

A practical guide to understanding cancer

WE ARE  
MACMILLAN.  
CANCER SUPPORT

# UNDERSTANDING HEAD AND NECK CANCERS



# About this booklet

This booklet is about head and neck cancers. Head and neck cancers include cancers of the mouth and throat, as well as rarer cancers of the nasal cavity (inside the nose), sinuses, salivary glands and middle ear. This booklet is for anyone who has a head and neck cancer.

The booklet explains:

- what head and neck cancer is
- the signs and symptoms
- the different 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. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

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. See page 144 for ways to order this information.

## How to use this booklet

The 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.

We have included a leaflet that you can remove in the back of this booklet. It has some useful questions to ask your doctor or nurse about treatment. There is space to write down the answers, or your own notes or questions. You may want to take it with you to your appointments. Finding out the answers to your questions may help you feel less anxious.

## Quotes

In this booklet, we have included quotes from people who have had head and neck cancer. Some are from our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). The others are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.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**, Monday to Friday, 9am 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 and your health 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. You can find more information at [\*\*macmillan.org.uk/cancerregistry\*\*](https://www.macmillan.org.uk/cancerregistry)

# Contents

About head and neck cancer	7
Diagnosing head and neck cancer	29
Treating head and neck cancer	47
After treatment	111
Further information	143



# ABOUT HEAD AND NECK CANCER

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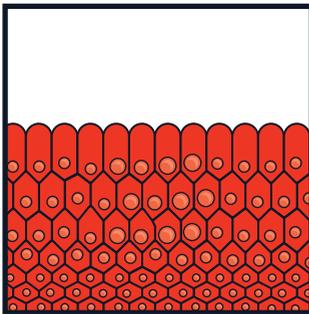
What is cancer?	8
The lymphatic system	10
Head and neck cancers	13
Risk factors and causes	21
Symptoms	25

# What is cancer?

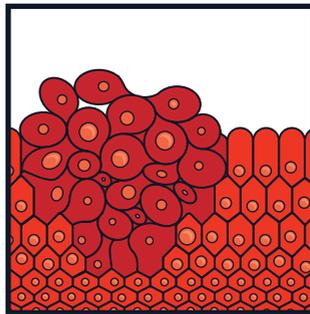
Cancer starts in cells in our body. Cells are tiny building blocks that make up the organs and tissues of our bodies. They divide to make new cells in a controlled way. This is how our bodies grow, heal and repair. Cells receive signals from the body telling them when to divide and grow and when to stop growing. When a cell is no longer needed or can't be repaired, it gets a signal to stop working and die.

Cancer develops when the normal workings of a cell go wrong and the cell becomes abnormal. The abnormal cell keeps dividing making more and more abnormal cells. These eventually form a lump (tumour). Not all lumps are cancerous. Doctors can tell if a lump is cancerous by removing a small sample of tissue or cells from it. This is called a biopsy. The doctors examine the sample under a microscope to look for cancer cells.

Normal cells



Cells forming a tumour



A lump that is not cancerous (benign) may grow but cannot spread to anywhere else in the body. It usually only causes problems if it puts pressure on nearby organs.

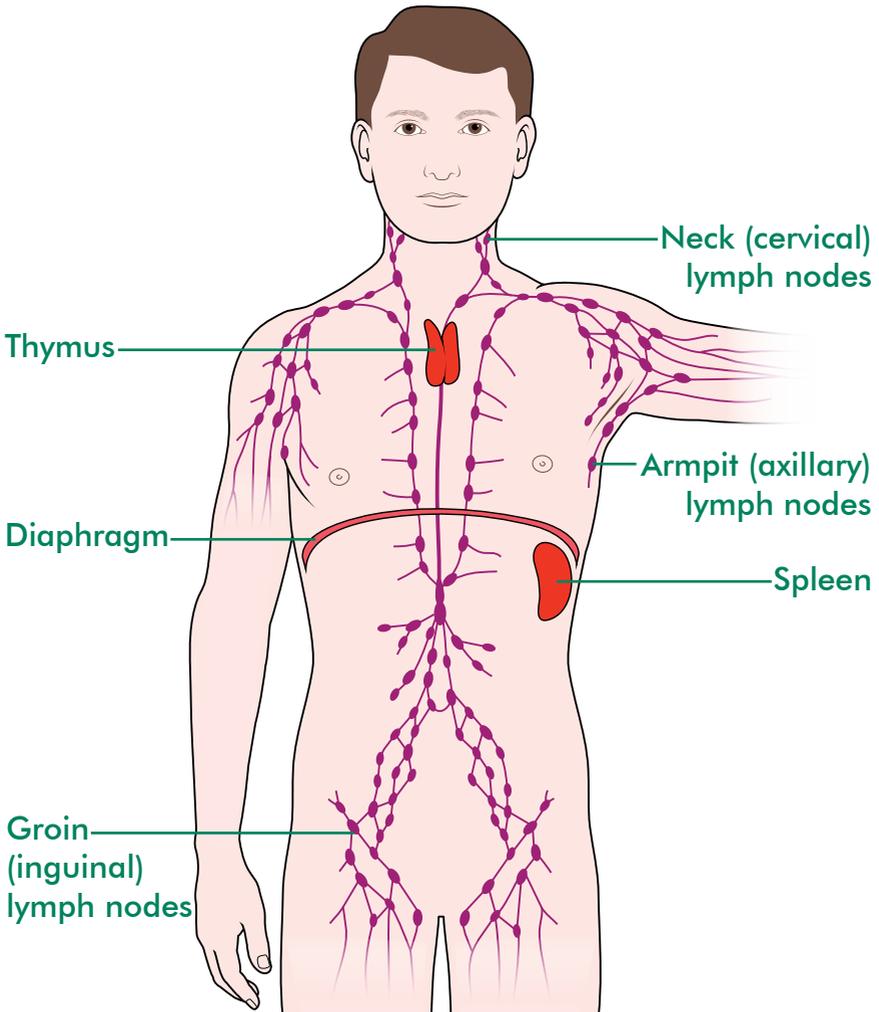
A lump that is cancer (malignant) can grow into nearby tissue. Sometimes, cancer cells spread from where the cancer first started (the primary site) to other parts of the body. They can travel through the blood or lymphatic system (see pages 10 to 11). When the cells reach another part of the body, they may begin to grow and form another tumour. This is called a secondary cancer or a metastasis.

# The lymphatic system

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

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

## The lymphatic system





# Head and neck cancers

Head and neck cancers include cancers of the mouth and throat, as well as rarer cancers of the nasal cavity (inside the nose), sinuses, salivary glands and middle ear.

People may use the word throat to describe different parts of the neck. These include the:

- pharynx
- voice box (larynx)
- thyroid gland
- food pipe (oesophagus)
- wind pipe (trachea).

When doctors talk about throat cancers, they mean the **pharynx** and **larynx**.

Cancers affecting the thyroid gland, oesophagus and trachea are treated differently and are not explained in this information. It is important to know what type of head and neck cancer you have to make sure you have the right information. Ask your doctor or specialist nurse if you are unsure. Head and neck cancers do not include cancers affecting the brain.

We have separate information about cancer of the thyroid, oesophagus and trachea, and about brain tumours. See page 144 for ways to order this information.

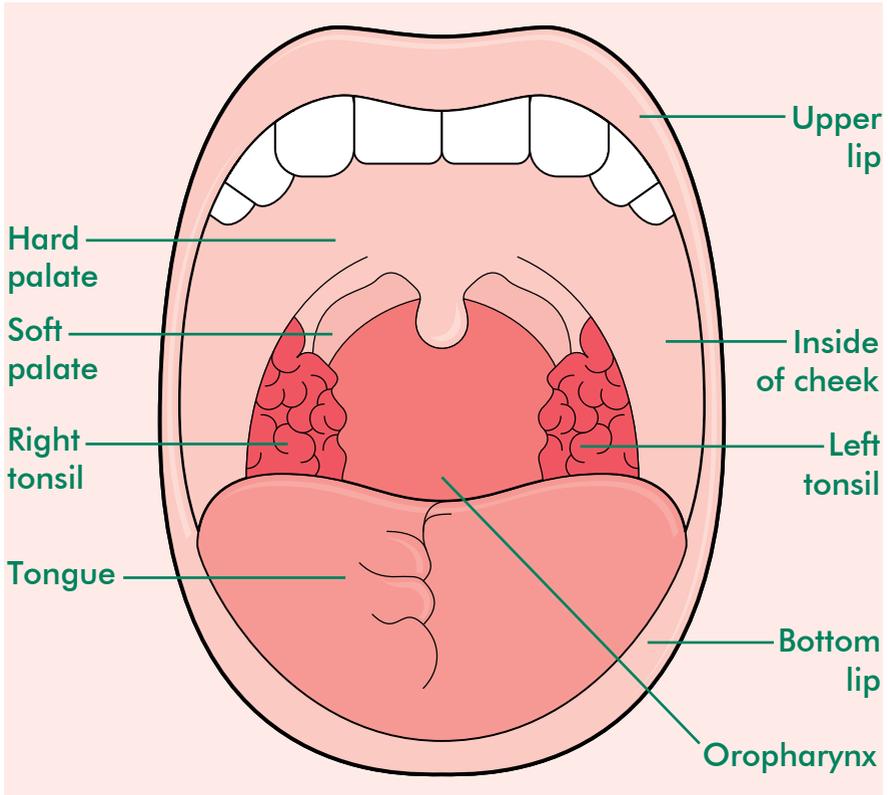
## Mouth cancers (oral cancers)

Mouth cancer can develop on the:

- lip
- tongue (front two-thirds)
- floor of the mouth (under the tongue)
- inside of the cheek
- roof of the mouth (the hard palate)
- area behind the wisdom teeth
- gum.

The most common places for cancer to develop inside the mouth are on the side of the tongue and the floor of the mouth.

## The inside of the mouth



## Throat cancers

### The pharynx

The pharynx is divided into three main parts:

- **Nasopharynx** – This is the upper part of the pharynx, behind the nose. Cancers that develop here are called nasopharyngeal cancers.
- **Oropharynx** – This is the middle part of the pharynx, behind the mouth. It includes the soft part of the roof of the mouth (soft palate), the base or the back of the tongue (the part you cannot see), the tonsils and the side walls of the throat. The most common places in the oropharynx for cancer to develop are on the tonsils and the base of the tongue. Cancers that develop here are called oropharyngeal cancers.
- **Hypopharynx** – This is the lower part of the pharynx, behind the voice box. Cancers that develop here are called hypopharyngeal cancers.

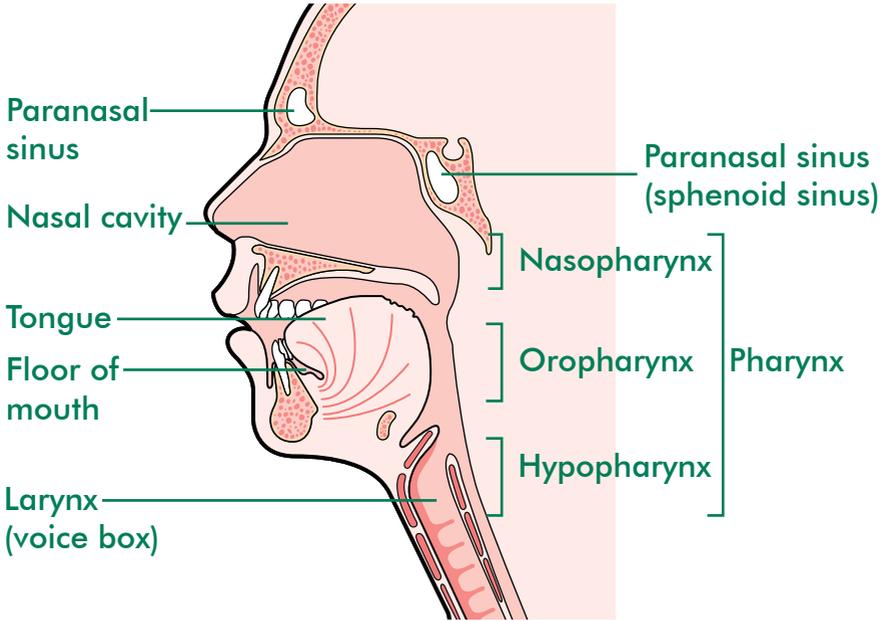
We have more information about cancers of the nasopharynx and oropharynx (see page 144).

### The voice box (larynx)

The larynx is the voice box. 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 (see page 144).

## Cross-section of the head



## Rarer cancers of the head and neck

### Cancer of the sinuses (paranasal sinuses)

There are air spaces called sinuses in the bones of the face, next to the cheekbone and nose (see page 17). Cancers can develop in the lining of these sinuses.

### Cancer of the salivary glands

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

- parotid glands, which are at the sides of the mouth, just in front of the ears
- submandibular glands, which are under each side of the jawbone
- sublingual glands, which are under the floor of the mouth and below either side of the tongue.

