
- nose and sinuses
- salivary glands
- middle ear.

Although the larynx (voicebox) is part of the throat, it is not included here. We have separate information about cancer of the larynx in our booklet **Understanding cancer of the larynx (voicebox)** – page 134.

To make sure you have the right information, it is important to know the type of head and neck cancer you have. If you are not sure, ask your cancer doctor or specialist nurse.

Other types of cancer can start in the head and neck area, but they are not head and neck cancers. These include cancers that start in the thyroid, oesophagus (gullet), windpipe (trachea) and brain.

We have more information about these types of cancers. Visit **macmillan.org.uk/information-and-support**

Types of head and neck cancer

Head and neck cancers are named after where they start – the area of the head or neck, and the type of cell.

Mouth cancer (oral cancer)

This is one of the most common areas for head and neck cancer to start. Mouth cancer often starts on the:

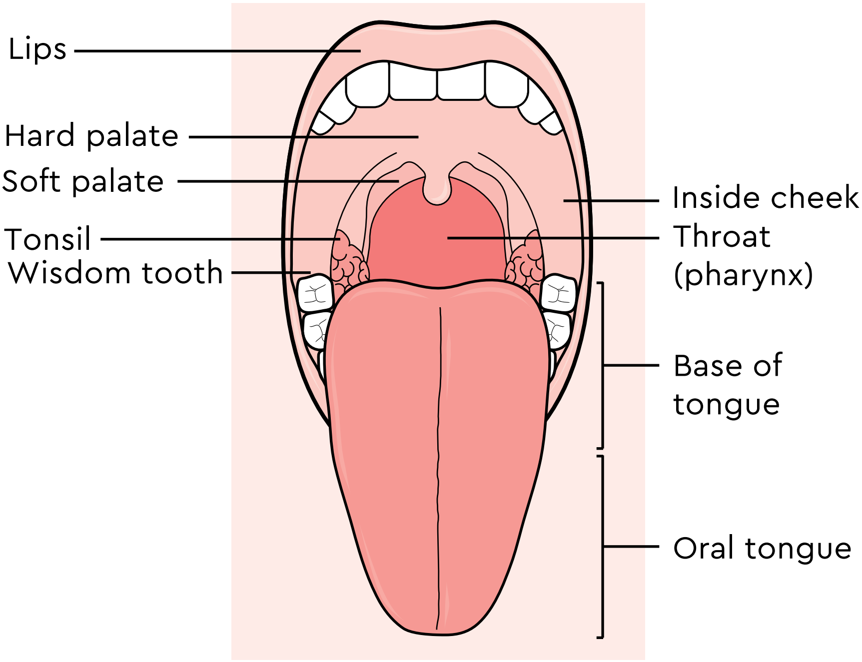
- tongue (front two-thirds), especially the side of the tongue
- floor of the mouth (under the tongue).

> **“I went to the doctor with a small lump in my mouth and he sent me for further tests at the hospital. The results came back within 2 weeks. It was mouth cancer.”**
>
> Jerry, diagnosed with mouth cancer

It can also start on the:

- lip
- inside of the cheek
- roof of the mouth (the hard palate)
- area behind the wisdom teeth
- gum.

The mouth



Cancers of the throat (pharynx)

These cancers start in different parts of the pharynx. The pharynx allows you to swallow, breathe and speak. It is divided into 3 main parts, and the cancer is named after the part it started in.

Nasopharyngeal cancer

These cancers start in the upper pharynx area, behind the nose. This area is called the **nasopharynx**. The nasopharynx allows air to flow from the nose, through the rest of the pharynx, larynx and trachea (windpipe) and into the lungs.

Oropharyngeal cancer

These cancers start in the middle pharynx, in the area behind the mouth. This is area is called the **oropharynx**. The oropharynx is a passageway for air and the food you swallow. It has muscles that help move food from the mouth to the gullet (oesophagus).

This oropharynx area includes the:

- soft part of the roof of the mouth (soft palate)
- base or the back of the tongue (the part you cannot see)
- tonsils and the side walls of the throat.

Oropharyngeal cancers usually develop on the tonsils or the base of the tongue.

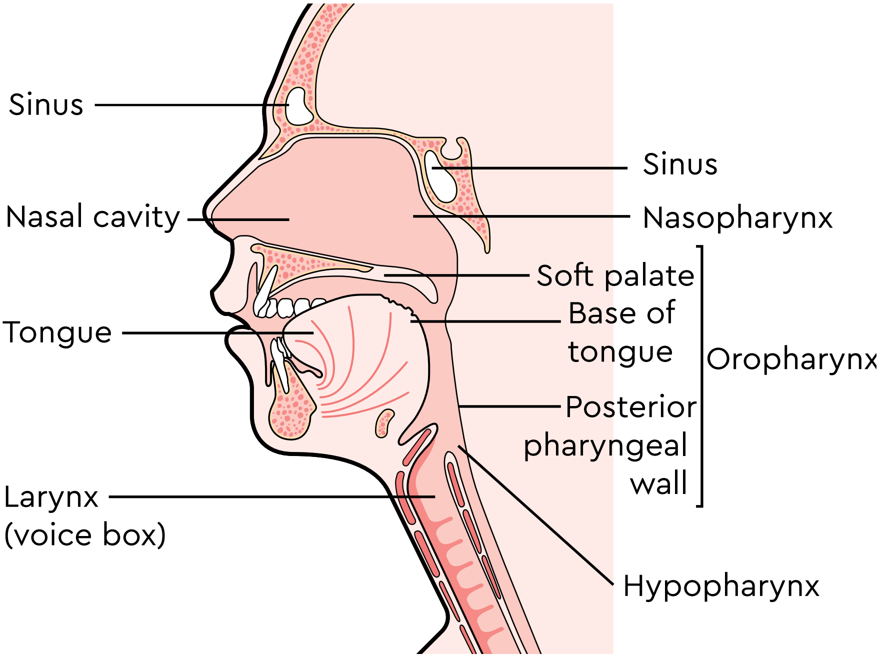
We have more information about cancers of the nasopharynx and oropharynx.
Visit **macmillan.org.uk/information-and-support**

Hypopharyngeal cancer

These cancers start in the lower part of the pharynx, behind the voicebox (larynx). This area is called the **hypopharynx**.

It has muscles that move food into the gullet (oesophagus), which it connects to. Air passes along the hypopharynx into the airways to the lung.

Cross-section of the head and neck



Cancer of the larynx (voicebox)

The larynx is the voicebox. It is a short passageway in front of the hypopharynx (lower pharynx). It contains the vocal cords. We have separate information about cancer of the larynx and how it is treated in our booklet **Understanding cancer of the larynx (voicebox)** – page 134.

Rarer cancers of the head and neck

Head and neck cancers can also start in the sinuses, the nose, the salivary glands or in the middle ear. But these are less common.

Cancer of the sinuses (paranasal sinuses)

The sinuses are small, air-filled spaces in the bones of the face, next to the cheekbone and nose. They are sometimes called paranasal sinuses because they are around or near to the nose. These sinuses affect the sound and tone of your voice.

Cancers can develop in the lining of these sinuses.

Cancer of the salivary glands

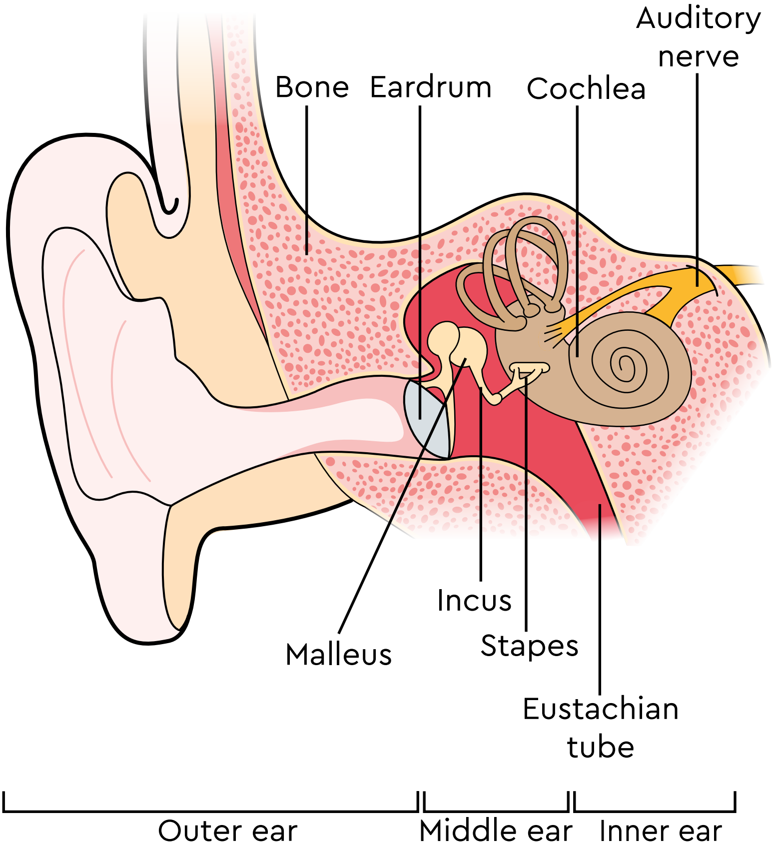
The salivary glands make saliva (spit), which keeps the mouth moist. The biggest pairs of salivary glands are the:

- parotid glands at the sides of the mouth, just in front of the ears – this is the most common place for salivary gland cancer to develop
- submandibular glands, under each side of the jawbone
- sublingual glands, under the floor of the mouth and below either side of the tongue.

Cancer of the middle ear

Rarely, cancer can develop in the middle ear. The middle ear is made up of the eardrum and a cavity called the tympanum. The tympanum contains 3 small bones – the malleus, incus and stapes. These bones connect the eardrum to the inner ear. The tympanum is connected to the nasopharynx by a tube called the eustachian tube.

The ear



Head and neck cancer and cell type

Head and neck cancers are also described based on the type of cell the cancer started in.

Squamous cell carcinoma (SCC)

The most common type of head and neck cancer is squamous cell carcinoma. About 9 out of 10 head and neck cancers (90%) start in squamous cells. Squamous cells line the surfaces inside the head and neck, such as the mouth, nose and throat.

Other cell types

A small number of head and neck cancers develop from other types of cells. These include:

- lymphomas, which develop from white blood cells called lymphocytes
- adenocarcinomas, which develop from cells that line the glands in the body
- sarcomas, which develop from the cells that make up muscles, cartilage, bone or blood vessels.

We have more information about these cancers on our website. Visit **macmillan.org.uk/information-and-support**

Risk factors and causes of head and neck cancer

About 12,200 people are diagnosed with head and neck cancer in the UK every year. This includes cancer of the larynx (voicebox). Head and neck cancer is much more common in men. In the UK, it is the 4th most common cancer in men.

Doctors do not know the exact causes of head and neck cancer. But certain things called risk factors can increase the chances of developing it. Having one or more risk factors does not mean you will get a head and neck cancer.

The main risk factors for head and neck cancer are tobacco and alcohol. About 3 out of 4 head and neck cancers (75%) are thought to be linked to tobacco or alcohol use.

Certain risk factors depend on the type of head and neck cancer you have. Many cancers of the oropharynx are linked to an infection with a virus called human papillomavirus (HPV).

Smoking cigarettes, cigars or pipes

Smoking tobacco increases the risk of developing many types of head and neck cancer. This includes mouth cancer, throat cancer and cancer of the voicebox (larynx). The more cigarettes someone smokes, and the more years they smoke for, the higher the risk.

Holding a pipe or cigarette on your lip when smoking also increases your risk of developing lip cancer.

Chewing tobacco or betel quid (paan)

Chewing tobacco or betel quid also increases the risk of developing mouth cancer. There are different names for tobaccos that are combined with other chewing products. Betel quid (paan) is one of these. The risk of mouth cancer is higher even if the betel quid does not contain tobacco.

