A practical guide to understanding cancer

UNDERSTANDING HEAD AND NECK CANCERS
‘I think initially cancer takes control away from you and you can feel very vulnerable. But eventually you’ve got to take back control.’

Paul, diagnosed with throat cancer in 2006
About this booklet

This booklet is about head and neck cancers. We hope it answers some of your questions about diagnosis and treatment, and addresses some of the feelings you may have.

We can’t tell you about the best treatment for you. This information can only come from your own doctor, who knows your full medical history.

This booklet contains a lot of information, but you don’t need to read it all at once and may not need to read every section. Read the information that you think is most useful to you. Your specialist nurse or doctor can help guide you and the list of contents will help you find the information that you want to read.

At the end of this booklet are some useful addresses and websites (see pages 148–153).

You may also want to discuss this information with our cancer support specialists on freephone 0808 808 00 00 (Monday–Friday, 9am–8pm). You can also visit macmillan.org.uk

If you’re hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available.
Throughout the booklet we’ve included some comments from people affected by head and neck cancer, which you may find helpful. Quotes are from the Macmillan online community macmillan.org.uk/community Some names have been changed. Some quotes are from Paul, who is on the cover of this booklet. He has chosen to share his story with us.

If you find this booklet helpful, you could tell your family and friends about it. They may want to get their own copy so they can help and support you.

Our booklet Managing the late effects of head and neck cancer treatment has a lot of detailed information about coping with the long-term side effects of treatment. You can order a free copy from be.macmillan.org.uk
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Understanding head and neck cancers
# About Head and Neck Cancers

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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.
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 8–9). 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 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.
Head and neck cancers

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

People use the word ‘throat’ to mean different parts of the neck. These include the:

• pharynx
• voicebox (larynx)
• thyroid gland
• food pipe (oesophagus)
• wind pipe (trachea).

When talking about throat cancers, doctors mean the pharynx and larynx.

Cancers affecting the thyroid gland, oesophagus and trachea are treated differently and are not covered in this booklet.

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, trachea, and brain tumours that we can send you. Contact our support line on 0808 808 00 00 to order your free information.
Mouth cancers (oral cancers)

Mouth cancer can develop on the:
• lip
• tongue
• 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 the side of the tongue and the floor of the mouth.
The oral cavity

- Top lip
- Hard palate
- Soft palate
- Right tonsil
- Left tonsil
- Oropharynx
- Bottom lip
- Tongue
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, behind the mouth. It includes the soft part of the roof of the mouth (soft palate), the base of the tongue (the part you can see), the tonsils and the side walls of the throat. The most common places in the oropharynx for cancer to develop are 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. Cancers in this area are called hypopharyngeal cancers.

We have more information about cancers of the nasopharynx and oropharynx that we can send you. Call our support line on 0808 808 00 00
The voice box (larynx)
This is a short passageway in front of the lower pharynx (hypopharynx). It contains the vocal cords.

We have a booklet about cancer of the larynx and how it is treated.

The 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, alongside the cheekbone and nose (see diagram on previous page). Cancers can develop in the lining of these sinuses.

Cancer of the salivary glands
Salivary glands make saliva, which keeps the mouth moist. There are three major pairs of salivary glands:

- parotid glands – which are on each side of the face, 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.

Salivary gland cancer is most likely to develop 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, which contains three little 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.
Head and neck cancer and cell type

Head and neck cancers are also described according to 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, which are the cells lining 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.
Causes and risk factors

The exact causes of head and neck cancer aren’t fully understood. We know that certain things called risk factors can increase a person’s chances of developing it. Having one or more risk factors doesn’t mean you will definitely get head and neck cancer. Equally, if you don’t have any risk factors, it doesn’t mean you won’t get it.

The main risk factors for head and neck cancer 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 voicebox (larynx). The more cigarettes someone smokes, and the more years they smoke for, the higher the risk.

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

Chewing tobacco or betel quid (paan)

Chewing tobacco or betel quid 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.