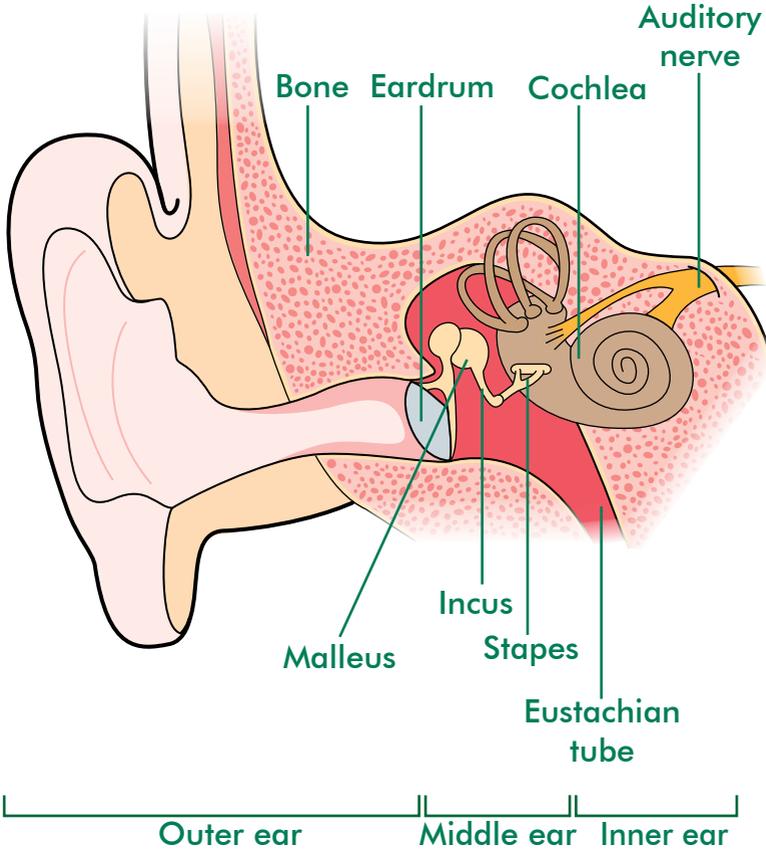
The most common place for salivary gland cancer to develop is in the parotid glands.

### 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 three 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 cancers 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 mouth, nose and throat.

### **Other cell types**

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

- Lymphomas develop from white blood cells called lymphocytes.
- Adenocarcinomas develop from cells that line the glands in the body.
- Sarcomas develop from the cells that make up muscles, cartilage, bone or blood vessels.

# Risk factors and causes

The causes of head and neck cancers are not fully understood. We know that certain things can increase a person's chances of developing it. These are called risk factors. Having one or more risk factors does not mean you will definitely get a head and neck cancer. And if you do not have any risk factors, it does not mean you will not get it.

The main risk factors for head and neck cancers are tobacco and alcohol. It is thought that about 3 out of 4 head and neck cancers (75%) are linked to tobacco or alcohol use.

## Smoking cigarettes, cigars or pipes

Smoking tobacco increases the risk of developing many types of head and neck cancer, including mouth cancers, throat cancers and cancer of the voice box (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 increases the risk of developing mouth cancer.

## 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 increase the risk of head and neck cancers. People who smoke and drink heavily over several years have the highest risk of developing head and neck cancers.

## Gender

Head and neck cancers are more common in men than in women.

## Age

The risk of developing a head and neck cancer increases as you get older. It is most common in people aged over 50, although younger people can be affected too.

## Human papilloma virus (HPV) infection

Cancers at the back of the tongue and in the tonsils (cancers of the oropharynx) have become more common over the last 20 years.

Many of these cancers are linked to infection with a type of virus called human papilloma virus 16 (HPV 16). HPV affects the skin and moist membranes that line the body, such as the mouth and throat.

HPV is spread through body-to-body contact, often during sexual activity. Exactly how a person gets the virus is uncertain, and it is not always possible to link the virus to sexual contact. It is thought there may be other ways of spreading the virus that have not yet been identified.

We have more information about HPV and cancer on our website (see page 144).

## Epstein-Barr virus (EBV) infection

Some cancers of the nasopharynx are linked to a type of virus called the Epstein-Barr virus. This is a type of virus that causes glandular fever. Only a very small number of people who have glandular fever go on to develop nasopharyngeal cancer in their lifetime.

## 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:

- do not have a healthy diet
- are taking medication to suppress your immune system after an organ transplant
- have a condition such as HIV (human immunodeficiency virus) or AIDS.

## Sunlight

Exposure to sunlight over a prolonged period of time increases the risk of developing cancer on the outside of the lip.

## Occupational exposure

Prolonged 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
- leather dust
- formaldehyde (found in leather and some types of furniture dust).

## Pre-cancerous conditions

Pre-cancerous conditions of the mouth increase the risk of a cancer developing in the mouth. These conditions include leukoplakia and erythroplakia. These are white or red patches in the mouth that are often linked to tobacco use.

Eythroplakia is less common than leukoplakia. But having eythroplakia is linked to a higher risk of cancer developing.

## Oral health

The risk of developing mouth cancer is slightly higher in people:

- with poor oral hygiene
- who have dental disease.

# Symptoms

The symptoms depend on where the cancer is in the head or neck.

These symptoms can be caused by conditions other than cancer, but it is important to have them checked by your GP or dentist, particularly if they do not go away or are getting worse.

Symptoms of head and neck cancer may include one or more of the following:

## Pain

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

## Swelling

- swelling in front of or behind the ear, or under the jawbone
- swelling in the upper neck caused by an enlarged lymph node (gland) – see page 11
- swelling in the cheek
- swelling around the eyes.

## Breathing problems

- a blocked nose that does not clear
- breathing more loudly than usual.

## Bleeding

- bleeding in the mouth
- nosebleeds.

## Changes to eating and speaking

- difficulty or pain with chewing, swallowing or speaking
- loose teeth for no obvious reason, or dentures that do not fit well anymore
- 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.

## Other symptoms

- a lump or ulcer, or both, in the mouth that does not heal
- a white (leukoplakia) or red (erythroplakia) patch in the mouth that does not go away
- changes in hearing
- unexplained weight loss
- bad breath (halitosis).

## 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. Lymph nodes are small, bean-shaped glands that are part of the lymphatic system (see pages 10 to 11).

If cancer begins to grow in the lymph nodes, it might show up as a painless lump in the neck.

Enlarged lymph nodes are much more likely to be caused by an infection than cancer. But if you have a lump on your neck that does not go away after 2 to 3 weeks, a specialist doctor should look at it. Talk to your GP about it. They can refer you to a specialist.



# DIAGNOSING HEAD AND NECK CANCER

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How head and neck cancers are diagnosed	30
Further tests	37
Staging	42
Grading	44
Testing for viruses	45

# How head and neck cancers are diagnosed

You usually start by seeing your GP or dentist. If they think that cancer could be causing your symptoms, or if they are not sure what the problem is, they will refer you to a specialist doctor. You will see the specialist at the hospital for advice, tests and treatment. You are likely to see 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.

## At the hospital

The specialist doctor will ask you about your symptoms, as well as any health conditions or recent illnesses. They will probably also ask you if you have any changes in your voice, swallowing, breathing, appetite or weight. They will carefully examine your mouth, throat and neck and explain what tests you need.

## Neck lump clinic

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

You will usually have an ultrasound scan. A sample of tissue will be taken from the lump using a fine needle aspiration or needle (core) biopsy (see page 34). You may also have a test called a nasendoscopy to look at the back of your mouth, nose and throat (see page 32).

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

## Ultrasound scan of the neck

This test uses soundwaves to produce a picture of your neck and lymph nodes on a computer screen. Lymph nodes are part of the lymphatic system, which helps to protect us from infection and disease (see pages 10 to 11).

The scan is painless and only takes a few minutes. The doctor puts some gel onto your neck and moves a small device which produces soundwaves over the area. They look for any changes in the size or appearance of the lymph nodes in your neck.

## Nasendoscopy

You may have this test in an outpatient clinic. It is used to look at the back of your mouth, nose, pharynx and larynx.

Your doctor uses a thin, flexible tube called a nasendoscope. They pass it into your nose, over the back of your tongue and down into the upper part of your throat. The tube has a camera and a light at the end to help the doctor get a better view of the back of your mouth and throat. You might find this a bit uncomfortable, but it only takes about a minute.

Before the test, your doctor may numb your throat with an anaesthetic spray. Some people prefer to have this done without the anaesthetic spray.

If you have the spray, you should not eat or drink anything for about an hour after the test, or until the numbness wears off. There is a risk that food and drink may go down the wrong way and into your lungs when you swallow. You could also burn your mouth or throat with hot food or drinks.

## Examination under anaesthetic (EUA)

Your doctor may suggest that you have a general anaesthetic if they:

- see anything unusual
- cannot see the area clearly with the nasendoscope.

This allows them to look at the area more closely using an endoscope. An endoscope is a thin, flexible tube with a camera and a light at the end.

When you are asleep under the anaesthetic, your doctor passes the endoscope down your throat. They can use the camera or attach a microscope to the end of the tube to closely look at the area.

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

## **Trans-nasal flexible laryngo-oesophagoscopy (TNFLO)**

A TNFLO is sometimes used instead of an endoscopy if you are not fit enough to have a general anaesthetic. It allows the doctor to look at your nose, throat, voice box and gullet (oesophagus).

A thin, flexible tube with a camera and a light at the end (endoscope) is inserted into your nose and to the back of your throat. Before the test, your doctor sprays your nose and throat with an anaesthetic to numb it. You are awake during the test. It takes about 30 minutes.

You should not eat or drink anything for about an hour after the test, or until the numbness wears off. This is because there is a risk that food and drink may go down the wrong way and into your lungs when you swallow. You could also burn your mouth or throat with hot food or drinks.

## Biopsy

To make a diagnosis, your doctor needs to remove a small piece of tissue or some cells from the area that looks abnormal. This is called a biopsy. A doctor who specialises in analysing cells (called a pathologist) looks at the sample under the microscope. They check the sample for any cancer cells.

If the biopsy is taken from inside your mouth or throat, it will take a few days for the tissue to heal. While it does, you may be told to:

- avoid hot food and hot fluids
- eat only soft foods.

There are different ways of taking a biopsy from the head and neck area.

### Needle (core) biopsy

Your doctor uses a needle to take small pieces of tissue from the lump or abnormal area. Before taking the biopsy, they inject some local anaesthetic into the area to numb it. 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). Depending on the size of the piece of tissue removed, you may need to have some stitches.

## Fine needle aspiration (FNA)

This is a simple test that you can have as an outpatient. It is often used to check neck lumps. But it can also be done to take samples from the mouth or throat.

The doctor passes a fine needle into the lump. They withdraw (aspirate) some cells into the syringe. Sometimes the doctor uses an ultrasound scan to help guide the needle into the area.

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.

After the test, a doctor examines the sample under a microscope to check for cancer cells.

**'It's hard to imagine how you will cope with the diagnosis of cancer. It has become a familiar word to all of us, but its meaning is highly personal.'**

**Christine**



# Further tests

If the biopsy shows that there is a cancer, you will have further tests to find out:

- its size
- its position
- whether it has spread.

This process is called staging. It may take 2 to 3 weeks before you get all the results. The results will help you and your doctor decide on the best treatment for you. Sometimes these tests may be repeated, during and after treatment, to check on your progress.

## X-rays

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

- see whether any bones have been affected by the cancer
- to check the health of your teeth.

You may have a chest x-ray. This is to check your general health and to see whether the cancer has spread to the lungs. It is rare for head and neck cancers to spread beyond the head and neck area. But sometimes they can spread to the lungs or other parts of the body. You may also have a CT scan to look at your lungs.

## CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body. The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation. This is very unlikely to harm you and will not harm anyone you come into contact with. You may be asked not to eat or drink for at least four hours before the scan.

You may be given an injection of a dye, which allows particular areas to be seen more clearly. This may make you feel hot all over for a few minutes. It is important to let your doctor know if you are allergic to iodine or have asthma. You could have a more serious reaction to the injection.

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

## Having a CT scan



## MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc. You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body.

If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly.

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

## PET-CT scan

This is a combination of a CT scan, which takes a series of x-rays to build up a three-dimensional picture, and a positron emission tomography (PET) scan. A PET scan uses low-dose radiation to measure the activity of cells in different parts of the body.

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for six hours before the scan, although you may be able to drink. A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes.

You should be able to go home after the scan.

# Staging

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

The staging is slightly different for each type of head and neck cancer. Your doctor or nurse can tell you more about the stage of your cancer.

The most commonly used staging systems for head and neck cancers are the TNM and number staging system.

## TNM staging system

TNM stands for tumour, node and metastases.

- **T** describes the size of the tumour. It is numbered between 0 to 4 depending on the size and extent of the tumour. **T0** means that there are no signs of a tumour, but there may be abnormal cells that are pre-cancerous. A **T1** tumour is small and has not spread, while a **T4** 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.
- **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

There are usually 3 or 4 number stages for each cancer type.

**Stage 1** describes a cancer at an early stage when it is usually small in size and has not spread. **Stage 4** describes a cancer at a more advanced stage when it has usually spread to other parts of the body.

Your doctor can tell you more about the stage of your cancer.

## Other terms used

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

- **Early** or **local** – 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 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.

# Testing for viruses

If you have oropharyngeal cancer, your doctor may also do another test. This is to see if the cancer might be linked to the human papilloma virus (HPV) – see pages 22 to 23. The result helps the doctor understand how a cancer may develop and how effective different treatments might be.

If you have nasopharyngeal cancer, your doctor may do a test to see if it is linked to the Epstein-Barr virus (EBV).



# TREATING HEAD AND NECK CANCER

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Treatment overview	48
Surgery	62
Radiotherapy	77
Chemotherapy	98
Targeted therapies	105
Research – clinical trials	107

# Treatment overview

Cancers affecting the head and neck are not common. People with this type of cancer are usually treated in specialist centres by a team of healthcare professionals.

For most people, the aim of treatment is to remove or destroy all of the cancer and to reduce the chances of it coming back. The treatment you are offered depends on:

- where the cancer is in your head or neck (see page 17)
- the stage of the cancer (see pages 42 to 43)
- its size
- your general health.