Drinking alcohol

Drinking alcohol is linked to cancers of the mouth and throat. The more alcohol a person drinks, and the more years they drink for, the higher the risk.

Drinking and smoking together greatly increases the risk of head and neck cancer. People who smoke and drink heavily over several years have the highest risk of a developing head and neck cancer.

Sex

Head and neck cancer is much more common in men than in women. In the UK, it is the 4th most common cancer in men. In women, it is the 13th most common cancer.

Age

Like all cancers, the risk of head and neck cancer increases as you get older. It is most common in people aged over 70. It is more likely to develop in people aged over 50, but it can affect younger people from their 30s onwards.

Human papilloma virus (HPV) infection

Cancer of the oropharynx (back of the tongue and tonsils) has become more common over the last 20 years. This is linked to HPV.

HPV can affect areas such as the genitals, inside the mouth and the throat. Most people have it at some point, and usually it does not cause any harm. HPV is spread through any sexual contact, including direct skin-to-skin genital contact, as well as the mouth and throat.

It is not always possible to link the virus to sexual contact. There may be other ways of spreading the virus that have not yet been identified.

There are many types of HPV. Only certain types increase the risk of developing cancer. Most people affected by high-risk HPV will not develop cancer. Usually the body's immune system gets rid of the virus naturally. We do not know exactly why some people go on to develop cancer.

Children in the UK are now offered the HPV vaccination. This is expected to reduce the number of head and neck cancers linked with this virus.

We have more information about HPV and cancer.
Visit **macmillan.org.uk/hpv**

Epstein-Barr virus (EBV) infection

Nasopharyngeal cancer is linked to a virus called the Epstein-Barr virus. This virus causes glandular fever. Only a very small number of people who have had glandular fever develop nasopharyngeal cancer.

Low immunity

Some people with reduced immunity have an increased risk of developing a head and neck cancer. Your immunity may be low if you:

- are taking medication to suppress your immune system after an organ transplant
- have a condition such as HIV (human immunodeficiency virus), or aids.

Sunlight

Long-term exposure to ultraviolet light from sunlight, including sun beds or sunlamps, increases the risk of cancer on the outer lip.

Occupational exposure

Long-term exposure to some types of dust and certain chemicals at work increases the risk of developing cancers of the nasopharynx and sinuses. These are:

- hardwood dust
- formaldehyde (found in leather and some types of furniture dust)
- polycyclic aromatic hydrocarbons (PAHs) – chemicals that occur naturally in coal, crude oil, and gasoline.

Pre-cancerous conditions

Pre-cancerous conditions of the mouth increase the risk of developing mouth cancer. These include having white patches (leukoplakia) or red patches (erythroplakia) in the mouth that do not go away. They are usually linked to tobacco use. Although erythroplakia is less common, it has a higher risk of developing into mouth cancer.

Oral health

The risk of developing mouth cancer is higher in people with poor oral health. Having several teeth missing, bleeding gums and gum disease may increase the risk. This can be made worse by not visiting the dentist regularly, so problems are not noticed early enough.

Dentures that do not fit properly may also increase the risk of mouth cancer.

Diet

A diet that is high in salted fish is a risk factor for nasopharyngeal cancer. Some studies show that a diet high in fruit and vegetables may help to protect against some head and neck cancers.

Symptoms of head and neck cancer

The symptoms depend on the type of head and neck cancer and the area where it started.

All the symptoms we mention here can be caused by conditions other than cancer. But it is important to get them checked by your GP or dentist, especially if they do not go away, or if they get worse.

Urgent referral symptoms

If you have certain symptoms, your dentist or GP should refer you to see a specialist within 2 weeks. This is called an urgent referral.

These symptoms include:

- an ulcer anywhere in the mouth area (including the tongue) lasting for more than 3 weeks
- a red patch (erythroplakia) or red and white patch (erythroleukoplakia) anywhere inside the mouth
- a white patch on its own (leukoplakia) anywhere inside the mouth
- a lump in the neck that does not go away
- a lump on the lip or anywhere inside the mouth that does not go away
- a sore tongue that is not getting better
- throat pain, persistent hoarseness and difficulty swallowing that is not improving.

Other symptoms

There are other symptoms that you should get checked by your doctor. These may include one or more of the following.

Pain or bleeding

Pain or bleeding could include:

- discomfort or pain, usually in the mouth
- bleeding in the mouth or nosebleeds
- a sore throat or earache that does not get better
- pain in the cheek or any part of your face
- pain behind the nose or in the upper teeth.

Swelling

You may have swelling:

- in the upper neck, caused by a swollen lymph node
- in front of or behind the ear, or under the jawbone
- in the cheek
- around the eyes.

Breathing problems

You might notice that you:

- have a blocked nose on one side that does not clear
- are breathing more loudly than usual.

Bad breath (halitosis)

If you have bad breath that does not improve with better oral hygiene, speak to your doctor.

Changes to eating, speaking and hearing

These changes could be

- difficulty or pain with chewing, swallowing or speaking
- loose teeth for no obvious reason, or dentures that do not fit well any more
- changes in your speech
- numbness of the cheek, upper lip, upper teeth or side of the nose
- drooping on one side of the face or difficulty opening your mouth
- changes in your hearing.

Losing weight

If you are losing weight for no obvious reason, speak to your doctor.

Lumps in the neck

If a cancer in the mouth or throat spreads from where it started, the first place it usually spreads to is the lymph nodes in the neck. This might cause a painless lump in the neck.

Swollen lymph nodes are more likely to be caused by an infection than cancer. If a lump on your neck does not go away after 2 to 3 weeks, your GP should refer you to a specialist doctor.

Or, they may refer you to a one-stop neck lump clinic, where they can do all the tests to diagnose the cause of your symptoms.

> **"I found a lump on the inside of my right cheek, but I didn't think anything of it. However, a few months later I noticed that the lump was still there, so my mum told me to go and see my doctor."**
>
> Rachel, diagnosed with mouth cancer


CAFE

Diagnosing head and neck cancer

How head and neck cancer is diagnosed

You usually start by seeing your GP or dentist. If they think your symptoms could be linked to cancer, they refer you straight away to see a specialist doctor. You will usually see a specialist within 2 weeks. This is usually an oral and maxillofacial surgeon, or an ear, nose and throat (ENT) specialist surgeon.

If your only symptom is a lump in your neck, you may be referred to a hospital that has a neck lump clinic.

Neck lump clinic

This is a one-stop clinic. You can have all the tests needed to check for cancer in a neck lump.

You usually have an ultrasound scan. A sample of tissue is also taken from the lump using a fine needle aspiration or needle (core) biopsy. You may also have a test called a nasendoscopy, to look at the back of your mouth, nose and throat.

They may give you the results of your tests on the same day. But you may need to wait up to 7 to 10 days.

At the hospital

The specialist doctor will ask you about your symptoms, as well as any health conditions or recent illnesses. They will ask if you have any changes in your voice, swallowing, breathing, appetite or weight. They carefully examine your mouth, throat and neck. You also usually have blood tests, to check your general health.

If you have an abnormal-looking area that can be seen and is easy to reach, you usually have a biopsy first. A biopsy is when your doctor removes a small piece of tissue or some cells from the area, so it can be checked for cancer cells. A doctor who specialises in analysing cells (pathologist) looks at the sample under the microscope. They check the sample for any cancer cells.

Your doctor and specialist nurse will explain the tests you need. You may have a biopsy taken on its own or during some of these tests.

Ultrasound scan of the neck

If you have a lump or swelling in your neck you usually have an ultrasound scan. It uses sound waves to produce a picture of your neck and lymph nodes on a screen (page 9).

The scan is painless and only takes a few minutes. The person doing the scan puts some gel onto your neck and moves a small device (ultrasound probe) over the area. The probe produces the sound waves that build up a picture.

The person doing the scan looks for any changes in the size or appearance of the lymph nodes in your neck. During the scan, they may use a fine needle to remove some cells from the lump into the syringe. This is called a fine needle aspiration biopsy.

Endoscope examination

An endoscope is a long, thin, flexible tube with a light and camera on the end. Images from the camera are shown on a screen. Different types of endoscopy may be used to look at the mouth, nose and throat. You can have this test in the outpatient clinic.

Before the test, your doctor may spray your nose and throat with an anaesthetic to numb the area.

After the test, you should not eat or drink anything for about 1 to 2 hours, until the anaesthetic spray wears off. This is to make sure you do not burn your mouth or throat. It also prevents a drink going down the wrong way into your lungs when you swallow.

Nasendoscopy

A nasendoscope allows your doctor to look inside your nose, the back of your nose and your throat. Some people prefer not to have the anaesthetic spray for this test.

The doctor gently passes the nasendoscope into your nose, over the back of your tongue and down into your upper throat. You might find this stage a bit uncomfortable, but it only takes about a minute. This test itself only takes a few minutes. If you are also having a biopsy, it could take longer.

Endoscope examination under general anaesthetic

Your doctor may suggest you have a general anaesthetic so they can look at an area more closely using a larger endoscope. This test is sometimes called a panendoscopy.

You may have this test if your doctor could not see the area clearly, or saw something unusual during a nasendoscopy.

During the examination, the doctor can take biopsy samples from any abnormal looking areas. You can usually have this test in a day surgery unit. Most people can go home on the same day.

Trans-nasal oesophagoscopy

If you are not able to have a general anaesthetic, you may have this test. It allows the doctor to look at your nose, throat, voicebox and gullet (oesophagus). It is sometimes called a trans-nasal flexible laryngo-oesophagoscopy (TNFLO).

You will be asked not to eat or drink for a few hours before the test. The doctor gently passes the endoscope into your nose, to the back of your throat and into your gullet. This sounds uncomfortable, but most people cope well with it. It does not usually cause problems with gagging. You usually have a biopsy taken during this test.

Other types of biopsy

There are different ways of taking a biopsy from the head and neck area. You usually have the following tests in an outpatient clinic.

Fine needle aspiration (FNA)

You may have this test to check a neck lump, or to take cells from the mouth or throat. The doctor passes a fine needle into the lump. They withdraw (aspirate) some cells into the syringe. Sometimes they use an ultrasound scan to help them guide the needle into the area.

Needle (core) biopsy

Your doctor injects some local anaesthetic into the area to numb it. Then they use a special needle to take small pieces of tissue from the lump or abnormal area. You may feel uncomfortable and have a feeling of pressure for a short time during the biopsy.

Incision biopsy

Your doctor numbs the area with an injection of local anaesthetic. They take a thin slice of tissue using a sharp knife (scalpel). You may need some stitches after this test, depending on the amount of tissue that was removed.

After the biopsy

If the biopsy is taken from inside your mouth or throat, it will take a few days for the tissue to heal. During this time, you may be asked to avoid hot food and hot fluids, or only eat soft foods.

It is common to have some bruising or soreness in the area the sample was taken from. The soreness may last for a week or so. Taking mild painkillers should help. Ask your nurse or doctor what they recommend.

> "I went to the hospital with my mum. I was called in to see the registrar who said that I would need an emergency biopsy 4 days later. I would then receive my results within 2 weeks. „

Rachel, diagnosed with mouth cancer

Further tests

If the biopsy result shows there is a cancer, you will have further tests to find out how far the cancer has grown (its stage).

It may take 2 to 3 weeks before you get all the results. Your test results help you and your doctor decide on the best treatment for you. You may have some of these tests again to check how well treatment is working.

X-rays

You may have x-rays of your face or neck to:

- see if any bones are affected by the cancer
- check your teeth.

You may have a chest x-ray to check your general health and to see if there is anything abnormal in the lungs.

CT scan

A CT scan makes a detailed picture of the inside of the body. The picture is built up using x-rays taken by the CT scanner. The scan uses radiation, but this is very unlikely to harm you. It will not harm anyone you come into contact with.

You have the scan at a hospital. You will get an appointment letter explaining whether you need to do anything before the scan. You should tell the person doing the scan if you are pregnant or think you could be.