Alcohol and tobacco together greatly increase the risk of head and neck cancer. People who both 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 head and neck cancer increases as we get older. It’s most common in people 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 past 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 lining 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’s not always possible to find a sexual cause. It’s thought there may be other ways of spreading the virus that have not yet been identified.

We have information about HPV and cancer that we can send you. Contact our support line on 0808 808 00 00.

**Low immunity**

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

- have a very poor 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 and sun beds**

Exposure to natural and artificial sunlight over a prolonged period of time increases the risk of developing cancer on the outside of the lip. About 1 in 3 people diagnosed with lip cancer (33%) work outdoors.

**Diet**

Some types of preserved or salted food can increase the risk of developing cancer of the nasopharynx.
Occupational exposure

Prolonged exposure to some types of dust and certain chemicals when at work increases the risk of developing cancers of the nasopharynx and sinuses. Hardwood dust, leather dust and formaldehyde (found in leather and some types of furniture dust) are linked to some cancers of the nasopharynx and sinuses.

Pre-cancerous conditions

Pre-cancerous conditions of the mouth, such as leukoplakia and erythroplakia (white or red patches in the mouth often linked to tobacco use), increase the risk of a cancer developing in the mouth.

Family history

There may be a slightly higher risk of developing a head and neck cancer if you have a close relative (a parent, brother, sister or child) who has had a head and neck cancer.

People who have a rare inherited condition called Fanconi anaemia have an increased risk of developing mouth and throat cancer.

Oral health

The risk of mouth cancer is slightly increased in people with poor oral hygiene and those who have dental disease.
Symptoms

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

Mouth cancers (oral cancers)

The two most common symptoms are:
• a lump and/or ulcer in the mouth that doesn’t heal
• discomfort or pain in the mouth that doesn’t go away.

Other symptoms include:
• a white or red patch in the mouth that doesn’t go away
• difficulty or pain with chewing, swallowing or speaking
• bleeding in the mouth
• loose teeth for no obvious reason or badly fitting dentures
• a lot of weight loss over a short time
• bad breath (halitosis)
• swelling in the neck caused by an enlarged lymph node (see page 25)
• earache.
Throat cancers

One of the first symptoms of a throat cancer is often a painless swelling or lump in the upper neck. Other symptoms may include any of the following:

Nasopharyngeal cancers
• headache
• a blocked nose
• nosebleeds
• changes in hearing or ringing in the ears (tinnitus).

Oropharyngeal cancers
• a sore throat or earache that doesn’t get better
• difficulty swallowing
• losing weight
• noisy breathing
• changes in your speech
• bad breath (halitosis).
Cancer of the sinuses

The symptoms can vary depending on which sinuses are affected. The most common symptoms include:

• loose teeth for no obvious reason (see page 22) or badly fitting dentures
• swelling in the cheek
• pain in the cheek
• a blocked nose that does not clear
• pain behind the nose or in the upper teeth
• swelling around the eyes.

Other symptoms may include:

• numbness of the cheek, upper lip, upper teeth or side of the nose
• nosebleeds
• headaches.
Cancer of the salivary glands

The most common symptoms include:

- a swelling in front of or behind the ear, or under the jawbone
- pain in part of your face
- difficulty swallowing
- drooping on one side of the face (facial palsy).

Although these symptoms can be caused by conditions other than cancer, it’s important to have them checked by your GP or dentist, particularly if they continue.

Lumps in the neck

If a cancer in the mouth or throat spreads from where it started, the first place it will usually spread to are the lymph nodes in the neck. Lymph nodes are small, bean-shaped glands that are part of the lymphatic system (see pages 8–9).

The cancer may begin to grow in the lymph nodes. This can show up as a painless lump in the neck.

Enlarged lymph nodes are much more likely to be due to an infection than cancer. But if you have a lump on your neck that hasn’t gone away within 3–6 weeks, it should be looked at by a specialist doctor (see page 28).
### Diagnosing Head and Neck Cancers

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How head and neck cancers are diagnosed

Your GP or dentist will refer you to hospital for specialist advice, tests and treatment. You’re likely to see an oral and maxillofacial surgeon or an ear, nose and throat (ENT) specialist (see page 45).