The main aim is to remove and destroy the cancer, but your doctors will also try to reduce the long-term effects of treatment. For example, they will plan your treatment so the effect on your appearance and ability to speak, chew and swallow is as little as possible.

Before you decide on the best treatment, it is important to talk to your doctor or specialist nurse about how the different treatments may affect you.

The team giving you your treatment will explain to you what is involved. They will give you help and support in coping with any side effects. Some people also use complementary therapies to help them cope with treatment side effects (see page 116). It is important to check with your cancer specialist first before trying a complementary therapy.

## Treating early-stage cancer

If a head and neck cancer is small and has not spread to lymph nodes or elsewhere, it can usually be treated with either surgery (see pages 62 to 76) or radiotherapy (see pages 77 to 97).

Small cancers in the mouth can often be removed with surgery. This may cause small changes to speech, chewing or swallowing. People can often adapt to these changes quite quickly.

Your doctors may suggest radiotherapy instead of surgery if:

- the cancer is in an area that is difficult to reach
- removing the cancer might cause major changes to speaking or swallowing.

## Treating locally advanced cancer

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

- 2 or 3 cycles of chemotherapy, followed by a combination of chemotherapy and radiotherapy (called chemoradiation or chemo-radiotherapy)
- a combination of a targeted therapy and radiotherapy
- surgery followed by radiotherapy, chemotherapy or chemoradiation.

## How treatment is planned

A team of specialists meets to discuss and decide on 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 specialist who has trained as a doctor and a dentist. They specialise in treating conditions affecting the mouth, jaw, face and neck. As well as doing surgery to remove the cancer, they rebuild any tissue that might be lost because of the cancer or surgery.
- **Plastic and reconstructive surgeon** – a surgeon skilled in rebuilding tissue in the head and neck.
- **Oncologist** – a doctor who specialises in cancer treatments, such as radiotherapy, chemotherapy and targeted therapy.
- **Radiologist** – a doctor who specialises in reading scans and x-rays.
- **Pathologist** – a doctor who specialises in looking at cells under a microscope and diagnosing the cell type.
- **Clinical nurse specialist** – a nurse who gives support and information about any aspect of your illness or treatment.
- **Speech and language therapist (SLT)** – a therapist who specialises in helping with communication and swallowing problems.
- **Dietitian** – someone who advises you on how to get all the nutrients your body needs.

The MDT often includes a number of other healthcare professionals, such as:

- **dentist**
- **oral hygienist**
- **restorative dentist** – a dentist who specialises in making sure your teeth look and work as normally as possible
- **physiotherapist** – someone who can help if you have problems moving around or with any neck and shoulder problems
- **occupational therapist** – someone who makes sure you are safe and comfortable at home, for example they can suggest and arrange minor changes to the home
- **psychologist or counsellor** – someone who can help you cope with any emotional difficulties.

One or more of the team meets with you to explain your treatment options and answer any questions you may have. You can bring a relative or friend with you to this appointment.

## Treatment decisions

Sometimes you may be offered the choice of two treatments that are equally effective for the type and stage of cancer you have. If this happens, your healthcare team can discuss the options with you, and help you choose the best treatment for you. If you have to decide between treatments, make sure you have enough information about the different options.

It is important to understand what each treatment involves, and the possible side effects, before you decide what is right for you. It can help to make a list of the questions you want to ask and to take a family member or close friend with you when you see the doctor. It may also help to take notes so you can remember what is said.

Remember to ask questions about anything you do not understand or feel worried about. You may find it helpful to discuss the benefits and disadvantages of each option with your doctor, specialist nurse, or with our cancer support specialists on **0808 808 00 00**.

## Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information.

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

## The benefits and disadvantages of treatment

Many people are frightened at the idea of having cancer treatments, particularly because of the side effects that can occur. However, these can usually be controlled with medicines. Treatment can be given for different reasons and the potential benefits will vary depending upon your individual situation.

If the cancer is advanced and has spread to other parts of the body, treatment may only be able to control it, improving symptoms and quality of life. However, for some people in this situation the treatment will have no effect on the cancer and they will get the side effects without any of the benefit.

If you have been offered treatment that aims to cure the cancer, deciding whether to accept it may not be difficult. However, if a cure is not possible and the purpose of treatment is to control the cancer for a period of time, it may be more difficult to decide whether to go ahead.

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

## Giving your consent

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

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

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

It is a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion.

You may also find it useful to write a list of questions before your appointment (see pages 156 to 157).

People sometimes feel that hospital staff are too busy to answer their questions, but it is important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you cannot make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you do not have it. It is essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You do not have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

## Before treatment starts

Before treatment starts, you see a dentist. You also see a dietitian or a speech and language therapist (SLT). If you smoke or drink alcohol, your doctor or nurse will give you advice on stopping.

### Dental care

You are more likely to get tooth decay if you have radiotherapy to the mouth area and salivary glands. If you have time before your treatment begins, you should have a complete dental check-up and have any dental work you may need.

Your cancer doctor may refer you to a dentist with experience in treating people who have head and neck cancers, or you may be asked to see your own dentist. If you are going to have radiotherapy and some of your teeth are unhealthy, you may need to have these removed before you start treatment.

Your doctor may also refer you to an oral hygienist. They can give you advice on how to look after your teeth and gums (see page 92). Knowing how to look after your mouth is very important. This is because cancer treatment may make it more sensitive and likely to get infections, particularly if you have radiotherapy.

## Eating and speech problems

Before having surgery or radiotherapy, you see a dietitian or SLT, or both. They can help with any swallowing, dietary, voice or speech problems you may have before treatment. They can also tell you about the effects treatment may have on swallowing and speaking, as well as what can be done to help.

Some people with a head and neck cancer have difficulty eating and may lose some weight. While you are waiting for treatment, it is important to eat as well as possible. You can use food supplements if needed. Increasing how much food you eat will help slow down weight loss and help you cope better with the treatments.

Sometimes radiotherapy can lead to severe difficulty in swallowing, particularly if it is combined with chemotherapy (chemoradiation). Usually this settles within a few months of finishing treatment. It can help to put on some weight before treatment starts.

If your cancer specialist thinks you may develop swallowing difficulties, they may suggest you need to be fed through a tube for a while, to ensure you have enough calories to maintain or gain weight (see page 58).

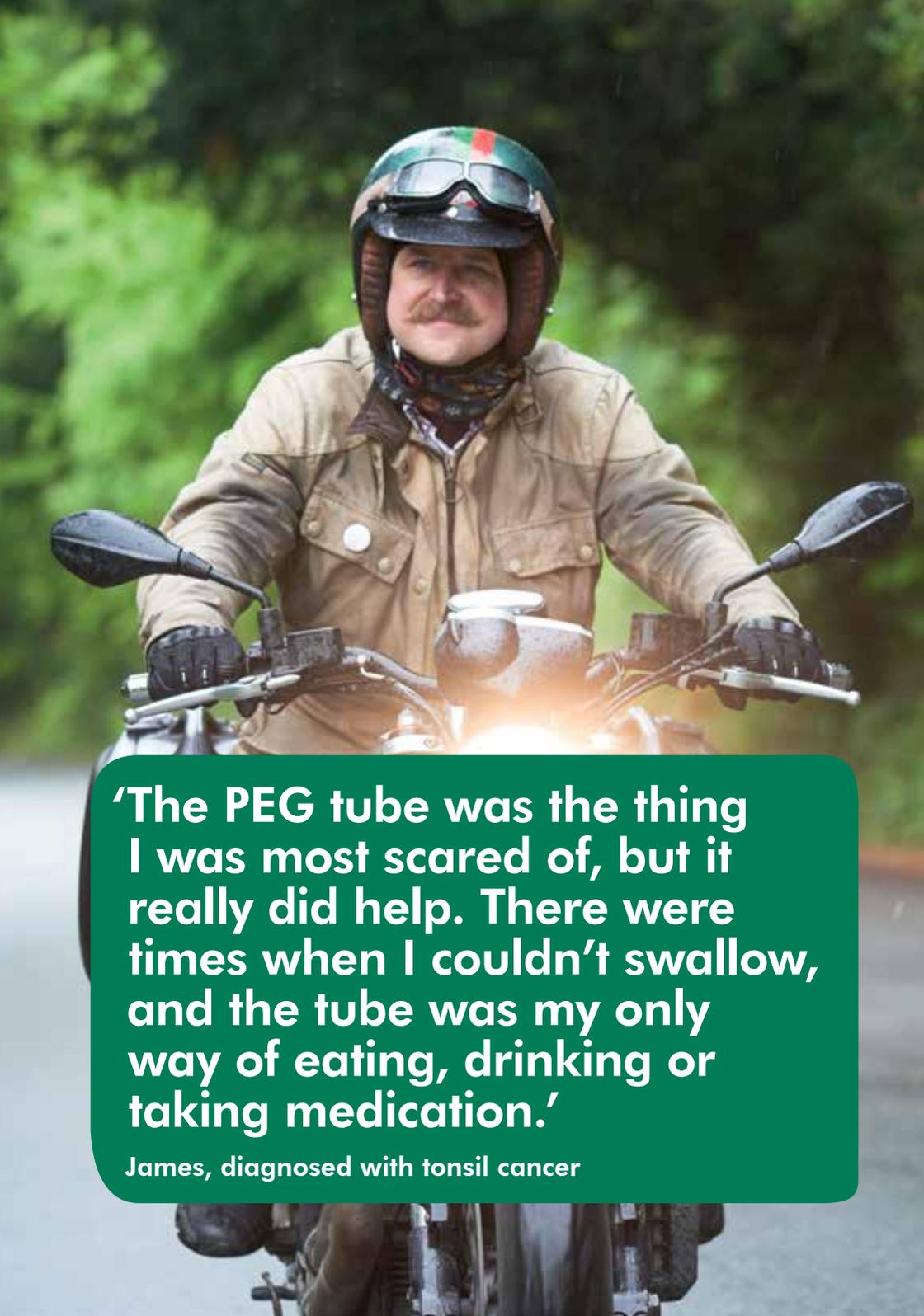
There are different ways you can be fed by a tube:

- **Nasogastric (NG) feeding** – a thin tube is passed up the nose and down into the stomach. It is used for shorter periods of time, for example less than 4 weeks.
- **Gastrostomy feeding** – a tube is passed through the skin and muscle of the tummy (abdomen) into the stomach. This is called a percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) tube, depending on how it is put into the stomach. This is usually used if tube feeding is needed for a longer period of time.

If you have swallowing problems and need tube feeding, your oncologist will explain which type is best for you. Once your swallowing improves, and you are able to eat more through your mouth, the tube can usually be removed.

You may need to go home with a feeding tube. If this happens, your dietitian, SLT or a nurse in hospital can teach you and your family members or friends to use and look after it safely. You can also have daily home visits from community nutritional care nurses, who can help with feeding tube care and setting up the feeds.

Our booklet **Eating problems and cancer** has more information about nutritional support and artificial feeding (see page 144).



**'The PEG tube was the thing I was most scared of, but it really did help. There were times when I couldn't swallow, and the tube was my only way of eating, drinking or taking medication.'**

**James, diagnosed with tonsil cancer**

## Smoking

If you smoke, there are lots of benefits of stopping smoking before treatment. Stopping smoking:

- increases the chances of your treatment being effective
- means you are likely to have fewer side effects from cancer treatment
- means the side effects of treatment may be less severe
- may reduce the risk of cancer coming back after treatment
- reduces your risk of developing a second cancer in the head or neck, and of developing cancer in other parts of the body, such as the lungs.

If you smoke and are going to have surgery, your surgeon will discuss the benefits of giving up smoking before your operation. It is best to try to stop 8 weeks before having surgery. Even if you only stop smoking 2 to 3 weeks before the operation and you do not smoke afterwards, this will reduce the risk of complications.

If you stop smoking before having surgery:

- you are likely to recover more quickly
- you are more likely have a shorter stay in hospital
- your wound is likely to heal more quickly.

It can be difficult to stop smoking, especially when you are stressed. You can ask for help and support with stopping smoking at your hospital. NHS Stop Smoking Services can really make a difference to your chances of success (see page 150). Research shows that people who use it are twice as likely to succeed as people who try to give up on their own.

Speak to your doctor or call a stop smoking helpline for more advice and to find out where your local Stop Smoking Service is.

Your GP can also give advice. They can provide nicotine replacement therapies on prescription, such as nicotine patches, gums and inhalers.

We have more information about giving up smoking that you may find helpful (see page 144).

## **Alcohol**

If you drink alcohol, you can help make your treatment more effective by not drinking alcohol. This helps reduce the risk of side effects.

Stopping drinking alcohol also reduces the risk of another head and neck cancer developing.

If you would like support to help reduce how much alcohol you drink, your specialist nurse or doctor can arrange this for you.

# Surgery

Surgery is one of the main treatments for cancers of the head and neck. The type of surgery you have depends on the size and position of the cancer, and whether it has spread (its stage) – see pages 42 to 43.

The main aim of surgery is to remove the cancer completely. But your surgeon will also do everything possible to minimise the changes that surgery may cause to your speech, swallowing and breathing (see pages 74 to 75).

Before your operation, your surgeon will discuss the type of surgery with you. It is important that you understand what they are going to remove and how this will affect you after the operation, in the short and long term.

There may be a risk your speech, swallowing or eating could be affected for a time after surgery. If this is the case, you may also meet a speech and language therapist (SLT) or dietitian before the operation.