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes.

It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

The scan is painless. It usually takes 5 to 10 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

We have more information about having a CT scan at **macmillan.org.uk/ct-scan**

Having a CT scan

MRI scan

An MRI scan uses magnetism to build up a detailed picture of areas of the body.

The scanner is a powerful magnet. You will be asked to complete and sign a checklist to make sure it is safe for you. This will check whether you have any metal implants, such as a pacemaker or surgical clips. Tell your doctor if you have ever worked with metal. This is because tiny bits of metal can sometimes lodge in the body.

You have the scan in the x-ray department of a hospital. The person who does the scan is called a radiographer. They may give you an injection of a dye called a contrast. This helps show certain areas of the body more clearly.

During the scan, you need to lie still on a bed inside a long cylinder (tube). If you worry about being in small spaces (are claustrophobic), you may be able to have a sedative to help you relax. Talk to your GP or cancer doctor about this before the scan.

The scan usually lasts between 15 minutes and 1 hour. It is painless, but you may find it uncomfortable to lie still for that long.

PET-CT scan

If your doctor thinks a cancer in the lymph nodes may have started in the head and neck, you usually have a PET-CT scan first. This is done before a biopsy. A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body.

You may have a PET scan and a CT scan together. This is called a PET-CT scan. It can give more detailed information about cancer or abnormal areas seen on other scans.

If you are pregnant or breastfeeding, call the scanning department before the scan for advice.

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer. The radiographer will encourage you to drink water. This helps move the tracer around your body. Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

The scan takes about 30 to 60 minutes. The scanner looks like a large, thick ring. You lie still on a narrow bed which moves slowly backwards and forwards through the ring.

The amount of radiation used is very small. But the radiographer will advise you not to have close contact with pregnant people, babies and young children for up to 24 hours after the scan.

We have more information about MRI, PET and PET-CT scans. Visit **macmillan.org.uk/tests-scans**

Testing for viruses

If you have cancer in the oropharynx, tests are done on the cancer cells to check if the cancer is linked to the human papilloma virus (HPV) – page 21. Your doctor will explain more about this. The results help your doctor plan the most effective treatments for you. HPV-related head and neck cancers usually have a good outlook.

If you have nasopharyngeal cancer, the cancer cells are tested to see if it is linked to the Epstein-Barr virus (EBV) – page 22.

Staging

The stage of a cancer describes its size and whether it has spread from where it started. Knowing the stage helps doctors advise you on the best treatment for you.

Staging is slightly different for each type of head and neck cancer. Oropharyngeal cancers that are HPV-positive have a separate staging system.

Your doctor or nurse can tell you more about the stage of the cancer. The most used staging systems for head and neck cancer are the TNM and number staging systems.

TNM staging system

TNM stands for tumour, node and metastases.

T describes the size of the tumour, how far it has grown and sometimes the depth of the tumour. It is numbered between 0 to 4.

- T0 means that there are no signs of a tumour, but there may be abnormal cells that are pre-cancerous.
- T1 and T2 means the tumour is small and has not started to spread.
- T3 tumours are bigger, or may have started to spread into nearby tissue.
- T4 is when a tumour has spread into nearby muscles, bones or skin.

N describes whether the cancer has spread to the lymph nodes.

- N0 means that no lymph nodes are affected.
- N1, N2 or N3 means there are cancer cells in the lymph nodes. The number depends on how many lymph nodes contain cancer cells, the size and where they are in the body.

M describes whether the cancer has spread to another part of the body. This is called metastatic cancer.

- M0 means the cancer has not spread.
- M1 means the cancer has spread to distant organs, such as the liver or lungs.

Number staging system

This system combines all the information from the TNM staging system and gives it a number from 1 to 4.

Stage 0

This is sometimes called carcinoma in situ or precancerous. There are abnormal cells in the lining of the affected area, but they are contained (in situ) and have not spread. If not treated, they are very likely to become cancerous.

Stage 1 and stage 2

This describes cancers at an early stage that are usually small and have not spread. Your doctor may call this early or localised cancer.

Stage 3 and stage 4

This describes bigger cancers that have spread further into nearby lymph nodes, surrounding tissue or both. Doctors sometimes call this locally advanced cancer.

Some stage 4 cancers may have spread to other parts of the body, such as the lungs or liver. This is called metastatic or secondary cancer. But it is more common for head and neck cancer to only spread in the area where it started.

Other terms used

Your doctor may use other terms to describe the stage of the cancer:

- **Early** or **localised** – a small cancer that has not spread.
- **Locally advanced** – cancer that has started to spread into surrounding tissues or nearby lymph nodes, or both.
- **Local recurrence** – cancer that has come back in the same area after treatment.
- **Secondary**, **advanced**, **widespread** or **metastatic** – cancer that has spread to other parts of the body.

Grading

The grade of a cancer gives the doctors an idea of how quickly it may develop. Doctors will look at a sample of the cancer cells under a microscope to find the grade of the cancer.

Grade 1 or **low grade** – the cancer cells look like normal cells and usually grow slowly.

Grade 2 and **3** – the cancer cells look different to normal cells and are slightly faster growing.

Grade 4 or **high grade** – the cancer cells look very different to normal cells and may grow more quickly.

Treating head and neck cancer

Treatment overview

Because head and neck cancer is not common, you are usually treated in a specialist head and neck unit by a team of specialists.

The aim of treatment is usually to remove or destroy all of the cancer and reduce the chances of it coming back.

The treatment you are offered depends on:

- where the cancer is in your head or neck (pages 12 to 17)
- the stage of the cancer (pages 40 to 42)
- the best way to maintain appearance, speech and swallowing
- your general health
- your preferences.

Your doctor and nurse will explain the benefits and disadvantages of different treatments. You and your doctor can then decide on the best treatment for you.

Doctors plan your treatment so the effect on your appearance, speech, swallowing and eating is as little as possible. If treatment is likely to affect any of these, your doctor and nurse will talk to you about this. They will explain how long this is likely to last and how they can support you.

You may see different specialists such as a dentist, speech or language therapist (SLT), or dietitian during treatment.

Treating early-stage cancer

Small cancers that have not spread to nearby tissue or lymph nodes can usually be treated with either surgery or radiotherapy (pages 64 to 77).

Small cancers in the mouth are often removed with surgery. If the operation causes any small changes to speech, chewing or swallowing, you can usually adapt to these quickly.

Your doctors may suggest radiotherapy instead of surgery if:

- the cancer is in an area that is difficult to reach
- an operation to remove the cancer may cause major changes to appearance, speech or swallowing.

Treating locally advanced cancer

If a head and neck cancer is bigger, or has spread to lymph nodes in the neck, you usually need more than one type of treatment.

Chemotherapy and radiotherapy are often used together. This is called chemoradiation. It may be your main treatment.

Some people have chemoradiation or radiotherapy after surgery. Chemoradiation causes more side effects, so it may not be suitable for some people.

You may have surgery to remove the cancer. You may also have lymph nodes in the neck removed, even if they do not seem enlarged. This is usually when the cancer is bigger, or if there are signs the cancer may have spread there.

Some people may need reconstructive surgery. This may be when an operation involves removing tissue used for speech or swallowing, or if the cancer is in the jawbone. The aim is to cause as little change as possible to the way the head and neck looks and works. The surgeon uses tissue, muscle or bone from another part of the body to replace what has been removed.

Chemotherapy on its own may be used to shrink a cancer before radiotherapy or surgery. It can also be used to try to control the cancer and improve symptoms.

A targeted therapy drug called cetuximab is sometimes given with radiotherapy if you cannot have chemoradiation. It may sometimes be given with chemotherapy to treat mouth cancer.

Some targeted drugs called immunotherapies may be given on their own if the cancer is advanced, or if it comes back after treatment (pages 106 to 107).

Treatment to control the cancer

If the cancer cannot be cured, you may be given treatment to control the cancer for as long as possible, and to manage the symptoms. You will usually have chemotherapy or targeted therapy, and an immunotherapy drug.

Your doctor and specialist nurse will help to make sure your symptoms are controlled. This is called supportive or palliative care. You may see a specialist palliative care doctor or nurse for expert help with your symptoms.

How your treatment is planned

A team of specialists meet to talk about the best treatment for you. This team is called a multidisciplinary team (MDT). It includes the following healthcare professionals:

- **Ear, nose and throat (ENT) surgeon** – a specialist in treating conditions of the ear, nose, throat and neck. They may also be called an otolaryngologist.
- **Oral and maxillofacial surgeon** – a doctor who does operations (surgery) on the mouth, jaw, face and neck.
- **Plastic and reconstructive surgeon** – a surgeon skilled in rebuilding tissue in the head and neck.
- **Oncologist** – a doctor who treats people who have cancer.
- **Radiologist** – a doctor who looks at scans and x-rays to diagnose problems.
- **Pathologist** – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- **Clinical nurse specialist (CNS)** – a nurse who gives information about cancer, and support during treatment.
- **Speech and language therapist (SLT)** – a therapist who specialises in helping with communication and swallowing problems.
- **Dietitian** – someone who gives information and advice about food and food supplements.

The MDT often includes other healthcare professionals, such as:

- **dentist** – an expert in treating problems or conditions that affect the teeth and gums
- **oral hygienist** – someone trained to clean your teeth and show you how to care for your teeth and gums to prevent gum disease
- **restorative dentist** – a dentist who specialises in making sure your teeth look and work as normally as possible
- **physiotherapist** – someone who gives advice about exercise and mobility, and can help with any neck and shoulder problems
- **occupational therapist (OT)** – someone who gives information, support and aids to help people with tasks such as washing and dressing
- **psychologist or counsellor** – someone who is trained to listen to people's problems and gives advice about managing feelings and behaviours.

> **"When I heard the word 'cancer' I wasn't totally surprised. 3 days later I was in hospital being prepared for the operation. I had a feeding tube fitted, pre-op assessments, and met my dietitian and cancer nurse."**
>
> Elise, diagnosed with cancer of the jaw

Talking about your treatment plan

After the MDT meeting, you will usually see your specialist doctor and nurse. They will talk to you about your treatment plan. It can help to write down your questions before you see them. You may want to ask a family member or friend to come with you. They can help remember what is said and talk with you about it afterwards. You need to know as much as possible before you can make any treatment decisions. Your specialist doctor should explain:

- the aim of the treatment – whether it is to cure the cancer or control it
- the benefits of the treatment
- the disadvantages of the treatment – for example, the risks and side effects
- any other treatments that may be available
- what may happen if you do not have the treatment.

Cancer treatments can be complex. It can also be hard to concentrate on what you are being told if you are feeling anxious. If the doctor says something you do not understand, ask them to explain it again.

Most people worry about the side effects of treatment. Your doctor or nurse will explain how side effects can be controlled and what you can do to manage them. They can also tell you if your treatment is likely to cause any late effects and how these can be managed.

You may need more than one meeting with your doctor or nurse to talk about your treatment plan.

> "The consultant asked if I had any questions. I had recently had my nose pierced and I really didn't want to remove it, so I asked, 'Can I keep this in?' The answer was no. „

Rachel, diagnosed with mouth cancer

Making treatment decisions

You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you. You can decide how involved you want to be in your treatment plan.

Sometimes doctors need to review a treatment plan. This may be when more information about the cancer becomes available – for example, when the doctor knows the results of surgery to remove the cancer. It may mean making more decisions with your doctor.

Choosing between treatments

Doctors sometimes ask you to choose between different treatments. This is usually when two treatments work equally well.

It can help to talk to your family or friends about your treatment options. Your doctor or nurse can help you with your decision. You do not usually need to decide straight away.

You could write a list of benefits and disadvantages for each treatment.

We have more information about making treatment decisions. Visit **macmillan.org.uk/making-treatment-decisions**

Decisions about advanced cancer

For advanced cancer, the aim of treatment is to control the cancer, help you live for longer and improve symptoms. You may need to have a treatment for a while to see if it is helping. Doctors will try to avoid you having unnecessary side effects from a treatment that is not working well.