If you have a lump in your neck and no specific symptoms of a head and neck cancer, you may be referred to a hospital with a neck lump clinic (see below).

At the hospital

The specialist will ask you about your symptoms as well as any health conditions or recent illnesses. They’ll probably also ask you if you’ve noticed any changes in your voice, swallowing, breathing, appetite or weight. After this, they will carefully examine your mouth, throat and neck and explain which tests you need.

Neck lump clinic

Neck lump clinics are one-stop clinics where you can have all the tests needed to check for cancer in a neck lump.

You’ll usually have an ultrasound scan and a sample of tissue taken from the lump using a fine needle aspiration and/or a needle (core) biopsy. You may also have a nasendoscopy. These tests are explained on pages 29–32.

Neck lump clinics can often give you the results of your tests on the same day, but you may need to wait longer.
Ultrasound scan of the neck

This test uses soundwaves to produce a picture of your neck and lymph nodes on a computer screen. It’s painless and only takes a few minutes. The doctor will put some gel on to your neck and pass a small device which produces soundwaves over the area. The doctor will look for any changes in the size or appearance of the lymph nodes in your neck.

Nasendoscopy

This test can be done as an outpatient. It is used to look at the back of your mouth, nose, pharynx and larynx.

The person doing the test will gently pass a thin, flexible tube with a light at the end (nasendoscope) up your nose and down into your throat. This lets them see your throat and voicebox. This will be a bit uncomfortable, but it only takes a few minutes.

Before the test you may be given a local anaesthetic lozenge or spray to numb the back of your throat. You shouldn’t eat or drink anything until the numbness has gone (usually about an hour). If you try to eat or drink when your throat is numb, food or liquid could go down the wrong way and into your lungs. Or you could burn your mouth or throat with hot drinks.

Examination under anaesthetic (EUA)

If the doctor sees anything unusual, or if they can’t see the area clearly with the nasendoscope, they will suggest that you have a general anaesthetic. This will allow them to look at the area closely using an endoscope. An endoscope is a thin, flexible tube with a light at the end.
The doctor passes the endoscope down your throat. They can pass a camera down the tube or attach a microscope and look at the area very closely.

During the examination the doctor can take samples from any areas that look abnormal (biopsy – see page 31).

This test can usually be done as day surgery and most people are able to go home the same day.

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

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

A thin tube (endoscope) is inserted into your nose and to the back of your throat. Your nose and throat are numbed using an anaesthetic spray and you will be awake. It takes about 30 minutes.
Biopsy

One of the most important tests for diagnosing cancer is a biopsy. This is when a doctor takes a sample of cells from the area that looks abnormal. A doctor, called a pathologist, looks at the sample under the microscope and checks for any cancer cells.

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

Incision biopsy
Your doctor will numb the area to be tested with an injection of local anaesthetic. They will 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 done as an outpatient. It’s often used to check neck lumps, but it can also be done to take samples from areas in the mouth or throat.

The doctor passes a fine needle into the lump to take a sample of cells. You may feel a little discomfort while this happens. Sometimes the doctor uses an ultrasound scan to help guide the needle into the area to be tested.

It’s common to have some bruising and/or soreness in the area the sample was taken from. The soreness may last for a week or so. This can usually be relieved by taking a mild painkiller. Ask your nurse or doctor what they recommend.
If the biopsy is taken from inside your mouth or throat, you may be told to avoid hot food and hot fluids and to eat only soft foods for a few days while the tissue heals.

‘After a short hospital stay, biopsies and scans revealed a tumour in the base of my mouth and tongue. It’s hard to imagine how you will cope with the diagnosis of cancer; it has become a familiar word to us all, 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 and position, and to see whether it has spread. This process is called staging (see pages 37–38), and may take 2 to 3 weeks. 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 taken of your face or neck to see whether any bones have been affected and to check the health of your teeth.

You may have a chest x-ray to check your general health and to see whether the cancer has spread to the lungs. It’s 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 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 10–30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.
You may be given a drink or 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’s important to let your doctor know if you are allergic to iodine or have asthma because you could have a more serious reaction to the injection.