## Types of surgery

You usually need to stay in hospital if you have surgery for a head and neck cancer. 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. In that case, there is no need to stay in hospital overnight.

If you have a small cancer in the mouth, the surgeon may operate through the open mouth. This means you will not have any external scars, unless you are having a neck dissection.

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.

If the cancer is in or near the voice box (larynx), the surgeon may need to remove some or all of the voice box. This is known as a partial or total laryngectomy. The surgery will affect your speech.

The surgeon will discuss the operation with you beforehand.

## **Neck dissection**

If the cancer spreads from where it started in the head or neck, it is likely to go to the lymph nodes in the neck.

If tests show the cancer has spread to the lymph nodes, you may have an operation to remove some or all of the lymph nodes in one or both sides of the neck. This is called a neck dissection. It may also be done if the cancer is large, even if there are no signs of cancer in the lymph nodes. This is because when the cancer is large, there may be small amounts of cancer in the lymph nodes that do not show up on scans or in other tests.

Your cancer specialist assesses the risk of the cancer being in lymph nodes in the neck. This helps them decide whether you need to have a neck dissection. Your risk depends on the type of head and neck cancer you have, the size of the tumour and where it is.

If you are having lymph nodes removed from the neck, you may have this done at the same time as the operation to remove the cancer. Or you may have a neck dissection before having radiotherapy or chemoradiation as your main treatment. A neck dissection may also sometimes be done if the cancer has come back (recurred) in the nodes after treatment.

After a neck dissection, the nerve that helps move the lower lip can sometimes be affected. This can cause weakness on one side of the mouth. It may mean your smile is a bit crooked (asymmetrical) for a while, but this usually returns to normal after a few months.

The nerve that helps with shoulder movement may also be affected. This can cause shoulder stiffness. A physiotherapist can give you exercises to help with this.

Other nerves may also be affected. Your surgeon can explain more about the possible effects after having a neck dissection.

## **Reconstructive surgery**

Your operation may involve removing tissue that is used for speech or swallowing. It might also affect your appearance. If this is the case, you may have reconstructive surgery as part of the operation. This is when 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 known as a flap.

If the cancer is in the jawbone, the surgeon needs to remove the affected bone, as well as the tumour. They may use bone from another part of the body (usually the lower leg) to replace the missing jawbone. This is known as a bone flap. Your doctor and specialist nurse can give you specific information about this type of operation. You can usually move your jaw again as soon as the operation is over.

Before you have surgery that is likely to change your appearance, it may help to talk to someone who has had a similar operation. Your surgeon or specialist nurse may be able to put you in touch with people. They can talk to you about how the surgery has affected them, and how they have coped.

We have more information about coping with changes to how you look (see pages 120 to 122).

'The doctors were extremely kind, honest and helpful. My best option was to have surgery to remove the tumour and reconstruct my mouth with muscle, fat and skin from my tummy.'

**Christine**

## **Prosthesis (artificial replacement)**

Sometimes, the surgeon may need to remove bones from the face, such as the cheekbone or palate, to remove all of the cancer. Depending on the extent of the operation, they may offer you an artificial replacement called a prosthesis (false part). This is a specially designed, soft, plastic replacement for the part of the face that has been removed.

The most common prosthesis is an obturator. This is a denture with an extension that is used to cover any gaps in the roof of the mouth.

If you are likely to need a prosthesis, your doctor and specialist nurse will discuss this with you before your operation. You will also talk to a prosthetics technician, who will be involved in designing and making your prosthesis.

It is important to discuss your operation in detail with your surgical team, so you know what to expect and how it will affect you.

## **Less common types of surgery**

### **Transoral laser surgery**

This type of surgery is sometimes used to treat smaller cancers on the lip, mouth or throat. Laser surgery is a way of removing a tumour using a high-power beam of light.

The light may be attached to a microscope, so the surgeon can see the tissue in detail when they are operating.

Transoral means the surgeon operates through the open mouth, so this surgery does not cause any external cuts or scars.

## Transoral robotic surgery

This type of surgery may be used to treat smaller cancers on the tonsils, tongue base or throat. The surgeon controls robotic instruments to perform the surgery. The surgeon operates through the open mouth, so this surgery does not cause any external cuts or scars.

## After the operation

Some people have surgery as a day patient, but surgery often involves a stay in hospital. This may be for several days or up to a few weeks. How long you stay depends on the type of surgery you have and whether or not you have 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. A physiotherapist will explain these to you.

If you have had a bigger operation, you may spend some time in intensive care immediately after the operation. This is a ward where you have one-to-one nursing care for as long as necessary to help you recover.

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

We have more information about drips, drains and tubes on pages 68 to 71.

## Drips

Operations to the mouth and throat area usually cause quite a lot of swelling. This can make eating and drinking uncomfortable for a time. Because of this, you will probably wake up from the operation with a tube going into a vein in your arm or neck (an intravenous drip). The nurses will give you fluids through this tube for a few days. They remove the drip when you are able to drink fluids again.

## Drains and dressings

Depending on the extent of your surgery, you may have 1 or 2 thin, plastic drainage tubes coming from the operation area. The tubes have bottles attached to them to collect fluid from the wound. This helps the wound to heal. Drains usually stay in place for 2 to 7 days.

If you have had reconstructive surgery using tissue taken from another part of your body, you may also have stitches, a drain and a dressing on this area.

When you go home, a district nurse can check and dress your wound and drain (if it is still in) if necessary. Or you may be asked to go back to the hospital every few days to have it checked. If you do not have dissolvable stitches, you usually have your stitches or staples removed about 7 days after your operation.

## Feeding tube

You may not be able to eat for a short time while your tissue heals. This means you may have to get the food and nutrition you need through a feeding tube that goes into your stomach. This may be put in before or during the operation.

If you need a feeding tube, your cancer specialist will talk to you about this before your operation. Your dietitian will also talk to you and provide support afterwards. They will prescribe high-protein, high-calorie, liquid food, which is given through the tube.

Once your mouth and throat have healed, your surgeon may arrange for you to have a swallowing assessment by your speech and language therapist (SLT). This is to check whether you have any swallowing difficulties. When you can eat and swallow safely, the feeding tube is removed.

If you are going to have radiotherapy after your surgery, you may need a feeding tube until all your treatment is completed. This is because radiotherapy can give you a sore mouth and throat, which can make it difficult for you to eat.

If you need to go home with a feeding tube, your dietician, SLT or a nurse in the hospital can teach you and your family members or friends how to use and to look after it safely. You can also have daily home visits from community nutritional care nurses. They can help with feeding tube care and setting up the feeds.

## Passing urine

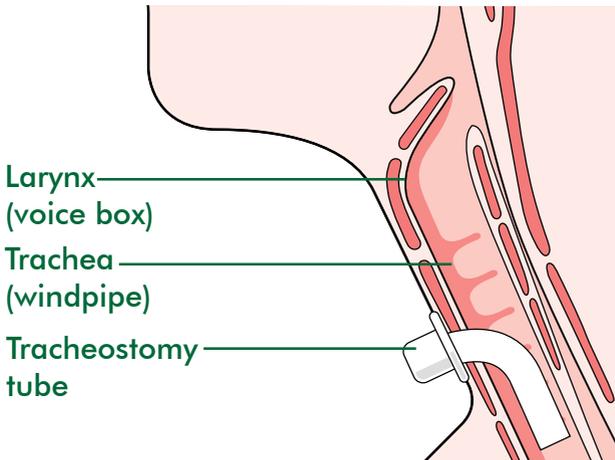
You may have a small tube (catheter) to drain pee (urine) from your bladder into a collecting bag. This stops you having to get up to pee (pass urine). It also helps the doctors monitor how well your kidneys are working. It is usually removed after a couple of days.

## Temporary tracheostomy tube

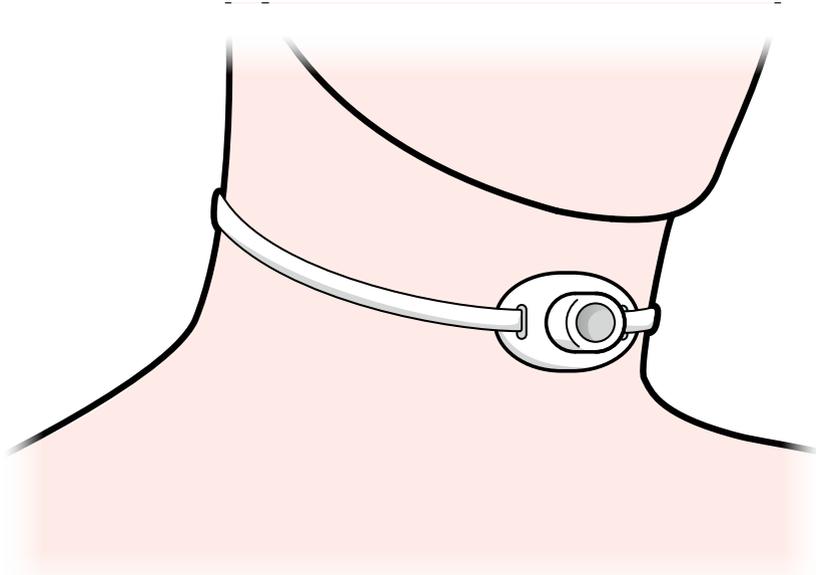
Sometimes surgery to the mouth or throat can cause temporary swelling around the throat. This can narrow the airway and make it difficult for you to breathe. If the type of surgery you are having is likely to cause this problem, the surgeon creates a small opening into the windpipe for you to breathe through. This is called a tracheostomy or stoma.

The opening is made in the lower part of the front of the neck. It is held open by a small plastic tube that is a few centimetres long. When the swelling from your operation goes down (after about 5 to 7 days) and you can breathe easily, the tube is taken out. The opening will then be left to heal over naturally.

## Position of a tracheostomy tube



## A tracheostomy tube



If you have a tracheostomy, you cannot usually speak with the tube in place. But you can use a pen and paper, or a mobile phone, laptop or tablet to communicate with other people.

If you are likely to have a temporary tracheostomy after your operation, your surgeon will explain this to you before your operation. You will also have time to ask the specialist nurse or SLT questions about it before you have your surgery.



## Recovery

### Pain

You may have some pain or discomfort for a few days or weeks after your operation. Your doctor or nurse will explain how to manage the pain. It is important to let the staff caring for you know if you are still in pain. If the painkillers are not relieving your pain, they may be able to increase the dose or change the painkillers.

Our booklet **Managing cancer pain** has more information you may find useful (see page 144).

### Changes in sensation or numbness

Surgery may affect the sensation or feeling in your mouth, face, 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 for normal sensation to come back.

If you have a scar on the surface of your skin after the operation, it is common for the skin around the area to feel numb. It may take several months for normal sensation to come back.

Sometimes, if a cancer is growing very close to a nerve, the only way to remove all of the cancer is by cutting the nerve. If this happens, the changes in sensation can be permanent.

Our booklet **Managing the late effects of head and neck cancer treatment** has more information about numbness and changes in sensation. See page 144 for ways to order this.

## Speech

Some operations to the mouth and throat can affect the way you speak. The throat, nose, mouth, tongue, teeth, lips and soft palate are all involved in producing speech. Any operation that changes one of these parts of the head and neck may affect your speech or voice, or both.

For some people, this is hardly noticeable. But for others, their speech or voice is temporarily or permanently changed. A speech and language therapist (SLT) can help you adapt to any changes, and help improve your communication.

We have more information about managing changes to speech and voice (see pages 129 to 130).

'It was a case of learning to use the new tongue. The main thing was speech therapy. I still had feeling in the tip of my tongue and that made things a lot easier. It still took time though.'

**Alison**

## Swallowing

When you are ready to start taking fluids and food by mouth, you will see a speech and language therapist (SLT). If chewing or swallowing is difficult, they will give you advice on foods that are easy to swallow. You may cough when you eat and drink. This can sometimes be sign that food is going down the wrong way (into the airway). Your SLT can teach you exercises to help with swallowing and stop this from happening.

We have more information about help with swallowing (see pages 124 to 128).

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

Some operations to the back of the mouth and throat can lead to 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 your operation, your surgeons and specialist nurse can talk to you about the possible changes in your appearance. It is important to have a good idea of what to expect.

Operations that are done in the mouth or throat can often cause swelling, so your face and neck may look very swollen immediately after the operation. This slowly gets better over a few months.

Whenever possible, your surgeon plans the operation so that if you have scars, they 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 slowly fade over time.

It can take some time to adjust to changes in how you look. It is important to know that support is available.

We have more information about coping with changes in your appearance (see pages 120 to 122).

### **Preparing to go home**

Before you leave hospital, you will be given an appointment for a check-up or to plan further treatment, such as radiotherapy. You will also be given appointments if you need to see any other members of the team, such as your SLT, specialist nurse or dietitian.

If it is needed, the ward nurses can arrange for district nurses to visit you at home and look at any wounds and dressings.

# Radiotherapy

Radiotherapy uses high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells. It is an important treatment for head and neck cancers. Radiotherapy can be used on its own, but is often given in combination with chemotherapy (see pages 98 to 104). This is called chemoradiation.

## 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 for cancers in harder-to-reach areas, such as the back of the mouth or throat. Radiotherapy may also be used when surgery could seriously affect important functions, such as speech and swallowing.

## Radiotherapy for locally advanced cancers

If a cancer is bigger, or is affecting other tissues nearby (locally advanced cancer), radiotherapy is usually combined with other treatments. It may be given:

- after surgery (with or without chemotherapy) to destroy any remaining cancer cells and reduce the risk of cancer coming back
- in combination with chemotherapy (chemoradiation), without surgery (see pages 98 to 104)
- in combination with the targeted therapy drug cetuximab (see pages 105 to 106)
- to reduce symptoms (palliative radiotherapy).