If it becomes difficult to control the cancer, you may decide not to have further treatment. Your doctor and nurse will support you and make sure your symptoms are managed.

We have more information on coping with advanced cancer at **macmillan.org.uk/advanced-cancer**

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (page 51).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to you specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion. Visit **macmillan.org.uk/second-opinion**

Preparing for treatment

Your doctor and nurse will talk to you about preparing for treatment. For example, this can involve having dental checks, eating well, or doing certain exercises to help reduce side effects. Improving your general health and getting ready mentally can also help with your recovery. This is sometimes called prehabilitation.

You will usually see other health professionals, including a:

- dentist
- dietitian
- speech and language therapist (SLT)
- physiotherapist.

They may recommend some dental treatment, or give you advice on your diet. You may need to be fed through a tube to gain weight or keep your weight stable. A dietitian will talk to you about this.

An SLT may talk to you about any effects that treatment may have on your speech or swallowing. If you smoke or drink alcohol, your head and neck team can give you advice on stopping.

Dental care

It is important to have a check-up and any dental care you need before treatment. This avoids problems later. You may be referred to a specialist dentist with experience in treating people with head and neck cancers. Or you may see your own dentist.

If any of your teeth are unhealthy, you usually have these removed. You may see an oral hygienist for advice on looking after your teeth and gums.

It is important to know how to look after your mouth and prevent problems. Cancer treatments, especially radiotherapy, may mean you are more likely to get mouth infections. After radiotherapy to the mouth area and salivary glands, you are more likely to get tooth decay. You need to continue looking after your mouth and teeth after treatment. You also need to visit the dentist regularly.

Eating, speech and voice problems

Before treatment you may see a dietitian and an SLT. They assess your weight and diet, and any problems with swallowing and speaking. They also explain how treatments may affect these things and what can help. You may have tests to assess your swallowing, speech and voice. Your SLT will continue to assess you during and after treatment. You may be given exercises to do.

Exercises

Your SLT may give you exercises before radiotherapy for your tongue, jaw, throat and larynx. These help you to swallow and open your mouth, which helps keep your weight up during treatment. Jaw exercises help reduce the risk of problems opening your mouth (trismus) after radiotherapy or surgery. You need to start these exercises early, and continue to do them long term.

Maintaining your weight

Before your treatment starts, it is important to eat as well as possible. Your dietitian may advise using food supplements and following a building-up diet to increase your weight. Radiotherapy, especially with chemotherapy (chemoradiation), causes difficulty swallowing and leads to weight loss. Putting on weight before treatment can slow this down and help you cope better with treatment. Our booklet **The building-up diet** has more information (page 134).

Feeding through a tube

Your treatment may make it difficult for you to eat enough by mouth. To make sure you get enough calories to keep up or gain weight, your doctor may suggest being fed through a tube for a while. You can be fed by a tube in different ways:

- **Nasogastric (NG) feeding** – a thin tube is passed up your nose and down into your stomach. It is usually only used for a few weeks.
- **Gastrostomy feeding** – a tube is passed directly into your stomach. This is called a percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) tube. You usually have this if tube feeding is needed for a longer time. It can be kept in place for several months if necessary.

When your swallowing improves and you can eat more through your mouth, the tube can be removed. You are taught how to use it and look after the tube safely. Family or friends can also be shown how to do this. Sometimes district nurses may set up the feeds for you at home. We have more information about nutritional support and artificial feeding at **macmillan.org.uk/tube-feeding**

Gastrostomy feeding

Exercise to get fitter

Being as fit as possible before treatment may help you cope better with the side effects of treatment. It may also help reduce the risk of complications after surgery. You can improve your fitness in a few weeks by doing regular exercise. You may be asked to do exercises that improve your heart health and make your muscles stronger.

You may need to do other exercises to reduce the effects of treatment on swallowing. If you are having surgery to remove the lymph nodes in your neck, a physiotherapist will give you exercises to reduce the side effects of this operation.

Smoking

If you smoke, stopping will:

- increase the chances of your treatment being effective
- mean you are likely to get fewer side effects, and that they are less severe
- reduce the risk of cancer coming back after treatment
- reduce the risk of getting another head or neck cancer or other smoking-related cancer.

Stopping smoking before surgery

It is best to try and stop smoking as soon as you can. If possible you should stop several weeks before surgery (page 64). Even stopping 2 to 3 weeks before surgery, and not smoking afterwards, reduces your risk of complications. Stopping smoking before surgery makes it more likely that:

- your wounds heal more quickly
- you have a shorter stay in hospital
- you recover more quickly.

Stopping smoking before radiotherapy

Stopping smoking increases the chances of radiotherapy and chemoradiation working better (pages 78 to 93). It also means side effects, such as sore mouth or difficulty swallowing, are likely to be less severe.

Support with stopping smoking

It can be difficult to stop smoking, especially when you are stressed. Your hospital will usually have a service to support you. Using the NHS Stop Smoking Services improves your chances of success. Your GP can also give you support and advice. They can provide nicotine replacement therapies on prescription. We have more information about stopping smoking at **macmillan.org.uk/stop-smoking**

Alcohol

If you drink alcohol, stopping drinking will help reduce the risk of side effects. It also reduces the risk of developing another head and neck cancer.

If you want support to reduce how much alcohol you drink, your nurse or doctor can arrange this for you.

Questions to ask about your treatment

Knowing more about what to expect can help you prepare for treatment. It might help to make a list of the questions you want to ask your doctor, nurse, SLT or dietitian. For example, you might want to ask about these things.

Eating and drinking

- Will the treatment make it hard for me to swallow?
- If my mouth is sore, how will I eat and drink?

Mouth care

- How can I look after my mouth during treatment?
- If my mouth is sore, what will help?

Controlling pain

- Am I likely to have pain?
- What can help reduce any pain?
- Who can help me manage my pain?

Communicating

- How might treatment affect my speech and hearing?
- Who will help me with any changes to my voice or speech?

My appearance

- Will the treatment affect how I look?
- Who can help me cope with any difficult feelings?
- Are there any support groups that may help?

After treatment

- How long will the side effects last and what might help?
- Who do I contact if I have problems after my treatment has finished?

Surgery

Surgery is one of the main treatments for head and neck cancer. The aim is to remove the cancer completely. You may have surgery:

- to completely remove the tumour and any tissue it has spread to
- to remove lymph nodes in the neck (pages 66 to 68).

If the cancer or lymph nodes have been removed, tissue may be taken from another part of the body to replace tissue that was taken away. This is called reconstructive surgery.

Some people have treatment with chemoradiation or radiotherapy after surgery (pages 78 to 93).

Before your operation, your surgeon or nurse will explain what is involved and what to expect. For example, they will explain:

- how much tissue or bone they plan to remove
- how they plan to repair or replace any affected tissue or tissue that is removed
- the possible side effects from the operation.

Your surgeon will do everything possible to minimise changes to your speech, swallowing, breathing and appearance (pages 113 to 131). They will explain how the surgery may affect you in the short and long term.

The type of operation you have depends on the size and position of the cancer and its stage. We have more information about surgery for types of head and neck cancer (pages 12 to 18).

Before your operation

You will see different people from your head and neck team to prepare you for the operation (page 49). They will give you advice on getting ready for surgery. It is important to follow this advice. You can read more about preparing for treatment . You usually have an appointment at a pre-operative assessment clinic. Tests to check your general health may include:

- blood and urine tests
- chest x-rays
- a recording of your heart (ECG).

You go into hospital on the day of your operation or the day before. The nurses give you elastic stockings (TED stockings) to wear during and after surgery, to help prevent blood clots.

Surgery to remove the tumour

Most operations are done under a general anaesthetic. If you have a very small cancer, it might be treated with a simple operation or laser surgery. You may be able to go home the same day as the surgery. The surgeon may operate through the open mouth (transoral resection). This means you will not have any external scars, unless you are also having a neck dissection (page 66).

If the cancer is bigger, or at the back of the mouth or in the throat, the surgeon usually needs to make a cut (incision) in the skin to reach it. This means you will have a scar afterwards. This usually fades over time.

Transoral resection

This is when the surgeon removes the tumour through the open mouth (transoral) using different techniques. This type of surgery is usually used to treat small cancers in the mouth, tongue, throat or tonsils. It may help to reduce the risks of certain side effects, such as swallowing difficulties, and help you to recover faster. You will not have any external cuts or scars afterwards. You have it done under a general anaesthetic.

Transoral laser surgery (TLM)

The surgeon uses a high-powered beam of laser light to remove the cancer and a small area of healthy tissue around it. They examine the area closely using a microscope attached to the laser before removing the cancer.

Transoral robotic surgery (TORS)

The surgeon controls robotic arms attached to a fine instrument to remove the cancer through the mouth. It can allow the surgeon to do very exact surgery to remove the whole tumour.

Removing the lymph nodes in the neck

Surgery to remove the lymph nodes in one or both sides of the neck is called a neck dissection. This surgery:

- tells your doctor more about the stage of the cancer
- removes any lymph nodes that contain cancer cells
- reduces the risk of the cancer coming back (if the lymph nodes contained cancer cells).

You have tests first to see if there are signs of cancer in the lymph nodes. If the cancer is large, your doctor may advise neck dissection surgery even if your test results are negative.

> “I had a neck dissection, which removed the mass on my tongue with my neck lymph nodes, so I was in hospital for just over a week. The scar and the healing was marvellous, and the registrars and doctors were fantastic. ”

Sue, diagnosed with head and neck cancer

With bigger cancers, there may be small amounts of cancer in the lymph nodes. This may not show up on scans or in other tests.

You may have a neck dissection:

- at the same time as surgery to remove the primary cancer
- before or after chemoradiation or radiotherapy, if there are still cancer cells in the lymph nodes
- if the cancer is still present or comes back in the nodes after treatment.

After a neck dissection, the nerve responsible for moving the lower lip can sometimes be affected. This can cause some weakness on one side of the mouth which may be noticeable when you smile. It usually returns to normal after a few months.

The nerve that helps control shoulder movement may also be affected, causing shoulder stiffness. You usually see a physiotherapist who will give you exercises to help with this.

More rarely, other nerves connected to the tongue and voicebox can also be affected. Sometimes there may be a change in the shape of your neck.

Your neck may feel stiff and tight after a neck dissection, especially if you have radiotherapy afterwards. You will be given exercises to reduce the risk of neck and shoulder problems.

Your surgeon and nurse will explain more about the possible side effects of a neck dissection. We have more information about neck and shoulder problems after treatment .

Reconstructive surgery

Your operation may involve removing tissue used for speech or swallowing. It may also affect your appearance. You may have reconstructive surgery at the same time as removing the tumour. The aim is to cause as little change as possible to the way everything looks and works.

The surgeon takes tissue from another part of the body, such as the forearm, thigh or chest. They use it to replace tissue taken from the head and neck. This is called a myocutaneous flap. Myo means muscle, and cutaneous means skin.

If the cancer is in the jawbone, they will need to remove the affected bone. The surgeon may use bone from another part of the body (usually the lower leg) to replace the missing jawbone. This is called a bone flap. Your doctor and nurse will give you more information about this operation. You can usually move your jaw again as soon as the surgery finishes.

> **"He explained that they would remove the inside of my right cheek and replace it with a radial forearm flap. Then he would take a skin graft of my tummy to put on my left arm, where the flap would be taken from."**
>
> Rachel, diagnosed with mouth cancer

Before an operation that is likely to change your appearance, it may help to talk to someone who has had a similar operation. They can tell you what helped them to cope. Your surgeon or specialist nurse may be able to arrange this for you.

Sometimes an area of bone, such as the hard palate, needs to be removed (page 13). If that happens, the surgeon may advise that you have a false part (prosthetic) fitted to fill the space. This is not usually necessary. But if you need this, your surgeon and nurse will explain it to you carefully before surgery.