You’ll probably be able to go home as soon as the scan is over.
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’s 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’ve ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it’s likely that you won’t be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you’ll be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which doesn’t usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you’ll 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’s also noisy, but you’ll 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 (see pages 33–34), 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 can’t 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. The scan is done after at least an hour’s wait. It usually takes 30–90 minutes.

You should be able to go home after the scan.

**Waiting for test results**

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with a partner, your family or a close friend. Your specialist nurse or one of the organisations listed on pages 148–153 can also provide support. You can also talk things over with one of our cancer support specialists on 0808 808 00 00.
Diagnosing head and neck cancers

Staging

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

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

The two main ways used to stage head and neck cancers are the TNM system and the number system.

TNM staging

- **T** describes the size of the tumour. This will be a number between 0 –4 depending on the size and spread of the tumour.

- **N** describes whether the cancer has spread to the lymph nodes and which nodes are involved. This will be a number between 0–3 depending on how many lymph nodes contain cancer cells, where they are and their size.

- **M** describes whether the cancer has spread to another part of the body such as the lungs. This is called secondary or metastatic cancer. The M stage will be 0 if it hasn’t spread and 1 if it has.
Number staging

There are usually three or four number stages for each cancer type. Stage 1 describes a cancer at an early stage when it’s usually small in size and hasn’t spread. Stage 4 describes a cancer at a more advanced stage when it has usually spread to other parts of the body.

Other terms used

- **Early or local** – this is a cancer that hasn’t spread.
- **Locally advanced** – this is a cancer that has begun to spread into surrounding tissues and/or nearby lymph nodes.
- **Local recurrence** – the cancer has come back in the same area after treatment.
- **Secondary/advanced, widespread or metastatic** – the cancer has spread to other parts of the body.
Understanding head and neck cancers
TREATING HEAD AND NECK CANCERS

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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’re offered will depend on:

- where the cancer is in your head or neck
- the stage of the cancer
- its size
- your general health.

The most important factor when trying to cure the cancer is making sure that all the cancer is removed or destroyed. But your doctors will also try to reduce the long-term effects of treatment. For example, they will plan your treatment so that your appearance and ability to speak, chew and swallow are affected as little as possible.

Before you decide on the best treatment, it’s important to discuss with your doctor or nurse specialist how the different treatments may affect you.
The team giving you your treatment will explain to you what’s 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. Most cancer specialists are happy for their patients to use complementary therapies but it’s important to check with them first before trying a complementary therapy.

We can send you our booklet Cancer and complementary therapies. Visit be.macmillan.org.uk to order your free copy.

Treating early-stage cancer

If the tumour is small and hasn’t spread to lymph nodes or elsewhere, it can usually be treated with either surgery (see pages 54–68) or radiotherapy (see pages 69–90).

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

Your doctors may suggest radiotherapy rather than surgery, if:

• the cancer is in an area that is difficult to reach

• removing the cancer might cause major changes in speaking or swallowing.
Treating locally advanced cancer

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

- a combination of chemotherapy and radiotherapy – called chemoradiation or chemoradiotherapy (see page 70)
- a combination of a targeted therapy (see page 100) and radiotherapy
- surgery followed by radiotherapy, chemotherapy (see pages 91–98) or chemoradiation.
How treatment is planned

In all hospitals, a team of specialists meets to discuss and decide on the best treatment for you. This multidisciplinary team (MDT) will include the following:

- An **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.

- An **oral and maxillofacial surgeon** – a specialist who has trained both as a doctor and a dentist. They specialise in treating conditions affecting the mouth, jaw, face and neck. As well as operating to remove the cancer, they also rebuild tissue lost due to the cancer or surgery.

- A **plastic and reconstructive surgeon** – a surgeon skilled in rebuilding tissue in the head and neck.

- An **oncologist** – a doctor who specialises in cancer treatments such as radiotherapy, chemotherapy and targeted therapy.

- A **radiologist** – a doctor who analyses scans and x-rays.