## **Radiotherapy after surgery (adjuvant radiotherapy)**

If you have surgery for advanced cancer, you are usually given radiotherapy afterwards. This is to reduce the risk of the cancer coming back. It is called adjuvant radiotherapy.

Sometimes chemotherapy and radiotherapy are given together after surgery. This is called adjuvant chemoradiation.

If you need adjuvant treatment, your specialist team will decide whether radiotherapy or chemoradiation is best for your situation.

## **Chemoradiation**

Chemoradiation is often the main treatment for advanced head and neck cancers. It may be used:

- to treat cancers that cannot be removed with surgery
- to treat cancers in harder-to-reach areas, such as the nasopharynx or throat
- when surgery could cause severe changes to speech or swallowing.

## **Radiotherapy and cetuximab**

Combining chemotherapy and radiotherapy (chemoradiation) is a very effective treatment for head and neck cancers, but it can also cause severe side effects. Some people cannot have chemoradiation because they:

- are not well enough to cope with these side effects
- have other health problems that could be made worse by chemotherapy.

Instead, they may be given radiotherapy in combination with a targeted therapy drug called cetuximab (see pages 105 to 106).

A radiotherapy machine



## **Palliative radiotherapy**

Sometimes it is not possible to cure a cancer, and the main aim of treatment is to relieve symptoms. This is called palliative treatment.

Palliative radiotherapy may be used to:

- 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. Your radiotherapy doctor (clinical oncologist) or specialist nurse will discuss the treatment with you.

### **Intensity-modulated radiotherapy (IMRT)**

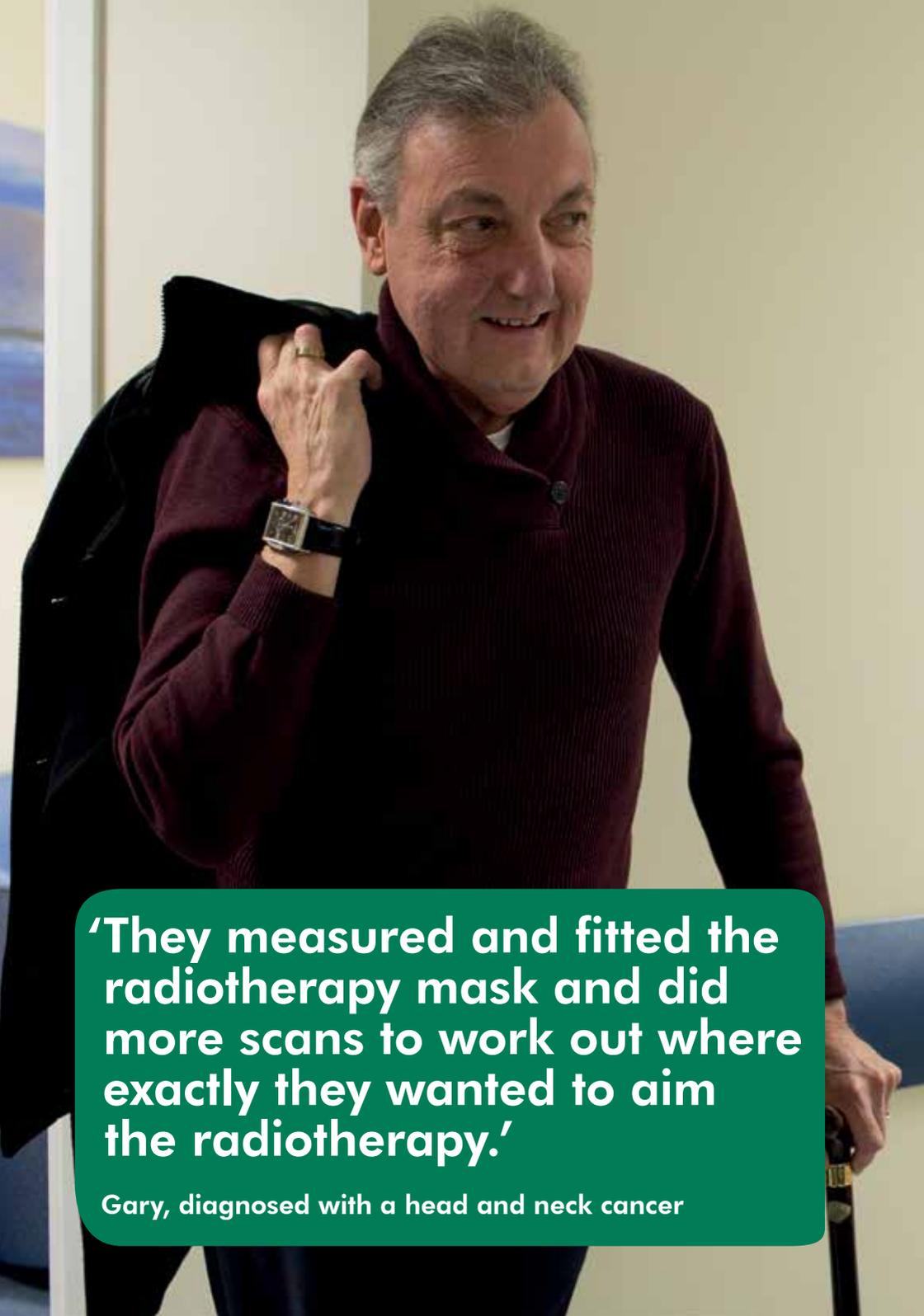
This is the most common type of external-beam radiotherapy used for head and neck cancers. It uses several beams of radiation that come from different directions. A special attachment on the radiotherapy machine arranges the radiation beams to match the shape of the cancer. Shaping the beams lets the 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.

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)**

This is a simpler type of external-beam radiotherapy. It may be used to give lower doses of radiotherapy.



**'They measured and fitted the radiotherapy mask and did more scans to work out where exactly they wanted to aim the radiotherapy.'**

**Gary, diagnosed with a head and neck cancer**

## Radiotherapy planning

To make sure your radiotherapy is as effective as possible, it has to be carefully planned. Planning makes sure the radiotherapy rays are aimed precisely at the cancer and cause the least possible damage to the surrounding healthy tissues. The treatment is planned by a specialist doctor called a clinical oncologist.

Radiotherapy planning is usually done during one visit to the radiotherapy department. It usually takes about 2 hours. Sometimes you may need to make more than one visit.

To start with, you meet the radiographers (experts in giving radiotherapy). They can answer any questions you have.

It is important that you lie still, in exactly the same position, for each treatment. To help you do this, you wear a clear plastic, mesh mask for each session of radiotherapy. The mask is designed so you can see and breathe normally while wearing it. It is sometimes also called a mould, head shell or cast.

The mask holds your head and neck as still as possible. You have it on for up to about 15 minutes at a time. It fits tightly but should not be uncomfortable. Most people soon get used to it. But it is important to talk to the radiographer, mould room technician or your specialist nurse if you find it difficult to wear the mask. They can suggest things that might help.

You have the radiotherapy mask made after you have met the radiographers. The radiographer or the mask room technician explains the process to you before starting.

Once you have your mask, you will have a CT scan of the area to be treated (see page 38). The radiographers take measurements to plan the treatment specifically for you. Some people also have an MRI scan as part of their radiotherapy planning (see page 40).

The radiographer's measurements and the information from the scans are entered into the radiotherapy planning computer. Your doctors then use this to plan your treatment precisely.

Sometimes, marks might be drawn on your mask. These help the radiographer position you accurately before each treatment.

### **Tracheostomy tube**

Very occasionally, radiotherapy to the mouth or throat can cause swelling in tissues around the airways. This can make breathing difficult. If this is likely to happen, 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 (see pages 70 to 71).

A tracheostomy is usually temporary.

## **Having radiotherapy**

Before each treatment session, the radiographer positions you on the treatment couch and carefully fits your mask. The treatment only takes a few minutes. During this time, you are left alone in the room, but the radiographer can see you from the next room. If you are worried about anything, you can speak to them through the intercom and they will come in to help you. If there is not an intercom in the room, the radiographers will tell you how you can get their attention if you need to.

In some treatment rooms, you can listen to music to help you relax during your treatment. If you would like to listen to your own music, ask your radiographers if this is possible.

You do not feel anything during the treatment. Some radiotherapy machines make a small beeping noise. This is just so that you know when the treatment is starting and when it has finished.

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



Having radiotherapy

## Side effects of radiotherapy

Radiotherapy to the head and neck can cause temporary side effects, such as a sore mouth or throat and difficulty swallowing (see pages 90 to 91). 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 to develop after about 2 weeks of radiotherapy. They may continue for 7 to 10 days after treatment ends, before slowly improving. Most people notice an improvement in their side effects 6 to 8 weeks after radiotherapy has ended.

Sometimes radiotherapy can cause long-lasting side effects, or new side effects that develop months or even years later. These are called long-term effects and late effects (see pages 96 to 97). Two of the most common late effects are a dry mouth and an increased risk of tooth decay. It is very important to follow a regular mouth care routine (see page 92) during and after radiotherapy.

Your specialist can tell you whether your treatment may cause any late effects. They will also tell you about things you can do to help reduce the risk of having problems.

## What you can do to help reduce side effects

### Look after your mouth

It is very important to look after your mouth during and after radiotherapy. Keeping your mouth as clean as possible can help protect your teeth, encourage tissue to heal and reduce the risk of problems in the future.

### Stop smoking

Smoking during radiotherapy is likely to make your side effects worse. It also reduces the effect of radiotherapy on the cancer. If you smoke, stopping smoking will help your recovery. We have more information and support to help you stop (see pages 114 to 115).

### Limit how much alcohol you drink

Alcohol, especially spirits, will irritate the areas affected by your treatment. So it is best not to drink alcohol or use mouthwashes containing alcohol during radiotherapy.

## Eat a healthy diet

Eating can be hard during treatment, but it is important to get the nutrition you need. This helps your tissues heal, increases your strength and may also reduce your risk of having some long-term effects of radiotherapy.

If you are finding it difficult to eat, tell your specialist nurse, doctor or radiographer. They can refer you to see a dietitian, if you do not already have one. There are lots of things that can help make sure you get the food and nutrition you need.

Your doctor may recommend you have a feeding tube inserted if you are not able to eat enough and you are losing weight. The tube is usually in place for a few weeks while you finish your treatment, and can normally be removed when you start to eat and drink again.

If swallowing is a problem, a speech and language therapist (SLT) can give you advice and support.

Our booklet **Eating problems and cancer** has more information about feeding tubes and how to cope with eating problems (see page 144).

## 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 (a bit like sunburn). This usually starts after about 2 weeks of treatment and lasts for up to 4 weeks after radiotherapy has finished.

The radiotherapy team will advise you on how to look after your skin. They can give you painkillers and advice about caring for your skin until it heals.

Wash your skin gently with soap or aqueous cream and lukewarm water and gently pat it dry. It is very important to only use the soaps, creams and lotions that the radiotherapy team recommend, as chemicals in some products can make the skin more sensitive to radiation. Moisturisers need to be sodium lauryl sulphate (SLS)-free. Your radiographer can give you more information about this. They can prescribe creams for you to use if your skin becomes very sore. It is also best to avoid wet-shaving for a time, as your skin will be very delicate.

Loose, cotton clothing is less likely to irritate sore skin. It is also best to avoid clothes with stiff or tight collars.

The skin in the area being treated will be more sensitive to the sun during and after radiotherapy, especially in the first year. Covering up with a sun hat and a soft, cotton or silk scarf around your neck will help protect your skin from the sun. Once any skin reaction has disappeared, use a sun-protection cream with a high SPF of at least 30.

The radiotherapy team can talk to you about when and how to use sun-protection cream after your treatment.

## Sore mouth and throat

Your mouth and throat are likely to become sore after a couple of weeks of treatment. You may also develop mouth ulcers. You will be prescribed painkillers to take regularly. Tell your cancer specialist if your mouth is still sore. You may need stronger painkillers, or you may have an infection in your mouth that needs treatment.

Towards the end of radiotherapy, your mouth is likely to be extremely 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.

Your dietitian will see you regularly during treatment, as it can be difficult to eat solid food while having radiotherapy to the head and neck area. They will make sure you are having enough nutrition and calories each day.

Some people need to be fed through a tube if they cannot eat and are losing lots of weight. This is known as artificial or tube feeding (see pages 57 to 58). It is only done for a short time until treatment is finished and your swallowing is back to normal.

Once your course of radiotherapy has finished, your mouth and throat slowly heal. Most people get back to eating normally after a few weeks. But it can sometimes take longer.

Radiotherapy to the head and neck often reduces the amount of saliva you make. Saliva washes your teeth and protects them from decay. So after radiotherapy, you are much more likely to get tooth decay.

You should see your dentist every 3 to 6 months and see a dental hygienist when your dentist suggests. Having regular check-ups means that if you develop any mouth problems, they can be picked up early when they are easier to treat. Your dentist or hygienist can give you a mouth care routine you can follow to help prevent problems.

Our booklet **Managing the late effects of head and neck cancer treatment** has more information on looking after your mouth during treatment (see page 144).