We have more information about coping with changes to how you look – pages 114 to 116.

Tracheostomy

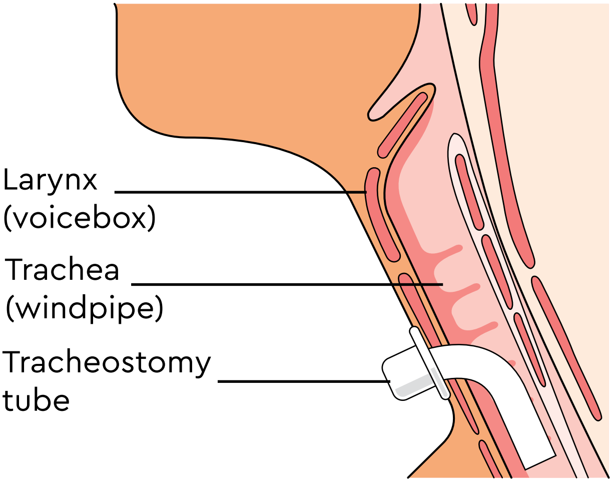
This is when your surgeon makes a small opening in your windpipe (trachea) to help with your breathing. They insert a small plastic tube to keep it open. A tracheostomy is usually temporary.

You may need a tracheostomy if surgery:

- may cause temporary swelling in the mouth and throat that makes breathing difficult
- removes part or all of the voicebox – because the cancer is nearby or has grown into it.

Your surgeon and nurse will tell you if you may need a tracheostomy and what to expect. You will also see a speech and language therapist (SLT) because your speech will be affected while the tube is in. The tracheostomy tube is usually removed after surgery, when the swelling has gone. If you have had all of the voicebox removed (laryngectomy), the tracheostomy is permanent.

A tracheostomy tube



After the operation

Although some people have surgery as a day patient, surgery often involves a stay in hospital. This may be for several days or up to a few weeks. This depends on the type of operation you have and whether you need reconstructive surgery.

After your operation, you will be encouraged to start moving around as soon as possible. This is an important part of your recovery. If you have to stay in bed, it is important to do regular leg movements and deep-breathing exercises. These help to reduce your risk of getting a blood clot or a chest infection. A physiotherapist will show you how to do these.

If you had a bigger operation, you may spend some time in intensive care or a high-dependency unit after the operation. You have one-to-one nursing care for as long as necessary to help you recover.

After surgery you may wake up with a number of drips, drains and tubes attached to you. These are gradually removed as you recover.

Drips

Operations to the mouth and throat area usually cause swelling. This can make eating and drinking difficult and uncomfortable for a time. You will usually have a tube going into a vein in your arm or neck (an intravenous drip). The nurses give you fluids through this tube for a few days. It is removed when you can drink fluids again.

Drains

Depending on the surgery, you may have 1 or 2 thin plastic drainage tubes coming from the operation area. The tubes have bottles attached to collect fluid from the wound. If you had reconstructive surgery, you may have a drain in the area where the tissue was taken from. Drains usually stay in place for 2 to 7 days. If you go home with a drain, the district nurse can check it. You usually come back to hospital to have it removed.

Your wound

The type of wound you have depends on the surgery. The nurses will check it regularly and change the dressings when needed. If you do not have dissolvable stitches, you usually have your stitches or staples removed about 7 days after surgery. The nurses will give you advice on what to do when you go home and how to recognise any signs of infection. District nurses can visit you at home and check your wound.

Feeding tube

A feeding tube can be used if you are not able to eat or drink in the usual way. If you are likely to need this, your team will discuss it with you. The tube may be put in before or during your operation.

You may have a thin tube passed through the nose and into the stomach. This is called a nasogastric tube. It can usually be removed when you are able to swallow. Having a feeding tube into your stomach means you get the nutrition you need while your tissue heals. Your dietitian prescribes high-protein, high-calorie, liquid food, to give through the tube.

Once your mouth and throat have healed, your speech and language therapist (SLT) may do a swallowing assessment (pages 118 to 119). When you can eat and swallow safely, they remove the feeding tube. If you are having chemoradiation or radiotherapy after surgery, you may need to keep the tube in until all your treatment is finished.

If you need to go home with a feeding tube, your head and neck team will teach you and your family or friends how to look after it. You can also have daily home visits from community nutritional care nurses. They can help with feeding tube care and setting up the feeds.

We have more information about feeding tubes at **macmillan.org.uk/tube-feeding**

If you have a tracheostomy tube

The swelling from your operation usually goes down after about 5 to 7 days and you can then breathe easily. When this happens, the tracheostomy tube is taken out. The opening is left to heal over naturally. You usually cannot speak with the tube in place. Your nurse or SLT will have talked to you about how best to communicate with others. This could be using writing materials, picture boards, a mobile phone, laptop or tablet.

Pain

You may have pain or discomfort for a few days or weeks after your operation. Your doctor or nurse will explain how to manage the pain. Always tell your doctor or nurse if you are still in pain. They can increase the dose or change the painkillers. We have more information about managing pain at **macmillan.org.uk/pain**

Changes in sensation or numbness

Surgery may affect the feeling in your mouth, face, ears, neck or shoulders. Some areas may feel numb. This can happen if nerves are bruised during the operation. It may take several months for the nerves to heal and sensation to come back.

The skin around any scars can feel numb. It may take several months for normal sensation to come back.

If a cancer is growing very close to a nerve, the only way to remove all the cancer is by cutting the nerve. If this happens, the changes may be permanent.

Speech

Sometimes surgery to the mouth and throat can affect the way you speak. The throat, nose, mouth, tongue, teeth, lips and soft palate are involved in producing speech. Any operation that changes one of these areas may affect your speech or voice, or both. For some people, this is hardly noticeable. But for others, their speech or voice is temporarily or permanently changed.

An SLT can help you adapt to any changes and improve your communication. We have more information about managing changes to speech and voice (page 120).

Swallowing

When you are ready to start having fluids and food by mouth, you may see an SLT. They can give you advice about foods that are easy to chew and swallow. If you cough when you eat and drink, it may be a sign that food is going down the wrong way (into your airway). Your SLT can teach you exercises to prevent this and help with swallowing. We have more information about help with swallowing (pages 117 to 119).

Difficulty opening your mouth due to a stiff jaw (trismus)

Some operations to the back of the mouth and throat can cause a stiff jaw. This can make it difficult to open your mouth (trismus). It is usually temporary. There are exercises you can do to help prevent this from becoming a permanent problem.

Changes to your appearance

Before surgery, your surgeons and nurse will talk to you about any possible changes to your appearance. It is important that you have a good idea of what to expect.

Surgery to the mouth or throat can often cause swelling. Your face and neck may look very swollen immediately after the operation, but this slowly gets better over a few months.

Scars

Your surgeon tries as much as possible to make sure any scars are in less noticeable places. For example, they could be in skin creases on your face or a fold in your neck.

Scars are usually red or dark to begin with, but fade over time. Your nurse will give you advice on what to expect after surgery. Using camouflage products can also help.

It takes time to adjust to changes in how you look. There is support to help you. We have more information about coping with changes in your appearance (pages 114 to 116).

Going home

How long you are in hospital for will depend on the type of surgery you had and your recovery. It may be 2 to 4 weeks if you had reconstructive surgery.

You will have an appointment to come back to the outpatient clinic a few weeks later to see your surgeon. You will also be given appointments if you need to see any other members of the team, such as your speech and language therapist (SLT), specialist nurse or dietitian.

At the outpatient appointment with your surgeon, they will check that your wound is healing and you are recovering well. They will talk to you about the results of your operation and any more treatment you might need. You can also ask any questions you have.

Recovering

It may take weeks or months to recover, depending on the type of operation you have had. Recovery takes time and it is faster for some people than others. Try to pace yourself and do not do too much too soon.

Your doctor and nurse will give you advice on what you can do to help your recovery. You can slowly build up your strength and fitness with light exercise, such as short walks.

Try to:

- eat healthily
- get enough rest
- do light exercise, such as short walks that you can gradually increase.

Driving

Your doctor will tell you when it is safe to drive after your operation. If you had surgery to your neck, it can take several weeks for you to be fit enough to drive.

Coping with other changes

We have more information about managing different changes after treatment on pages 114 to 122. This includes possible effects on eating, speech, appearance and your sex life and relationships.

Radiotherapy

Radiotherapy uses high-energy x-rays to destroy cancer cells, while doing as little harm as possible to normal cells. It is an important treatment for head and neck cancer.

Radiotherapy may be used on its own but is often given in combination with chemotherapy (page 96). This is called chemoradiation.

Chemoradiation

Chemoradiation is often the main treatment for head and neck cancer. The chemotherapy helps the radiotherapy to work better.

It may be used:

- as your main treatment, if the cancer is locally advanced
- for cancers that cannot be removed with surgery
- when surgery could have serious effects on your speech or swallowing
- after surgery, to reduce the risk of the cancer coming back (adjuvant treatment)
- to treat cancers in harder-to-reach areas, such as the nasopharynx or throat (oropharynx).

Chemoradiation can cause severe side effects so it may not be suitable for everyone. If you are not well enough to cope with the side effects of chemoradiation, you may be given radiotherapy on its own.

Radiotherapy for early stage cancers

Radiotherapy can be used on its own to treat cancers that are small and have not spread. It is often used to treat cancers in harder-to-reach areas. For example, it may be used for cancers in the back of the mouth or throat. Radiotherapy can also be the main treatment when surgery could have a serious effect on your speech or swallowing.

Radiotherapy for locally advanced cancers

If a cancer is bigger or has spread into tissues nearby (locally advanced cancer), you usually have radiotherapy along with chemotherapy (chemoradiation). We have more information on staging and grading of head and neck cancers on pages 40 to 43. Some people may have radiotherapy on its own.

Radiotherapy can be given:

- with chemotherapy (chemoradiation) as your main treatment
- after surgery, usually with chemotherapy or on its own to reduce the risk of cancer coming back (adjuvant treatment)
- with the targeted therapy drug cetuximab, although this is less common (pages 106 to 107)
- to reduce symptoms (palliative radiotherapy).

If you have surgery first, you usually start chemoradiation or radiotherapy 3 to 6 weeks later.

Radiotherapy to control the cancer and reduce symptoms

If it is not possible to cure a cancer, treatment will aim to control the cancer and relieve symptoms. This is sometimes called palliative treatment.

You may have palliative radiotherapy to:

- help control the cancer for as long as possible
- stop bleeding from a tumour
- shrink a tumour that is causing swallowing or breathing difficulties
- relieve symptoms if the cancer has spread to other parts of the body, such as the lungs or bones.

How radiotherapy is given

Radiotherapy is usually given from outside the body as external-beam radiotherapy. A beam of x-rays is directed at the cancer from a large machine called a linear accelerator.

External-beam radiotherapy

External-beam radiotherapy is given in the hospital radiotherapy department. It can be used in different ways. It may be given:

- Monday to Friday, with a rest at the weekend – this is the most common method
- more than once a day
- every day, including at the weekend.

Treatment may take 4 to 7 weeks, depending on the type and size of the cancer. If you are having palliative radiotherapy, you may have a single treatment or 1 to 3 weeks of treatment.

Your cancer doctor (clinical oncologist), specialist nurse, or radiographer will discuss the treatment with you.

Intensity-modulated radiotherapy (IMRT)

This is the most common type of external-beam radiotherapy used for head and neck cancer. It uses multiple beams of radiation that come from different directions, and shapes the beams to match the shape of the cancer. Shaping the beams lets the doctors give higher doses of treatment to the cancer and lower doses to the surrounding healthy tissue.

Research has found that, for some people, having IMRT rather than standard radiotherapy may reduce some long-term side effects, such as a dry mouth.

This is because the radiotherapy shapes the beams to avoid the salivary glands, which is where saliva (spit) is produced.