- A **pathologist** – a doctor who advises on the type and extent of the cancer.

- A **clinical nurse specialist** – a nurse who gives support, practical advice and information about any aspect of your illness or treatment.

- A **speech and language therapist** – a therapist who specialises in helping with communication and swallowing problems.

- A **dietitian** – someone who advises you on how to make sure you get all the nutrients your body needs.
The team will often include a number of other healthcare professionals, such as a dentist, an oral hygienist, a restorative dentist (who specialises in making sure your teeth look and work as normally as possible), a physiotherapist, an occupational therapist and a psychologist or counsellor.

One or more of the team will meet with you, and a relative or friend, to explain your treatment options and answer any questions you may have.

**Treatment decisions**

If two treatments are equally effective for the type and stage of cancer you have, your doctors may offer you a choice. If you have to decide between treatments, make sure that you have enough information about the different options.

It’s 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 relative or close friend with you when you see the doctor. Take notes about what has been said so you can refer back to them afterwards.

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

We have a booklet called *Making treatment decisions*, which we can send you. Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) to order a free copy.
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 happen. However, these can usually be controlled with medicines. Treatment can be given for different reasons. The potential benefits will vary depending on your situation.

Your doctor can tell you if the aim of treatment is to cure the cancer, to control the cancer for a time, or to reduce symptoms and improve your quality of life. They can also tell you the possible side effects of each treatment and whether these are likely to only last a short time or be permanent.

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

People sometimes feel that hospital staff are too busy to answer their questions, but it’s 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 can’t 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 don’t have it. It’s essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don’t 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.

**Second opinion**

Your multidisciplinary team uses national treatment guidelines to decide on 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.

Before treatment starts

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

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’re going to have radiotherapy and some of your teeth are unhealthy, you may need to have these removed before you start treatment.

‘I had my four back bottom teeth removed prior to radiotherapy. The rest of my teeth appear to have stood up to the trauma fairly well because I followed the hygiene advice I was given before treatment began. I still maintain that regime, almost two years after treatment ended.’

Gary
You may also be referred to an oral hygienist. They can give you advice on how to care for your teeth and gums. Knowing how to care for your mouth is very important because cancer treatment may make it more sensitive and prone to infection, particularly if you have radiotherapy.

You can find out more about looking after your mouth and teeth, during and after treatment, on page 84.

**Speech, swallowing and eating**

You will be seen by the dietitian and/or the speech and language therapist before having surgery or radiotherapy. They can help with any swallowing, voice, speech or dietary issues you may have before your treatment. They will also tell you about the likely effects that treatment may have on swallowing and speaking, as well as what can be done to help.

Some people with head and neck cancer have difficulty eating and may lose some weight. While you’re waiting for treatment it’s important to eat as well as possible. You can use food supplements if needed. Increasing your calorie intake will help to slow down weight loss and help you cope better with the treatments.

Sometimes radiotherapy can lead to severe difficulty in swallowing, particularly if it’s combined with chemotherapy (chemoradiation). Usually this settles within a few months of completing treatment. It can help to put on a bit of weight before treatment starts.
If your oncologist thinks you may develop swallowing difficulties, they may suggest a small operation to put a tube through the skin of your tummy into your stomach. This is so you can be fed through the tube for a while. It is known as a PEG (percutaneous endoscopic gastrostomy) tube or RIG (radiologically inserted gastrostomy) tube. Once your swallowing improves, and you are able to eat more through your mouth, the tube can usually be removed.

We have information on PEG tubes and RIG tubes that we can send you.
Smoking
If you smoke, stopping smoking will increase the chances of your treatment being effective. Continuing to smoke increases treatment side effects and the risk of the cancer coming back. Smoking also increases your risk of developing a second cancer in your head or neck, and of developing cancer in other parts of your body, such as your lungs.

Smoking can be a difficult habit to break, especially when you’re stressed. There are organisations and self-help groups that can help you (see pages 149–150). Your doctor or specialist nurse can also give you help. Your GP can give advice and provide nicotine replacement therapies on prescription, such as nicotine patches, gums and inhalers.