## Tips for looking after your mouth and teeth

- Brush your teeth or dentures with a small, soft toothbrush after each meal.
- Use fluoride toothpaste and fluoride gel. The fluoride helps to protect and strengthen your teeth.
- Rinse your mouth daily with a non-alcohol-based mouthwash, prescribed by your doctor.
- You could try a salt mouth wash. Add 1 teaspoon of salt to 900ml of cooled, boiled water. You can use the mouthwash at least 4 times a day. After using it, rinse your mouth with cold or warm water. Make a fresh mouthwash each day.
- Use dental floss or tape daily to clean between your teeth. If you are having chemotherapy or radiotherapy, check with your specialist doctor or nurse before doing this.
- If your dentures are uncomfortable, you may need to leave them out for a few weeks.
- Inspect your mouth daily for signs of infection – ask your dentist or specialist nurse what to look for.
- Take sips of water and rinse your mouth regularly during the day to keep your mouth moist.
- Only have sugary and acidic foods and drinks at mealtimes.
- Do not smoke.
- Do jaw exercises as advised by your specialist to prevent jaw stiffness.

## 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.

Sipping water regularly helps reduce the dry feeling, so carry a bottle of water with you. Eating soft, moist foods with gravy and sauces is easier than dry or chewy foods.

You may be prescribed artificial saliva to help your mouth feel more comfortable. It comes in different forms, such as sprays, gels, lozenges and pastilles. You may have to try different types to find one that works for you.

Some people find that using a humidifier in their home helps, as it makes the atmosphere less dry.

'I'm 15 months post radiotherapy and my saliva has come back slowly. Taste is also coming back. I can eat most things now, but I have to chew twice as much so I can swallow food.'

**Dave**

Your lips can also feel dry and chapped. You can keep your lips comfortable by using a lip balm regularly. But during radiotherapy, you should avoid products that are coloured, perfumed or flavoured.

After a few months, you may begin 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.

Our booklet **Managing the late effects of head and neck cancer treatment** has more information about coping with a dry mouth that you may find helpful (see page 144).

### **Thick, sticky saliva (mucus)**

Radiotherapy can change the consistency of your saliva. It may become thicker, stringy and sticky, like mucus. The mucus does not flow as well as normal saliva, so it may build up in the mouth and throat.

You may feel the need to spit frequently 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 every 3 to 4 hours may help clear thick saliva. To make the mouthwash, add 1 tablespoon of sodium bicarbonate to 900ml of cooled, boiled water. Rinse the mouthwash around your mouth and then spit it out. You should make a fresh mouthwash each day.

Alternatively, your specialist nurse can give you advice on the type of mouth rinse that might be best for you.

Sometimes a build-up of mucus can cause coughing, especially at night. Your nurse or doctor may prescribe a nebuliser. This is a small machine that changes liquid medicine into a fine mist or spray, to help to loosen the mucus. If your sleep is disturbed by coughing, using a nebuliser before bed may help.

Changes in your saliva may get better within about 8 weeks of radiotherapy ending. But sometimes it continues for several months or longer. If the mucus continues, tell your cancer specialist or nurse. They may be able to prescribe medicines to reduce the amount you make.

## **Bad breath**

Bad breath is usually caused by changes to your saliva and can be reduced by regular mouth care (see page 92). It may also be caused by an infection in the mouth, which is common during radiotherapy treatment. If you have an infection, it can be treated with antibiotic or antifungal medicine.

## **Loss of taste**

Radiotherapy to your head and neck affects your sense of taste. Some people lose their sense of taste completely or find that everything tastes the same (usually quite metallic or salty). Although your sense of taste should recover, it may take many months for this to happen.

We have more information on coping with taste changes and other eating problems (see page 144).

## **A hoarse voice**

You may notice your voice becomes hoarse during treatment. If this happens, do not strain it. Try to rest your voice and avoid smoky atmospheres. A speech and language therapist (SLT) can give you more advice on what to do if your voice becomes hoarse. Your voice usually recovers after a few weeks.

## Feeling sick (nausea)

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

We have more information about controlling nausea and vomiting (see page 144).

## Tiredness (fatigue)

You are likely to become more tired as treatment goes on and have 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.

Our booklet **Physical activity and cancer** has more information about managing fatigue (see page 144).

## Possible late (long-term) effects of radiotherapy

Modern ways of planning and giving radiotherapy are designed to limit the chances of late side effects as much as possible. But some people do have long-term effects after radiotherapy to the head and neck.

Many treatment side effects get better over time. If you have side effects that are not getting better or if you develop new symptoms, let your cancer specialist know. They will assess your symptoms and explain if they are likely to be a result of treatment. You may have tests to find out the cause.

Not everyone will have a long-term effect of treatment. If you are concerned about the risk of developing particular side effects, speak to your cancer doctor or specialist nurse.

The most common late effects include:

- a dry mouth
- difficulty swallowing
- taste changes
- a higher risk of tooth decay
- stiffness in the jaw, neck or shoulders
- changes to your hearing
- changes in how you look.

We have more information about managing the late effects of head and neck treatment (see page 144).

# Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. Cytotoxic means toxic to cells. These drugs disrupt the way cancer cells grow and divide but they also affect normal cells.

## Having chemotherapy

Chemotherapy is usually given in combination with radiotherapy to treat locally advanced head and neck cancers (see pages 77 to 97). This is called chemoradiation.

Sometimes chemotherapy can be given before radiotherapy. This is to shrink the tumour and help to make the radiotherapy more effective.

Chemotherapy may also be used to relieve symptoms and improve quality of life if it is not possible to cure the cancer. This is called palliative chemotherapy.

Chemotherapy drugs are usually given into a vein (intravenously), but some are given as tablets. The drugs travel in the blood, which means they can reach cancer cells that might be elsewhere in the body.

Chemotherapy is usually given as several sessions of treatment, with rest periods in between the sessions. Chemotherapy and the rest period make up a cycle of your treatment. Your cancer doctor will explain the number of cycles you need to treat the cancer. This is your course of treatment.

## Having chemotherapy



Sometimes, intravenous chemotherapy is given continuously over a few days. The chemotherapy can sometimes be given through a small, portable pump. This allows you to go home during your treatment. The pump is attached to a thin tube that is inserted into a vein in:

- the bend of the arm (PICC line)
- the chest (central line).

Our booklet **Understanding chemotherapy** has more information about this treatment (see page 144).

Chemotherapy drugs commonly used to treat head and neck cancers are:

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

## Possible side effects of chemotherapy

### 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
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

**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.

## **Bruising and bleeding**

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. If you develop any unexplained bruising or bleeding, such as nosebleeds, bleeding gums, blood spots or rashes on the skin, contact your doctor or the hospital straight away.

## **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. These symptoms happen because the red blood cells contain haemoglobin, which carries oxygen around the body.

If your haemoglobin is low you may be offered a blood transfusion. You'll feel more energetic and any breathlessness will be eased.

## **Feeling sick**

Some chemotherapy drugs can make you feel sick (nauseated) or possibly be sick (vomit). Your cancer specialist will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take.

We have more information about nausea and vomiting on our website (see page 144).

## **Sore mouth**

Your mouth may become sore or dry, or you may notice small ulcers during treatment. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help to reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems, as they can prescribe mouthwashes and medicine to prevent or clear mouth infections.

## **Numbness or tingling in the hands or feet**

If you have treatment with cisplatin, paclitaxel or docetaxel, you may have changes in sensation in your hands and feet. This is caused by the effect these drugs can have on nerves. It is called peripheral neuropathy. You may also notice you have difficulty doing up buttons or similar fiddly tasks.

Tell your doctor if you notice these symptoms. They may need to lower your chemotherapy dose slightly or change the drugs.

Changes in sensation can continue to get worse for 2 to 3 months after stopping chemotherapy, before slowly improving. It can take up to 2 years for symptoms to improve. Sometimes changes are permanent.

We have more information about peripheral neuropathy on our website (see page 144).

## **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 ends. Tell your doctor if you notice any loss of hearing or tinnitus. They may suggest changing the dose of your chemotherapy.

## Tiredness (fatigue)

Chemotherapy affects people in different ways. Tiredness can build up over a course of treatment. And if you have had a lot of chemotherapy or a combination of treatments, it can last for several months or more after your treatment has finished.

Try to cut down on any unnecessary activities. Ask your family or friends to help with jobs such as shopping and housework. Gentle exercise can sometimes help with the symptoms of fatigue.

## Hair loss

Some chemotherapy drugs 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 what 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 3–6 months of the end of treatment. 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.

Our booklet **Coping with hair loss** has more information (see page 144).

## 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 peeing (passing urine) much.

# Targeted therapies

Targeted therapies interfere with the way cells grow and divide. They are sometimes known as biological therapies. They can be used to:

- stimulate the immune system
- control the growth of cancer cells
- improve side effects of treatment.

The most commonly used targeted therapy to treat head and neck cancers is cetuximab (Erbix<sup>®</sup>). It belongs to a group of cancer drugs known as monoclonal antibodies. They work by targeting specific proteins (receptors) on the surface of cells. Cetuximab is given as a drip (infusion) into a vein.

Targeted therapies may be used to treat some head and neck cancers:

- in combination with radiotherapy (see pages 77 to 97), for people who are not fit enough to cope with the side effects of chemoradiation
- as part of a clinical trial (see pages 107 to 109) in combination with chemoradiation
- with palliative chemotherapy (see pages 98 to 104).

## How cetuximab works

Most squamous cell cancers (see page 20) of the head and neck have proteins called epidermal growth factor receptors (EGFRs) on their surface. The body makes chemical messengers, called growth factors. These attach to the receptors on the cancer. This stimulates the cancer to grow and divide.

Cetuximab stops the growth factors from attaching to receptors on the cancer. This can stop the receptors from stimulating the cancer cells to divide and grow. It may also make the cancer more sensitive to the effects of radiotherapy.

## Side effects of cetuximab

The side effects of cetuximab are generally 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.

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.

# Research – clinical trials

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

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

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

## Taking part in a trial

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

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

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)** – see page 144.

## Blood and tumour samples

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

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of cancer and its treatment, which will hopefully improve the outlook for future patients.

PATIENT'S  
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CUPS



# AFTER TREATMENT

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After treatment	112
Coping with physical changes	120
Who can help?	133
Your feelings	134
If you are a relative or friend	138
Relationships	139

# After treatment

## Follow-up

After your treatment, you will have regular follow-up appointments for several years. For the first two years, you will have follow up appointments more often. Your specialist will regularly examine your head and neck area. This is the most important part of your follow-up. You may also have scans from time to time.

It can take several months for the side effects of the treatment to get better. Tell your specialist about any ongoing side effects or symptoms that are not improving. You should also tell them about any new symptoms that do not get better within two weeks. Symptoms could include new ulcers or lumps in your neck, pain, or difficulty swallowing or speaking.

If you have any problems or notice any new symptoms in between these appointments, tell your GP, specialist or nurse specialist as soon as possible.

If you cannot attend a follow-up appointment, contact your doctor, clinic or someone from your ENT (ear, nose and throat) team to make another appointment.

## Well-being and recovery

When cancer treatment ends, it can be a time of mixed emotions. You will probably feel relieved, but may also feel anxious and uncertain about the future. It can take time to rebuild confidence and accept what you have been through.

You may be keen to get back to doing all the things you did before cancer. But often this is not possible straight away. It may take time to recover from treatment.

There may be physical changes in the way you look. Or there may be changes in the way you speak or what you can eat. There will also be emotional changes to deal with. It is important to give yourself time to adjust.

There are organisations that can support you (see pages 149 to 155). Or you can speak to one of our cancer support specialists on **0808 808 00 00**. We also have information about life after cancer treatment and body image which you may find helpful (see page 144).

After treatment, you may find that everyday things that you did before cancer will slowly start to fit back into your life. Going back to work (see page 148) and getting back to the interests you had before can be important steps forward. You can talk to your specialist or nurse about the right time to return to work or restart other activities.

Some people feel that the treatment has helped them think about their priorities. They may decide to focus more on relationships with family and friends. Or they may decide to do the things they have always wanted to do.

You may want to think about making changes to your lifestyle and find out more about healthy living. Perhaps you already followed a healthy lifestyle before your cancer. But now you may want to focus more on making the most of your health. There are things you can do to help your body recover. These can also help improve your well-being and lower your risk of getting other illnesses and some cancers.

## **Eat a well-balanced diet**

If you can, try to eat a healthy, well-balanced diet, even if you have less of an appetite or interest in food.

A well-balanced diet includes:

- lots of fresh fruit and vegetables
- wholegrain foods and pulses
- a low amount of sugary food and drinks – this is particularly important if you have less saliva
- a low amount of processed and red meats and other high calorie foods, such as fast foods.

Eating well helps you keep your strength and increases your energy and sense of well-being. It can also help reduce the risk of new cancers and other diseases, such as heart disease, diabetes or having a stroke. It can be difficult to eat well after treatment for head and neck cancer, but your dietitian can help you.

## **Stop smoking**

If you are a smoker, it is important to try to give up. Smoking is the main cause of head and neck cancers.

Stopping smoking may lower the risk of cancer coming back after treatment. It will reduce your risk of developing a second cancer in your head or neck. It will also reduce your risk of developing cancer in other parts of your body, such as your lungs.

Giving up smoking can be difficult, but there is lots of support available. Speak to your doctor or call a stop smoking helpline for further advice. They can tell you where your local stop smoking service is. There are other useful organisations that can help, such as Quit (see page 150 for contact details).

Our booklet **Giving up smoking** has more advice and tips (see page 144).

## Drink less alcohol

Drinking alcohol as well as smoking greatly increases your risk of developing another head and neck cancer. If you drink alcohol, drinking less will help reduce this risk.

Many people find making this positive choice helps give them back a sense of control. It can also help you feel that you are doing the best for your health.