The treatment machines can also take pictures and scans. Some people may have frequent scans during their treatment. This is to make sure the treatment accurately targets the treatment area. Changes can be made if needed, for example if you lose weight during treatment.

Conformal radiotherapy (CRT)

Many types of external beam radiotherapy are conformal. This means the beams are specially shaped to fit the treatment area. Conformal radiotherapy can be used to treat many different types of cancer.

Proton beam therapy

Proton beam therapy uses proton radiation rather than x-rays to destroy cancer cells. Proton beams can be made to stop when they reach the area being treated. This is different to standard radiotherapy beams, which pass through the area and some healthy tissue around it. Proton beam radiotherapy may help to reduce side effects and the risk of long-term effects. It is not widely available in the UK and is only suitable for a small number of people.

We have more information at **macmillan.org.uk/proton-beam-therapy**

Radiotherapy planning

To make sure your radiotherapy is as effective as possible, it has to be carefully planned. Planning makes sure the radiotherapy beams are aimed precisely at the cancer and cause the least possible damage to the surrounding healthy tissues. The treatment is carefully planned by a team of experts. This includes your cancer doctor and the radiographer who gives you the radiotherapy.

Planning is usually done during one visit to the radiotherapy department. It usually takes about 2 hours. You will meet the radiographers, who are experts in giving radiotherapy. They will answer any questions you have.

Radiotherapy mask

To help you lie in exactly the same position during radiotherapy, you wear a plastic mesh mask. This is made individually for you. It holds your head and neck as still as possible. You have it on for up to about 15 minutes at a time. You can see and breathe normally while wearing it. It fits tightly but should not be uncomfortable. Most people get used to it quickly. It is sometimes called a mould, head shell or cast.

The radiographer and the technician who makes the mask will explain what is involved. But it is important to tell your radiographer or nurse if you find it difficult to wear the mask. They can suggest things that might help.

Radiotherapy mask

After the mask is made

When the mask is ready, your treatment can be planned. You will have a CT scan of the area to be treated (pages 36 to 37). The radiographers take measurements to plan the treatment specifically for you. Some people also have an MRI scan as part of their radiotherapy planning (page 38).

The radiographer's measurements and the information from the scans are entered into the radiotherapy planning computer. This is used to plan your treatment precisely.

Sometimes, the radiographer draws marks on your mask. These help them to position you accurately each day before treatment. They may also make a very small permanent mark on your chest to help them position the mask.

Rarely, radiotherapy to the mouth or throat can cause swelling in tissues around the airways. This can make breathing difficult. If this is likely, your doctors arrange for you to have a small opening made in your windpipe before you have radiotherapy. This is called a tracheostomy (or stoma) and allows you to breathe comfortably (pages 70 to 71). A tracheostomy in this situation is usually temporary. If you have any breathing difficulties during radiotherapy, contact your doctor straight away.

Having radiotherapy

Before each treatment session, the radiographer will position you on the treatment couch and carefully fit your mask. They will leave the room before the treatment starts. The treatment only takes a few minutes. There is a camera in the room, so the radiographer can see you from the next room. They can also hear you through an intercom. If you need help, you can raise your hand and the radiographers will return to the room.

External radiotherapy does not make you radioactive. It is safe for you to be with other people, including children and pregnant people, throughout your treatment.

> **"When they put the material on your face to mould it into the mask, it just feels warm, and it's actually not a bad experience. Very much like when you get a heated towel if you're on a long-haul flight somewhere. You just lie there and think happy thoughts."**
>
> Jerry, diagnosed with mouth cancer

Side effects of radiotherapy

Radiotherapy to the head and neck causes temporary (or acute) side effects. Side effects can be mild or more severe, depending on the size of the area being treated and the length of your treatment. They are usually more severe if you have radiotherapy combined with chemotherapy.

Side effects usually begin after about 2 weeks of radiotherapy. They continue to develop for up to 2 weeks after treatment ends, before slowly improving. Most people notice an improvement 6 to 8 weeks after radiotherapy has finished.

Radiotherapy to the head and neck can also cause late effects (page 110). These are side effects that do not go away, or that develop months or years after treatment. Your doctor can tell you about any possible late effects and what you can do to help reduce the risk of these.

What you can do to manage side effects

Following the advice your team gives you will help to reduce side effects and improve your recovery. This includes advice about preparing for treatment. For example, the advice may include:

- not smoking
- avoiding alcohol, especially spirits
- eating as well as you can to keep to a healthy weight
- drinking plenty of fluids
- doing exercises to prevent jaw or shoulder stiffness, or to help with swallowing
- trying to keep as active as you can.

Tell your nurse, radiographer or doctor about your side effects. There are things they can do to improve your side effects. They can also tell you things you can do yourself.

Managing side effects during radiotherapy

Sore and sensitive skin

The skin on your face and neck will slowly redden or darken and may feel sore and itchy. This usually starts after about 2 weeks of treatment. The skin may get dry and start to peel. Or the area may become moist. You may be given non-stick dressings to cover the area.

The radiotherapy team will give you advice on how to look after your skin. They can prescribe creams, dressings or painkillers if needed. A skin reaction may be at its worst 2 weeks after treatment, but should start to improve after this.

Tips for looking after your skin

- Wash your skin gently with soap or aqueous cream and lukewarm water. Gently pat it dry. Only use soaps, creams and lotions that the radiotherapy team recommends.
- Avoid wet shaving for a time, as your skin will be very delicate.
- Try to wear loose, cotton clothing, as this is less likely to irritate sore skin. Avoid anything with a stiff or tight collar.
- The skin in the treated area will be more sensitive to the sun during and after radiotherapy, especially in the first year. Cover up with a hat and a soft cotton or silk scarf around your neck to protect your skin. Use sun-protection cream with an SPF of at least 30 after any skin reaction has gone.

Sore mouth and throat

Your mouth and throat are likely to become sore after a few weeks. You may develop mouth ulcers or a mouth infection. Your doctor, radiographer, nurse or dentist will tell you what to look for. Keeping your mouth clean can help to prevent an infection.

Your doctor or nurse will prescribe treatment for any infection, and painkillers to take regularly. Towards the end of radiotherapy, your mouth may be very sore and it can be painful to eat. You may need strong painkillers, such as morphine. Your doctor or specialist nurse can discuss this with you.

We have more information about mouth problems in our booklet **Managing the late effects of head and neck cancer**.

Your dietitian will see you regularly to make sure you get enough nutrition and calories each day. We have more information in our booklet **The building-up diet**.

You may need to be fed through a tube if you cannot eat and are losing lots of weight. This is only until treatment is finished and your swallowing is back to normal. You might get back to eating normally a few weeks after radiotherapy has finished. But it may take longer than this.

You can order our booklets and leaflets for free.
Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

Tips for looking after your mouth and teeth

These actions will help to prevent infection:

- Brush your teeth or dentures with a small, soft toothbrush after each meal using fluoride toothpaste and gel.
- Rinse your mouth daily with a non-alcohol-based mouthwash, prescribed by your doctor.
- Use a salt or sodium bicarbonate mouthwash at least 4 times a day. Add 1 teaspoon of salt to 900ml of cooled, boiled water. Your cancer centre may have a certain mouthwash they recommend you use as well.
- If your dentures are uncomfortable, you may need to leave them out for a few weeks. But speak to the radiotherapy staff first, as this may affect how your radiotherapy mask fits.

Radiotherapy reduces saliva, which helps protect your teeth from decay. After radiotherapy, you are more likely to get tooth decay. It is important to continue looking after your mouth and teeth. You should see your dentist every 3 to 6 months and a dental hygienist when your dentist suggests. Any problems can be found early when they are easier to treat. Your dentist or hygienist can give you a mouthcare routine you can follow to help prevent problems.

We have more information about looking after your mouth at **macmillan.org.uk/dry-mouth**

Dry mouth

Radiotherapy can affect the salivary glands, so you may not make as much saliva as before. Your mouth and throat may become dry. This can make eating and speaking more difficult.

Here are some tips for coping with a dry mouth:

- sip water regularly and always carry a bottle of water with you
- eat soft, moist foods with gravy and sauces instead of dry or chewy foods
- use artificial saliva which your doctor can prescribe – it is available as sprays, gels, lozenges and pastilles
- chew sugar-free gum
- use a humidifier to make the atmosphere in your home less dry
- use a lip balm for dry lips, but ask your radiographer for advice on which one to use.

After a few months, you may start to make saliva again, but there may not be as much as before. Sometimes the salivary glands do not recover, which leaves the mouth permanently dry. We have more information about coping with a dry mouth.

Thick, sticky saliva (mucus)

Radiotherapy can change the consistency of your saliva. It may become thicker, stringy and sticky, like mucus. It may also build up in the mouth and throat. Tell your nurse or doctor if your mucus is not white or clear (discoloured). This may be caused by an infection.

You may feel the need to spit often to get rid of the mucus build-up, so it is a good idea to keep tissues with you. Rinsing your mouth regularly can help.

Using a sodium bicarbonate mouthwash may help clear thick saliva. Ask your specialist nurse for advice about the type of mouthwash that is best for you, and how to prepare it.

Sometimes mucus build-up can cause coughing, especially at night. Using a nebuliser regularly, and especially before bed, may help. A nebuliser changes liquid medicine into a fine mist or spray, to help to loosen the mucus. Your nurse or doctor can prescribe a nebuliser and explain how to use it.

Changes in your saliva may improve within about 8 weeks of radiotherapy finishing. But sometimes it continues for several months or longer. Tell your doctor or nurse if this happens. They may be able to prescribe medicines to help.

Bad breath

This is usually caused by changes to your saliva or an infection in the mouth. If you have an infection, it can be treated with antibiotics or antifungal medicine.

Loss of taste

You may lose your sense of taste or find everything tastes the same. The taste is usually quite metallic or salty. Your sense of taste should recover, but it may take many months for this to happen.

We have more advice on coping with taste changes and other eating problems at **macmillan.org.uk/eating-problems**

A hoarse voice

You may notice your voice becomes hoarse during treatment. If this happens, do not strain. Talk in a normal voice and avoid whispering or shouting.

Try to rest your voice and avoid smoky atmospheres. A speech and language therapist (SLT) can give you more advice. Your voice usually recovers after a few weeks.

Feeling sick (nausea)

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

We have more information about controlling nausea and vomiting at **macmillan.org.uk/nausea-vomiting**

Tiredness (fatigue)

You are likely to become tired as treatment goes on and may need to take things slowly. Try to pace yourself and save your energy for things that you want to do, or that need doing. Balance rest with some physical activity – even going for short walks will help you to feel less tired. Fatigue can continue for a few months after treatment finishes, but slowly gets better.

You may find our booklets **Physical activity and cancer** and **Coping with fatigue (tiredness)** useful.

Late effects of radiotherapy

If your side effects are not improving, or you develop new symptoms, tell your cancer doctor. They will assess if your symptoms are linked with treatment and may arrange tests.

Late effects may include:

- a dry mouth
- higher risk of tooth decay
- difficulty swallowing
- stiffness in the jaw, neck or shoulders
- swelling in the head and neck area called lymphoedema.

We have more information about late effects of head and neck treatment and how to manage them on pages 114 to 122, and in our booklet **Managing the late effects of head and neck cancer treatment**.

You may also find our booklet **Understanding lymphoedema** useful.

You can order our booklets and leaflets for free.
Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. Your doctor and nurse will talk to you about the chemotherapy that is best for your situation. They will explain how long your treatment is likely to take. Some chemotherapy treatments for head and neck cancer involve a short stay in hospital.

Chemotherapy is often used to treat locally advanced or advanced head and neck cancer.

Chemoradiation

If the cancer is locally advanced, you usually have chemotherapy in combination with radiotherapy (pages 78 to 93). This is called chemoradiation. You may have it:

- as your main treatment
- after surgery, to reduce the risk of the cancer coming back (called adjuvant treatment).

You may have chemotherapy each week or every 3 weeks during your course of radiotherapy. Your doctor or nurse will explain this to you.

Chemotherapy before other treatment

You may have chemotherapy on its own before radiotherapy or surgery. This helps shrink the cancer and make treatment work better. This is called neo-adjuvant chemotherapy.

It may be given every 3 weeks for 1 to 3 treatments, before radiotherapy or surgery. This depends on the type of head and neck cancer and how the cancer responds to chemotherapy. You may have more chemotherapy after surgery or radiotherapy.

Chemotherapy to help control the cancer

If the cancer is more advanced, or comes back, you may have chemotherapy on its own or with a targeted therapy drug. It may help control the cancer and relieve symptoms. This can help to improve your quality of life. It is sometimes called palliative chemotherapy.

Chemotherapy drugs used

You usually have a drug called cisplatin, which may be given on its own or along with other chemotherapy drugs. Chemotherapy drugs commonly used to treat head and neck cancers are:

- cisplatin
- carboplatin
- docetaxel (Taxotere®)
- paclitaxel
- capecitabine (Xeloda®)
- fluorouracil (5FU)
- gemcitabine.

How chemotherapy is given

You may have chemotherapy as an outpatient, or during a short stay in hospital.

Usually the nurse gives your chemotherapy drugs into a vein (intravenously). You have some other drugs, such as capecitabine, as tablets.

Chemotherapy is usually given as several sessions of treatment, with rest periods in between. This makes up one cycle of treatment. Your cancer doctor will explain the number of cycles you need for your course of treatment.

Chemotherapy into a vein

Chemotherapy given into a vein (intravenously) can be given through:

- a cannula – a short, thin tube put into a vein in the arm or the back of the hand
- a central line – a long, thin tube put into a vein in the chest
- a PICC (peripherally inserted central venous catheter) line – a long, thin, flexible tube put into a vein in the arm and threaded through to a vein in the chest
- a portacath – an implantable line (catheter) put into a vein, with an opening (port) under the skin on the chest or arm.

Sometimes, you may have intravenous chemotherapy over a few days through a small, portable pump attached to your central line or PICC line. This allows you to go home during your treatment.

Possible side effects of chemotherapy

Chemotherapy drugs cause different side effects. These can usually be well controlled with medicines. Most side effects usually go away once treatment has finished. Your doctor or nurse will tell you about the most likely side effects and how they can be controlled or managed.

Risk of infection

This treatment can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

If you have an infection, it is important to treat it as soon as possible. Contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) a lot, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

The number of white blood cells will usually return to normal before your next treatment. You will have a blood test before having more treatment. If your white blood cell count is low, your doctor may delay your treatment for a short time, until your cell count increases.

Bruising and bleeding

This treatment can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (reduced number of red blood cells)

If chemotherapy reduces the number of red blood cells in your blood, you may become very tired and feel you have no energy. You may also become breathless and feel dizzy and light-headed. Tell your doctor or nurse if you have these symptoms. If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Feeling sick

Your doctor will give you anti-sickness drugs to help prevent or control sickness during your treatment. Take the drugs exactly as your nurse or pharmacist tells you. It is easier to prevent sickness than to treat it after it has started.

If you feel sick, take small sips of fluids often and eat small amounts regularly. It is important to drink enough fluids. If you continue to feel sick, or are sick (vomit) more than once in 24 hours, contact the hospital as soon as possible. They will give you advice. Your doctor or nurse may change the anti-sickness drug to one that works better for you.

Sore mouth

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids
- avoid alcohol, tobacco and foods that irritate your mouth and throat.

Sucking ice chips may sometimes help relieve mouth or throat pain. But if you are having radiotherapy to the head or neck, do not suck on ice. It can cause damage.

Changes in hearing

If you have treatment with cisplatin, you may have changes in your hearing. You may have ringing in the ears (tinnitus) and may lose the ability to hear some high-pitched sounds. Hearing loss can be more severe with higher doses and longer courses of treatment. Very occasionally, your sense of balance may be affected.

Any hearing loss may be permanent. But tinnitus usually improves when treatment finishes. Tell your doctor if you notice any loss of hearing or tinnitus. They may suggest changing the dose of your chemotherapy.

Feeling tired

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy.

If you feel sleepy, do not drive or use machinery.

Hair loss

Drugs such as docetaxel and paclitaxel may cause hair loss. Some people may have complete hair loss, including eyelashes and eyebrows.

Others may only experience partial hair loss or thinning. It depends on the chemotherapy drugs you are having. Your doctor or nurse can tell you more about what to expect. If you do experience hair loss, your hair should start to grow back within about 3 to 6 months of treatment finishing. It may grow back straighter, curlier, finer, or a slightly different colour than it was before. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

Numb or tingling hands or feet (peripheral neuropathy)

This treatment affects the nerves, which can cause numb, tingling or painful hands or feet. You may find it hard to fasten buttons or do other fiddly tasks.

Tell your doctor if you have these symptoms. They sometimes need to lower the dose of the drug. The symptoms usually improve slowly after treatment finishes, but for some people they may never go away. Talk to your doctor if you are worried about this.

Changes in the way the kidneys work

Cisplatin can affect how the kidneys work. You will have blood tests before and during treatment to check this. Your nurse will ask you to drink plenty of fluid. This is to protect your kidneys. Tell them if you are not passing urine much.

We have more information about different chemotherapy drugs and their possible side effects at **macmillan.org.uk/chemotherapy**

Targeted therapies and immunotherapies

Targeted and immunotherapy drugs are used to treat locally advanced or advanced head and neck cancer. Targeted therapy drugs target something in or around the cancer cell that helps it grow and survive. Some targeted drugs also help your immune system to find and attack cancer cells. They may also be called immunotherapy drugs.

Targeted therapy drugs

Cetuximab (Erbitux®) is a targeted therapy that is sometimes used to treat head and neck cancer. It belongs to a group of cancer drugs called monoclonal antibodies. They target specific proteins (receptors) on the surface of cells.

Cetuximab is sometimes given with radiotherapy if chemoradiation is not suitable for you. Your nurse will give you cetuximab as a drip (infusion) into a vein. You have your first treatment before radiotherapy starts. You have 1 treatment a week during your course of radiotherapy.

Cetuximab may also be given with platinum chemotherapy drugs (page 96). This treatment is used to treat some cancers that started in the mouth area but have spread or come back (page 11).

Side effects

The side effects of cetuximab are usually mild. Some people have flu-like symptoms when the infusion is being given, such as a headache, fever, chills or dizziness. Your nurse will give you medication before the infusion to reduce the risk of this happening.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The most common side effect is a skin rash. It usually starts within 2 weeks of having the first treatment, but goes away when treatment finishes. Your nurse will give you advice on how to look after your skin while you are having cetuximab. Other side effects are a sore mouth and nose, which may cause mouth ulcers or nosebleeds. You may also feel tired or sick, or have diarrhoea.

Immunotherapy drugs

Immunotherapy drugs help the immune system to find and attack the cancer cells. The immunotherapy drugs used to treat head and neck cancer are pembrolizumab (Keytruda®) and nivolumab (Opdivo®). They target and block a protein (receptor) called PD-L1.

These drugs are usually given on their own. You have them as a drip (infusion) into a vein. A nurse gives them to you in the chemotherapy day unit.

You may have pembrolizumab:

- if the cancer has spread to other parts of the body and you have had no other treatment
- if the cancer comes back and it cannot be removed with surgery.

Tests are done on the cancer cells first, to see if pembrolizumab is likely to be helpful for you. If it works well and you have no serious side effects, it can be given for up to 2 years.

You may have nivolumab if the cancer comes back, or if it was advanced and gets worse. But this needs to have happened within 6 months of you having platinum chemotherapy.

Side effects

Some of the common side effects of immunotherapy drugs are:

- diarrhoea
- tiredness
- a skin rash
- thyroid problems.

Immunotherapy drugs can sometimes make the immune system attack other parts of the body. This is not common, but it can cause serious side effects in areas such as:

- the lungs
- other organs, like the liver or bowel
- glands that make certain hormones.

If you have immune side effects, you may need to stop treatment. You may need steroids for a short time to suppress your immune system. Rarely, these side effects can happen up to 2 years after treatment finishes. If you think you have any of these side effects, contact your cancer doctor or nurse straight away.

Your doctor or nurse will explain all these side effects to you. Always tell them about any side effects you have.

We have more information about specific targeted therapy and immunotherapy drugs at **macmillan.org.uk/treatment-types**

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about clinical trials on our website. Visit **macmillan.org.uk/clinicaltrials**

After treatment

Follow-up

After your treatment, you will have regular follow-up appointments for several years. Your specialist will regularly examine your head and neck. This is the most important part of your follow-up. You may also sometimes have scans.

It can take several months for the side effects of the treatment to improve. Always tell your specialist about:

- ongoing side effects or symptoms that are not improving
- any new symptoms that do not get better within 2 weeks.

Your nurse can tell you what to look out for. For example, this might be a new ulcer or a lump in your neck, pain, or difficulty swallowing or speaking.

Contact your doctor or nurse as soon as possible if you notice any symptoms or side effects. You do not need to wait until your next appointment.

Late effects

These are side effects that do not improve, or that develop years after treatment has finished. They may be mild or more serious. Your doctor or nurse will explain any likely late effects of your treatment. Not everyone gets late effects. It depends on the treatment you had.

Always tell your doctor if you have any new symptoms, or if side effects are not improving. They will monitor them and arrange for you to have tests, if needed. We have more information in our booklet **Managing the late effects of head and neck cancer treatment** (page 134).


Speech
&
uage Therapy

Changes in how you look

If treatment causes changes in the way you look, or how you feel about your body, it can take time to adjust.

Sometimes cancer and its treatment causes visible changes to the way you look or how your body works.

These changes can affect the way you think and feel about your body. This is called body image. The changes can also be a reminder of the cancer and treatment. It takes time to get used to a change in appearance. Everyone adjusts at their own pace and in their own way.

There are things you can do to improve your body image. There are also different ways to get help and support. Your team will give you lots of support before and after treatment.

You can get advice and support from organisations such as Changing Faces or Saving Faces (page 141). They help people to cope with changes to their appearance.

Saving Faces has a telephone support line. They can help you contact someone else who is in a similar situation and understands the challenges.

Skin camouflage products

Camouflage products can help to reduce the difference in skin colour and improve the appearance of scars. They can be matched to all skin types and colours. If an area of skin has been replaced with skin from another part of the body, you can use camouflage to match it with surrounding skin.

Your specialist nurse and some organisations can give you advice on camouflage services. Some nurses can also give you advice on how to apply it.

Skin camouflage products can be applied to a facial prosthesis, to match your skin tone. This can be useful in the summer when your skin tone changes. If you would like this to be done, you should take the prosthesis back to the person or organisation that supplied it.

We have more information in our booklet **Body image and cancer** (page 134).

Meeting other people

After treatment, you and the people close to you will become more familiar with any visible changes. You may think about seeing other people or going back to work. If you are finding it hard to go out and see people, start with something small like going for a walk with someone close to you. You can then try to build this up.

You could decide in advance how to deal with certain situations. For example, you could decide to explain that you have a visible difference and why. How much you say could depend on how you feel and the situation. Saying you have had an operation is enough. You do not have to explain the details.

Changing Faces has information about ways to improve your confidence (page 141). This may help you to cope with other people's reactions. You might also find our booklet **Body image and cancer** useful.

Sex and relationships

Treatment for head and neck cancer can affect the way you feel about yourself sexually and your ability to enjoy sex. Tiredness during and after treatment can also make you lose interest in sex. After treatment, you may not enjoy kissing the way you used to. If you have a partner, they may also need time to adjust. Talking about how you both feel is important, as it can help you deal with any fears or worries you may have.

If you want to start a new relationship, it can be difficult to decide what and when to tell a new partner about the cancer. We have more information in our booklet **Cancer and relationships: support for partners, families and friends**.