NHS guidelines suggest that both men and women should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over three 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, one 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](http://drinkaware.co.uk)**

## Try to keep 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 how much and what type of exercise would be helpful for you. Start slowly and increase your activity over time.

Our booklet **Physical activity and cancer** has more information about the benefits of exercise (see page 144).

## Complementary therapies

Some people find that complementary therapies can help them feel better and reduce symptoms. Complementary therapies can include acupuncture, massage, aromatherapy and relaxation techniques. Many hospitals and hospices offer these therapies.

If you would like to try a complementary therapy, check with your cancer specialist or GP before using it. This is important because some complementary therapies should be avoided during, and for a short time after, cancer treatments.

## Talking to someone or sharing your experience

Talking about your feelings can help reduce feelings of stress, anxiety and isolation.

Try to let your family and friends know how you are feeling so that they can support you.

Talking about your feelings is not always easy. We have more information that has helpful tips about talking about cancer. See page 144.

You can call us on **0808 808 00 00** or visit **macmillan.org.uk** for information about cancer support groups in your area.

If you find it hard to speak because of the effects of cancer or its treatment, you may find it more helpful to share your experience and find support online. See page 118.

## Online support

Many people now get support through the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by cancer. You can use these to ask questions and share your experience.

Our Online Community is a social networking site where you can talk to people on our forums, blog your journey, make friends and join support groups. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

There are also national support groups that you may find helpful:

- Changing Faces offers advice and information to anyone who is affected by a change in their appearance (see page 149 for contact details).
- The Mouth Cancer Foundation gives information and support to people affected by head and neck cancers (see page 150 for contact details).

‘When treatment finished, I was left wondering, “what next?”. My nurse told me about a course for people who had finished treatment. There I could talk to people who had faced the same situation.’

**Catherine**

## Support groups

Self-help or support groups offer a chance to talk to other people in a similar situation. Joining a group can be helpful if you live alone. Or it can help if do not feel able to talk about your feelings with people around you.

Not everyone finds talking in a group easy, so it might not be for you. Try going along to see what the group is like before you decide.

## Specialist help

Sometimes it is easier to talk to someone who is not directly involved with your illness. Your hospital consultant, nurse specialist or GP can refer you to a doctor or counsellor who specialises in the emotional effects of cancer.

Our cancer support specialists can tell you more about counselling and let you know about services in your area. Call **0808 808 00 00** for more information.

We have more information about the feelings you may have and helpful tips on how to deal with them (see pages 134 to 137).

# Coping with physical changes

Some side effects that develop during treatment may take a long time to improve, or may sometimes become permanent. These are called long-term effects. Other effects can develop many years after treatment has finished. These are known as late effects. You may not have any long-term or late effects. If you do, they may range from being mild to being more serious.

Always let your doctors know if you have any new symptoms or if side effects are not improving. Your doctor will monitor them and arrange for you to have tests, if necessary.

## Changes in your appearance

Head and neck cancer and its treatments can cause changes to the way your face looks. These changes can sometimes affect your body image. This is the picture you have in your mind of how you look, and how you think and feel about your body. Changes can also be a constant reminder of the cancer and treatment.

Thoughts and feelings about your body image can be difficult to deal with. You may find that you go through many different emotions.

It takes time to get used to a change in appearance. Everyone adjusts at their own pace and in their own way. For some people it may take weeks. For others it may take months or even years. This experience will be unique to you, but you may meet other people who have similar thoughts and feelings.

You can get advice and support from organisations such as Changing Faces, Let's Face It or Saving Faces which help people to cope with changes to their appearance (see pages 149 to 150 for contact details). Your healthcare team can also support you.

Some people find it helpful to talk to someone who has been in a similar situation. Saving Faces has a telephone support line. It can put you in touch with someone whose appearance has changed after having a head and neck cancer and who understands the challenges.

### **Skin camouflage products**

Parts of the skin on your face or neck may have been replaced with skin from another part of the body. The colour of the new skin may not match the surrounding skin. You may also have visible scars. Using camouflage products can help to reduce the difference in skin colour and the appearance of scars. Camouflage products can be matched to all skin types and colours.

Some head and neck clinical nurse specialists and organisations offer specialist skin camouflage services (see pages 149 to 150). They can give you advice on how to apply it.

Some types of skin camouflage products can be applied to facial prostheses. This can improve the colour to better match your skin tone. It can be useful in the summer when skin tone changes. If you need this, you should take the prosthesis back to the person or organisation that supplied it.

Our booklet **Body image and cancer** has more information to help you cope with changes in appearance (see page 144).

## Meeting other people

After your treatment, you and the people close to you will start to become more familiar with your changed appearance. As this happens, you may think about seeing other people and going back to work (see page 148). Avoiding social situations for a long time might make it harder to go out. It is best to start by going somewhere familiar. You may want to take someone with you for support.

Be prepared for mixed reactions. You may find that people take far less notice of you than you expected. But some people may make insensitive remarks or unhelpful suggestions. Children are often openly curious and may ask why you look different. You may want to decide in advance how to answer. Saying that you have had an operation should be enough. You do not have to go into the details.

Being able to cope with social situations will help build your self-confidence. This will increase as you gradually start doing your normal activities. These skills are not difficult to learn, but do need practice. In time, you will gain the confidence to manage social situations.

You can get more information about how to manage people's reactions from organisations such as Changing Faces or Let's Face It (see page 149 for contact details).

## Sexual relationships

Treatment for head and neck cancers can also 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, some people may no longer enjoy kissing the way they used to.

If you have a partner, they may also need time to adjust. Talking about how you both feel is important, as you can overcome any fears or worries that 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 your cancer.

If you are having difficulties with your sex life, talk to your GP. There might be a counsellor or psychologist in the practice. If not, your GP can tell you how to contact one. You could also talk to your hospital team or specialist nurse about which sexual health services are available locally. The College of Sexual and Relationship Therapists has a nationwide list of counsellors and therapists (see page 152 for contact details).

We have more information about how cancer and its treatment can affect sexuality, and what can help (see page 144).

## Changes to eating

Surgery, radiotherapy and chemoradiation to the head and neck area may affect the movements of your mouth, tongue or throat. This can make it more difficult to eat or drink.

Some people find that after treatment, foods can take longer to eat and can taste different. They might only be able manage to eat certain foods.

Some of these changes are temporary and are caused by swelling in the mouth or throat immediately after treatment. 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. It is important to talk with your family and friends about how you are feeling so they can help. You can also talk to your specialist nurse. They will understand what you are going through and may be able to help. Or they can put you in touch with 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 will assess your eating and swallowing at every stage and advise you on what you can do.

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

If you no longer have follow-up appointments, ask your GP to refer you to your specialist at the cancer centre to be assessed.

## Swallowing tests

If you are having swallowing difficulties, you may have tests to assess your swallowing.

There are two tests that can be used. These are:

- videofluoroscopy (VF)
- fiberoptic endoscopic evaluation of swallowing (FEES).

Your SLT will decide which test is best for you.

### Videofluoroscopy (VF)

A VF is a special x-ray test which shows what happens in your mouth and throat when you swallow. It can show:

- if anything gets stuck in your throat
- if any food or drink goes down the wrong way.

This helps your SLT see how they can make swallowing safer and easier for you.

This test is done in the x-ray department by a radiographer and your SLT. They will ask you to swallow different foods of different textures. This might be:

- liquid or food with a semi-solid texture, like yoghurt
- food with a solid texture, like a biscuit.

A special substance is added to the food to make it show up on the x-ray. They may also ask you to try different techniques to see if they help when you swallow. The test takes about 30 minutes and is painless. The x-rays are recorded on video or DVD.

### **Fiberoptic endoscopic evaluation of swallowing (FEES)**

A FEES is another test to show what happens in your mouth and throat when you swallow. Your SLT passes a thin, flexible tube through the nose to look at the back of your throat. The tube contains a small camera, which records your swallowing while you eat and drink. The test takes about 10 to 20 minutes.

### **After the tests**

Your SLT will meet with you to discuss the results of the tests. The tests help them to recommend exercises and other ways to make swallowing easier for you. They will also advise you on what types of food you can eat. For example, moister foods may be easier to swallow. It may help to bring a partner, family member or friend with you when you see your SLT.

The results may show that food or liquid is getting stuck in your throat or going into the lungs. Your doctor, SLT and dietitian will discuss the best way to make sure you have enough food and fluids.

You may need to be fed directly into the stomach through a tube (see page 69). This can be put directly into your stomach or down your nose and into your stomach. Usually, this is only temporary until your swallowing recovers. Your SLT will show you exercises and techniques to help with recovery.

Sometimes, if swallowing is unsafe, the feeding tube will be permanent.



**'When I go to the hospital for follow-up appointments now, my speech therapist pops in and measures my swallow. So I know they're still there. It's quite a relief.'**

**Gary, diagnosed with a head and neck cancer**

## Tips for coping with eating problems

Here are some suggestions for coping with eating problems:

- Choose high-calorie foods that contain a lot of protein (such as soft meat, fish or cheese).
- Mix food with sauces to make them easier to swallow.
- Cook with butter or oil and add cream to appropriate foods.
- If your mouth is sore, or if swallowing is difficult, try soft foods such as creamy yoghurts, custards, scrambled eggs or mashed vegetables or fruit, such as avocado.
- Avoid foods that may irritate your mouth, such as spicy or salty foods, citrus fruit or drinks (orange, lemon and lime) and tomato sauces.
- Use marinades or strongly flavoured seasonings and herbs to flavour your food. Only use these once your mouth is no longer sore after treatment.
- Choose foods that look and smell appealing to you.
- Eating several small meals or snacks during the day may work better for you than having three large meals.
- Complement meals with nourishing fluids such as milkshakes, malt drinks and creamy soups.

Our booklet **Eating problems and cancer** has more information and helpful tips (see page 144).

## Changes to speech

Any change to your lips, teeth, tongue, soft palate or voice box is likely to make your speech or voice sound different. You may have difficulty making one or two specific sounds or saying some words. Changes to your voice may be more severe. People may not be able to easily understand what you are trying to say or hear you clearly.

For some people, these changes are only a minor problem. Their speech or voice returns to normal, or near normal, as the affected area heals. For others, it is more of a problem and causes permanent changes to the way they speak.

Losing the ability to talk, even for a short time, can be frightening and frustrating. In the first few days after your operation, you could communicate by writing things down. This will help you tell people what you need. A speech and language therapist (SLT) will be involved in your recovery from an early stage. They will be able to give support and helpful advice.

## Speech therapy

Speech therapy can help you learn to communicate in the clearest and most effective way. Therapy usually begins as soon as possible after surgery. It normally continues after you go home. It is likely to involve:

- exercises to improve the range and strength of mouth and tongue movements
- finding new ways to produce speech sounds.

If you wear dentures, they may need to be changed. Sometimes, you may need an individually designed prosthesis to improve your speech.

There are also special aids that your SLT will discuss with you, if necessary.

It can take time for you and your family and friends to adjust to changes in your speech or voice. The reactions of people you do not know may be harder to get used to. But it will get easier. You can explain that you have had an operation that has made it difficult to talk. This can help to put yourself and other people at ease.

## Changes to hearing

Some people with cancer in areas of the head and neck such as the nasopharynx may have changes in their hearing. These may be caused by the cancer, or may be a side effect of treatment. If you have problems with hearing after your treatment, you may be referred to a specialist clinic. Your specialist will recommend the best treatment for you.

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 (the Eustachian tube) becomes blocked after treatment (see pages 18 to 19). The Eustachian tube helps to regulate air pressure in the ear. If it is blocked, it can affect hearing. If this happens, you can have a simple operation to put in a tiny tube (grommet) to help the ear to drain and improve hearing. This is usually done under a local anaesthetic.

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

Our booklet **Managing the late effects of head and neck cancer treatment** has more information about coping with hearing problems and other physical changes (see page 144).



# 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's common to feel overwhelmed by different feelings when you're told that you have cancer. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You'll cope with things in your own way. Talking to people close to you or other people affected by cancer can often help.

## Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have cancer. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the cancer. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the cancer. This is because your mind is trying to process what you're going through.

## Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how many people can benefit from a type of treatment. But they cannot be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

## Avoidance

Some people cope by not wanting to know very much about the cancer and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have cancer. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have cancer. They may not want to talk about it or they might change the subject. This is usually because they are also finding the cancer difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

## Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them.

Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

## Guilt and blame

Some people feel guilty or blame themselves or others for the cancer. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's cancer. Over time, several different factors may act together to cause a cancer. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups** You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.

## If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them (see page 144).

## If you are a relative or friend

Some people find it hard to talk about cancer or share their feelings. You might think it's best to pretend everything is fine, and carry on as normal. You might not want to worry the person with cancer, or you might feel you're letting them down if you admit to being afraid. Unfortunately, denying strong emotions can make it even harder to talk, and may lead to the person with cancer feeling very isolated.

Partners, relatives and friends can help by listening carefully to what the person with cancer wants to say. It may be best not to rush into talking about the illness. Often it's enough just to listen and let the person with cancer talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking, to help friends and family support their loved ones affected by cancer. Visit [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) to find out more.

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer (see page 144).

Our booklet **Looking after someone with cancer** has more information that is helpful if you are looking after a family member or friend with cancer (see page 144). It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at [macmillan.org.uk/carers](https://www.macmillan.org.uk/carers)

# Relationships

The experience of cancer may have improved your relationships with people close to you. The support of family and friends may have helped you cope. But cancer is stressful, and this can have an effect on relationships. Any problems usually improve over time, especially if you can talk openly about them.