If you are having difficulties with your sex life, talk to your GP. They may be able to refer you to a counsellor or psychologist. Your hospital team or specialist nurse can tell you about sexual health services that are available locally. The College of Sexual and Relationship Therapists (COSRT) also has a nationwide list of counsellors and therapists (page 145).

We have more information about how cancer and its treatment can affect your sex life, and what can help, in our booklet **Cancer and your sex life**.

You can order our booklets and leaflets for free.
Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

Changes to eating

Treatment may affect the movements of your mouth, tongue or throat. This can make it more difficult to eat or drink. It may take you longer to eat some foods or they may taste different. We have more information in our booklet **Eating problems and cancer**.

Some changes are caused by swelling in the mouth or throat after treatment. These are temporary. As the swelling goes down, your ability to eat and drink should gradually improve. For some people, it may never be quite the same as before.

These changes may make you feel embarrassed and frustrated. You may find it hard to eat with others. Tell your family and friends how you feel so they can help. You can also talk to your nurse for support and advice. They can often help you contact other people who have had similar difficulties.

Your speech and language therapist (SLT) and dietitian will help you learn to cope with any changes. They can assess your eating and swallowing and give you advice about what you can do.

If you start having difficulty with swallowing after treatment, it is important to tell your doctor as soon as you notice. They may need to refer you for a swallowing test.

Swallowing tests

If you are having swallowing difficulties, your SLT may advise having one or both of the following tests. These tests show how you eat, drink and swallow. They can find out if there is anything affecting this, for example something causing things to get stuck in your throat, or to go down the wrong way.

Videofluoroscopy (VF)

This is an x-ray which shows what happens in your mouth and throat when you eat or drink. The test is done in the x-ray department by your SLT and radiographer. A special substance (contrast) is added to fluid or food you have during the test, to make it show up on the x-ray.

Your SLT asks you to swallow liquids and foods of different textures, depending on your ability to swallow.

They may ask you to try different techniques to see if they help when you swallow. The test takes about 30 minutes, but it can be stopped anytime if you find it difficult.

Fibreoptic endoscopic evaluation of swallowing (FEES)

This is another test to show what happens when you swallow. Your SLT passes a thin, flexible tube through the nose to look at the back of your throat and upper larynx (voicebox). The tube has a small camera on the end, which records your swallowing while you eat and drink. The test takes about 30 minutes.

After the tests

Your SLT will talk to you about the results of your tests. They may recommend exercises to strengthen your swallow. They will also explain ways to make swallowing easier and safer. They will advise which food and fluids are easier for you to cope with. It may help to bring a partner, family member or friend with you when you see your SLT.

We have information on managing eating difficulties and building up your weight in our booklets **Eating problems and cancer** and **The building-up diet** (page 134).

Changes to speech and voice

If your treatment causes changes to your lips, teeth, tongue, soft palate or voicebox, it may make your speech more difficult to understand. Or it may make your voice sound different in quality.

Sometimes these changes are short-term problems. Your speech or voice may return to normal, or near normal, as the affected area recovers from surgery or radiotherapy.

In some situations, treatment may cause more changes to the way you speak. You may need therapy to improve your speech.

An SLT will be involved in your recovery from an early stage in your treatment. They will be able to give you support and advice.

Speech therapy can help you learn to communicate in the clearest and most effective way. Therapy usually begins as soon as possible after treatment and continues after you go home.

Changes to hearing

Some people with cancer in areas such as the nasopharynx may have hearing changes. These may be caused by the cancer, or they may be a side effect of treatment. If you have problems with hearing after your treatment, you may be referred to a specialist clinic.

Hearing loss may be helped with hearing aids, or digital hearing aids that can recognise speech (cochlear implants). Sometimes, the small tube between the ear and the throat (eustachian tube), which regulates air pressure in the ear, becomes blocked after treatment. There are different ways this can be managed. Sometimes, it is treated with a simple operation to put in a tiny tube (grommet). This helps the ear to drain.

If you have ringing in the ears (tinnitus), you may be referred to a tinnitus management clinic. The clinic can help you learn how to reduce the effects.

Well-being and recovery

After treatment, you may think about making changes to your lifestyle and want to find out more about being healthy. You may already have followed a healthy lifestyle, but now want to focus more on making the most of your health.

There are things you can do to help your body recover and improve your well-being. Certain changes may reduce the risk of other illnesses and some cancers. Many people find making positive health choices helps give them back a sense of control.

Eating healthily

If you can, try to eat a healthy, well-balanced diet, even if you have less of an appetite or interest in food. We have more information in our booklet **Healthy eating and cancer** (page 134). If treatment has affected how you eat and swallow, your dietitian will give you advice on the type of foods to eat and getting enough nutrition.

A well-balanced diet includes:

- plenty of fresh fruit and vegetables
- less red or processed meats
- more chicken, fish, beans and pulses
- carbohydrates
- less sugary food and drinks – this is particularly important if you have less saliva.

Eating well helps you keep your strength and increases your energy and sense of well-being. A healthy diet may also help to reduce the risk of other conditions such as heart disease or diabetes.

Stop smoking

Smoking is the main cause of head and neck cancer. Stopping smoking may lower the risk of cancer coming back after treatment. It reduces your risk of developing a second cancer in your head or neck. It also reduces your risk of other smoking related cancers, such as lung cancer.

Drink less alcohol

Drinking alcohol as well as smoking greatly increases the risk of developing another head and neck cancer.

If you drink alcohol, drinking less will help reduce this risk. NHS guidelines suggest that you should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is half a pint of ordinary strength beer, lager or cider, 1 small glass (125ml) of wine, or a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

Being active

Keeping active can be an important part of your recovery after treatment. It can increase your energy levels and improve your sense of well-being. It also reduces the risk of heart disease, stroke and diabetes.

You should do physical activity at your own pace. Gentle exercise, such as going for a short walk, may be enough. Your doctor, nurse or physiotherapist can advise you about how much and what type of exercise would be helpful for you. Start slowly and increase your activity over time.

We have more information in our booklet **Physical activity and cancer**.

You can order our booklets and leaflets for free.
Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

Complementary therapies

Some people find that using some complementary therapies helps them feel better and reduce symptoms. Some hospitals and support groups may offer therapies such as massage, relaxation or aromatherapy.

If you would like to try a complementary therapy, check with your cancer doctor or GP before using it. Some therapies should not be used during, and for a short time after, cancer treatment.

Talking and getting support

Talking about your feelings can reduce feelings of stress, anxiety and loneliness. Try to tell your family and friends how you are feeling, so that they can support you. Talk to your doctor or specialist nurse if you think you may be depressed, or feel low or anxious a lot of the time.

They can refer you to a psychologist or counsellor who specialises in helping people with cancer talk through confusing or upsetting emotions. Our cancer support specialists can tell you more about counselling and let you know about services in your area.
Call **0808 808 00 00**, 7 days a week, 8am to 8pm.

Online support

Many people get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people living with cancer. You can use these to:

- share your experience
- ask questions
- get and give advice based on your experience.

Our Online Community is a social networking site where you can talk to people in our chat rooms, write blogs, make friends and join support groups. Visit **macmillan.org.uk/community**

Support groups

Self-help or support groups offer a chance to talk to other people who understand what you are going through. Ask your cancer team what support is available in your area.

You can also call the Macmillan Support Line on **0808 808 00 00**, or read our information about support groups in the UK (page 139).

> **"At first, I was very apprehensive about talking to a stranger about my experience. Therapy might not be for everyone, but for me it has really helped me identify triggers to my panic and how to allow my unhelpful thoughts to come and go."**
>
> Rebecca, diagnosed with tongue cancer

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes. Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions and in our booklet **How are you feeling? The emotional effects of cancer** (page 134).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups**

Or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on page 136 about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information in our booklets **Cancer and relationships: support for partners, families and friends** and **Talking about cancer**.

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone and in our booklet **Talking with someone who has cancer**.

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet **Looking after someone with cancer**.

You can order our booklets and leaflets for free.
Visit **orders.macmillan.org.uk** or call **0808 808 00 00**.

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer**.

> **"Since my diagnosis and treatment, I have made a conscious effort to notice all the good things that happen. Whilst they don't take away the bad things, noticing the good things does make coping easier."**
>
> Paul, diagnosed with tonsil cancer

Further information

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **orders.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **informationproductionteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. We can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

Macmillan Grants

Macmillan Grants are small, one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Head and neck cancer support organisations

British Association of Skin Camouflage

Tel **0125 470 3107**
www.skin-camouflage.net
Shows people how to use make-up as skin camouflage. Holds camouflage-awareness presentations and demonstrations for patient support groups. Most creams used by the British Association of Skin Camouflage can be prescribed by GPs.

Cancer Laryngectomee Trust

Tel **0142 220 5522**
www.cancerlt.org
Provides support to people who are about to have, or have had, a laryngectomy.

Changing Faces

Tel **0300 012 0275**
www.changingfaces.org.uk
www.changingfaces.org.uk/skin-camouflage
Offers support and information for people who have any condition or injury that affects their appearance, and for their families. It has skin camouflage practitioners, who can teach people how to self-apply specialist cover creams.

Mouth Cancer Foundation

Helpline **0192 495 0950**
www.mouthcancerfoundation.org
Raises awareness and provides information and support to people affected by head and neck cancer.

Oracle Cancer Trust

Tel **020 3875 8991**
www.oraclecancertrust.org
A charity that funds research into head and neck cancer.

Salivary Gland Cancer UK

www.salivaryglandcancer.uk
This charity supports people with rare salivary gland cancers, such as adenoid cystic carcinoma and unknown carcinoma.

Saving Faces

Tel **0203 417 7757**
www.savingfaces.co.uk
Reducing the incidence of facial injuries, disorders and diseases including oral cancer. Funds and leads research to improve treatments.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 3000 118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 5883 300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

College of Sexual and Relationship Therapists (COSRT)

Tel **0208 5432 707**
www.cosrt.org.uk
A national specialist charity for sex and relationship therapy. Has a list of qualified practitioners and clinics providing sex or relationship therapy in the UK.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Equipment and advice on living with a disability

British Red Cross

Helpline **0808 196 3651**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients (formerly called Live Through This)

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services.

There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
www.phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Your notes and questions

Disclaimer

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Chris Alcock, Consultant Clinical Oncologist.

With thanks to: Mr Kevin Andi, Head and Neck Surgeon; Dr Shreerang Bhide, Consultant Clinical Oncologist; Dr Ashoke Biswas, Consultant Clinical Oncologist; Lesley Dempsey, Macmillan Head and Neck Clinical Nurse Specialist; Margaret Doyle, Macmillan Head and Neck Clinical Nurse Specialist; Dr Bernie Foran, Consultant Clinical Oncologist; Jane Hall, Macmillan Specialist Radiographer; Sarah Harris, Speech and Language Therapist; Sian Lewis, Macmillan Clinical Lead Dietitian; Kathleen Mais, Head and Neck Cancer Nurse Clinician; Amanda Naylor, Macmillan Head and Neck Advanced Nurse Practitioner; Andrea Nelson, Senior Macmillan Head and Neck Clinical Nurse Specialist; Mr Iain Nixon, Consultant Ear Nose and Throat Surgeon; Miss Lakshmi Rasaratnam, Consultant in Restorative Dentistry; Maria Smith, Macmillan Head and Neck Clinical Nurse Specialist; and Dr Iain Soulsby, Dental Surgeon.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our information about head and neck cancer. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

Machiels J.-P, Leemans C. R. et al. Squamous cell carcinoma of the oral cavity, larynx, oropharynx and hypopharynx. EHNS- ESMO-ESTRO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology, 2020. Volume 31, Issue 11, Pages 1462–1475.
National Institute for Health and Care Excellence (NICE). Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over. NICE guideline NG36 2016 (updated 2018).

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number
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Valid from
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Expiry date
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Security number
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Signature

Date / /

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Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

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Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

This booklet is about head and neck cancer. It is for anyone who has been diagnosed with head and neck cancer. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of head and neck cancer. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

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