## Your partner

Some couples become closer through a cancer experience. However, cancer can put a lot of strain on a relationship. Problems sometimes develop, even between couples who have been together for a long time. If a relationship was already difficult, the stress of a major illness may make things worse. Even couples that are close may not always know how their partner is feeling.

Talking openly about your feelings and listening to each other can help you understand each other.

Our booklet **Cancer, you and your partner** has more information that may help (see page 144).

## Family and friends

Your family and friends may not always understand if you are not feeling positive about getting on with things, and may not know how big an effect treatment is having on your life. Talking about how you feel will help them give you the support you need.

Our booklet **Talking about cancer** has more information that you might find helpful (see page 144).

## Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children depends on their age and how mature they are. It can help to be honest with your children, as it can give them a chance to express how they feel, especially if they have sensed that you are not well. It may be best to start by giving small amounts of information, and gradually tell them more to build up a picture of your illness. It can also help to tell the school teachers as they can offer support.

## Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It is important that they can carry on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website [riprap.org.uk](http://riprap.org.uk) which has been developed especially for teenagers who have a parent with cancer.



# FURTHER INFORMATION

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About our information	144
Other ways we can help you	146
Other useful organisations	149
Your notes and questions	156

# 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 leaflets or booklets like this one. Visit [be.macmillan.org.uk](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

## Online information

All of our information is also available at [macmillan.org.uk/information-and-support](https://www.macmillan.org.uk/information-and-support)

There you'll also find videos featuring real-life 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](https://www.macmillan.org.uk/otherformats)

If you'd like us to produce information in a different format for you, email us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk) or call us on **0808 808 00 00**.

## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk) You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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 Monday to Friday, 9am to 8pm. Our cancer support specialists 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.

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://www.macmillan.org.uk/talktous)**

## Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://www.macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## 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's why we help to bring people together in their communities and online.

## Support groups

Whether you are someone living with cancer or a carer, 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](https://www.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](https://www.macmillan.org.uk/community)

## The Macmillan healthcare team

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.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

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## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've 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 benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

### Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're 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](https://www.macmillan.org.uk/work)**

### My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

There are lots of other organisations that can give you information or support.

## 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 for patient support groups. Most creams used by the British Association of Skin Camouflage can be prescribed by GPs.

### Cancer Laryngectomy Trust

**Tel** 0142 220 5522

**Email** [info@cancerlt.org](mailto:info@cancerlt.org)

**www.cancerlt.org**

Provides support to people who are about to have, or have had, a laryngectomy.

## Changing Faces

**Tel** 0300 012 0275

**Email** [support@](mailto:support@changingfaces.org.uk)

[changingfaces.org.uk](http://changingfaces.org.uk)

**www.changingfaces.org.uk**

Offers support and information for people who have any condition or injury that affects their appearance, and for their families.

## Skin camouflage service

**Tel** 0300 012 0276

**Email** [skincam@](mailto:skincam@changingfaces.org.uk)

[changingfaces.org.uk](http://changingfaces.org.uk)

**www.changingfaces.org.uk/**

**skin-camouflage**

Changing Faces has a skin camouflage service. It has skin camouflage practitioners, who can teach people how to apply specialist cover creams.

### **Let's Face It**

**Tel** 01843 491291

**Email** [chrisletsfaceit@aol.com](mailto:chrisletsfaceit@aol.com)

**www.lets-face-it.org.uk**

An international network for people with facial disfigurement. Links together patients and their families, friends and professionals for self-help, information and mutual support.

### **Mouth Cancer Foundation**

**Helpline** 01924 950 950

(Mon to Fri, 9am to 5pm)

Gives information and support to people affected by head and neck cancers.

### **Oracle Cancer Trust**

**Tel** 0207 922 7924

**www.oraclecancertrust.org**

A charity that funds research into head and neck cancers.

### **Saving Faces**

**Helpline** 07487 235438

(Mon to Fri, 9am to 5pm)

**Email** helpline

[@savingfaces.co.uk](mailto:@savingfaces.co.uk)

**www.savingfaces.co.uk**

Fund and lead research to reduce the effects of surgery to the mouth and face.

### **Skin-camouflage service**

**Tel** 0300 012 0276

**Email** [skincam@](mailto:skincam@changingfaces.org.uk)

[changingfaces.org.uk](http://changingfaces.org.uk)

**www.changingfaces.org.uk/skin-camouflage**

Changing Faces has a skin-camouflage service. It has skin camouflage-practitioners, who can teach people how to apply specialist cover creams.

### **Stop smoking services**

#### **NHS Smoking Helpline**

**Tel** 0300 123 1044

(Mon to Fri, 9am to 8pm,

Sat and Sun, 11am to 4pm)

**www.nhs.uk/smokefree/help-and-advice/support**

Offers free information, advice and support to people who are giving up smoking, and those who have given up and do not want to start again.

#### **Quit**

**Tel** 0207 553 2132

**Quitline** 0800 00 22 00

**www.quit.org.uk**

A national organisation that provides information and support to people who want to stop smoking.

## General cancer support organisations

### Cancer Black Care

**Tel** 020 8961 4151

**Email**

[info@cancerblackcare.org.uk](mailto:info@cancerblackcare.org.uk)

**[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)**

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

### Cancer Focus

#### Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

**Email**

[nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

### Cancer Research UK

**Helpline** 0808 800 4040

(Mon to Fri, 9am to 5pm)

**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

### Cancer Support Scotland

**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

**Email**

[info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### **Maggie's Centres**

**Tel** 0300 123 1801

#### **Email**

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Has a network of centres in various 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.

### **Tenovus**

**Helpline** 0808 808 1010

(Daily, 8am to 8pm)

#### **Email**

[info@tenovuscancercare.org.uk](mailto:info@tenovuscancercare.org.uk)

**[www.tenovuscancercare.org.uk](http://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.

### **Counselling and emotional support**

#### **British Association for Counselling and Psychotherapy (BACP)**

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

#### **College of Sexual and Relationship Therapists**

**Tel** 0208 5432 707

**Email** [info@cosrt.org.uk](mailto:info@cosrt.org.uk)

**[www.corst.org.uk](http://www.corst.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.

## **Mind**

**Helpline** 0300 123 3393

**Text** 86463

**Email** [info@mind.org.uk](mailto:info@mind.org.uk)

**[www.mind.org.uk](http://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](mailto:jo@samaritans.org)

**[www.samaritans.org](http://www.samaritans.org)**

Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

## **General health information**

### **Health and Social Care in Northern Ireland**

**[www.hscni.net](http://www.hscni.net)**

Provides information about health and social care services in Northern Ireland.

### **Healthtalk**

#### **Email**

[info@healthtalk.org](mailto:info@healthtalk.org)

**[www.healthtalk.org](http://www.healthtalk.org)**

**[www.healthtalk.org/young-peoples-experiences](http://www.healthtalk.org/young-peoples-experiences) (site for young people)**

Has information about cancer, and videos and audio clips of people's experiences. Also provides advice on topics such as making decisions about health and treatment.

### **NHS Choices**

**[www.nhs.uk](http://www.nhs.uk)**

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

## **NHS Direct Wales**

**[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)**

NHS health information site for Wales.

## **NHS Inform**

**Helpline** 0800 22 44 88

(Daily, 8am to 10pm)

**[www.nhsinform.scot](http://www.nhsinform.scot)**

NHS health information site for Scotland.

## **Patient UK**

**[www.patient.info](http://www.patient.info)**

Provides people in the UK with information about health and disease.

Includes evidence-based information leaflets on a variety of medical and health topics. Also reviews and links to many health and illness-related websites.

## **Support for carers**

### **Carers Trust**

**Tel** 0300 772 9600

(Mon to Fri, 9am to 5pm)

**Email** [info@carers.org](mailto:info@carers.org)

**[www.carers.org](http://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

(Mon to Wed, 10am to 4pm)

**Helpline (Northern Ireland)**

028 9043 9843

**Email** [advice@carersuk.org](mailto:advice@carersuk.org)

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and support to carers across the UK. Has an online forum and can put people in contact with support groups for carers in their area.

## **Financial or legal advice and information**

### **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 in the phone book or by contacting:

#### **England**

**Helpline** 03444 111 444  
**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

#### **Scotland**

**Helpline** 0808 800 9060  
**[www.citizensadvice.org.uk/scotland](http://www.citizensadvice.org.uk/scotland)**

#### **Wales**

**Helpline** 03444 77 2020  
**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

#### **Northern Ireland**

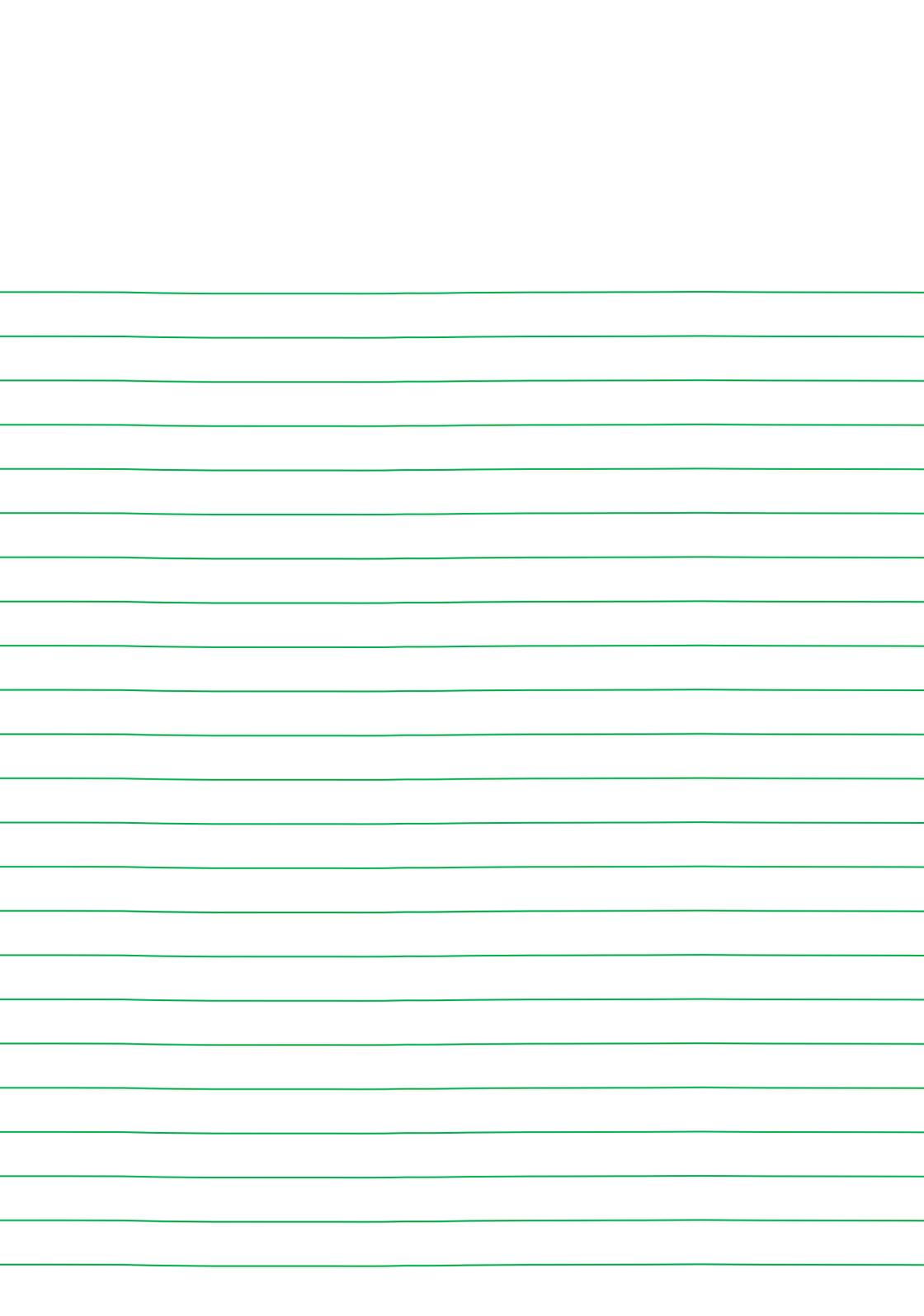
**Helpline** 0800 028 1881  
**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

### **GOV.UK**

#### **[www.gov.uk](http://www.gov.uk)**

Has information about social security benefits and public services in England, Scotland and Wales.





## Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

## Thanks

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

With thanks to: Mr Kavin Andy, Consultant Oral and Maxillofacial/Head and Neck Surgeon; Dr Shreerang Bhide, Consultant Clinical Oncologist; Dr Mary Lei, Consultant Clinical Oncologist; Tina McClosky, Advanced Practitioner Radiographer; Vicky Poole, Macmillan Head and Neck Clinical Nurse Specialist; Cherith Semple, Macmillan Head and Neck Clinical Nurse Specialist Nurse; and Professor Francis Vaz, Consultant ENT and Head and Neck Surgeon.

We welcome feedback on our information. If you have any, please contact [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)

## Sources

If you would like further information about the sources we use, please contact us at [cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)

# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



## **Share your cancer experience**

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

## **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.

## **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?

## **Raise money**

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

## **Give money**

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

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**

## 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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Security number

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Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't let the taxman keep your money

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.

- I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

Please cut out this form and return it in an envelope (no stamp required) to:  
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,  
89 Albert Embankment, London SE1 7UQ

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

The booklet explains the signs and symptoms of head and neck cancers, and how they are diagnosed and treated. It also has information about emotional, practical and financial issues.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, Monday to Friday, 9am to 8pm, 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

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CANCER SUPPORT**