We can send you our booklet Giving up smoking, which has practical tips on how to stop smoking and ‘stay stopped’. Visit be.macmillan.org.uk to order our free information.

Alcohol
Avoiding alcohol will also help make your treatment more effective and reduce the risk of side effects.

If you’d like support to help reduce your alcohol intake, your specialist nurse or doctor can arrange this for you.
Treating head and neck cancers
Surgery

Surgery is one of the main treatments for cancers of the head and neck. 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 and swallowing.

The type of surgery you have depends on the size and position of the cancer, and whether it has spread.

Before your operation, your surgeon will discuss the type of surgery with you. It’s important that you understand what’s going to be removed and how this will affect you after the operation, both in the short- and long-term.

If there is a risk your speech, swallowing or eating could be affected for a time after surgery, you may also meet a speech and language therapist or dietitian before the operation (see page 45).

Types of surgery

Most surgery for head and neck cancer involves a hospital stay and an operation under general anaesthetic. But in some situations, if you have a very small cancer, it may 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 your mouth, the surgeon may operate through your open mouth. This means you won’t have any external scars, unless you are having a neck dissection (see next page).
If the cancer is larger, or at the back of your mouth or in your throat, the surgeon will usually need to make a cut (incision) in your skin to reach it. This means that you’ll have a visible scar afterwards. This often fades over time.

If the cancer is in the hypopharynx, the surgeon may need to remove some or all of your voicebox (larynx). This is known as a partial or complete laryngectomy. The surgery will affect your speech (see pages 50–51). The surgeon will discuss the operation with you beforehand.

There is more information about having a laryngectomy in our booklet *Understanding cancer of the voicebox (larynx)*. You can order the booklet on our website [be.macmillan.org.uk](http://be.macmillan.org.uk)

**Neck dissection**

If cancer cells spread from the head or neck, the first place they are likely to go to is the lymph nodes in the neck (see pages 8–9).

A neck dissection is an operation to remove some or all of the lymph nodes in one or both sides of the neck. It is done if tests show cancer has spread to the lymph nodes. It’s also done if the cancer has reached a certain size, even if there are no signs of cancer in the neck. This is because very small amounts of cancer in the lymph nodes don’t show up on scans or in other tests.

Your cancer specialists will assess the risk of cancer having spread to lymph nodes in your neck. This will help them decide whether a neck dissection is appropriate for you. Your risk will depend on factors such as 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 your neck, you will often have this done at the same time as the operation to remove the cancer. You may also have a neck dissection before you have radiotherapy or chemoradiation as your main treatment.

A neck dissection may sometimes be done if the cancer has come back (recurred) in the nodes after initial 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 your mouth. It may mean your smile is a bit crooked (asymmetrical) for a while, but this will usually return 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.

**Reconstructive surgery**

If your operation involves removing tissue that is important for your speech, swallowing or appearance, 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, and uses it to replace tissue taken from the head and neck. This is known as a **flap**.

If the cancer is in your jawbone, the surgeon will need to remove the affected bone with the tumour. Bone taken from another part of your body (usually the lower leg) may be used to replace the missing jawbone. This is known as a **bone flap**. Your doctor and specialist nurse will be able to give you specific information about this type of operation. You will usually be able to 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 (see page 146). Your surgeon or specialist nurse may be able to put you in touch with other people who can talk to you about how the surgery has affected them, and how they coped with the changes. Changes to appearance are discussed in more detail on pages 113–116.

‘The doctors were extremely kind, frank and helpful. My best option was to have surgery to remove the tumour and reconstruct my mouth with muscle, fat and skin from my belly.’

Christine

**Prosthetics**

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

The most common prosthesis is an obturator. This is a denture with an extension that’s 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’s important to discuss your operation fully with your surgical team so that you know what to expect and how it will affect you.

**Less common types of surgery**

**Mohs surgery**
Small cancers on the lip are sometimes treated with a type of surgery called micrographic surgery or Mohs surgery.

The surgeon removes the cancer in thin layers. The tissue that has been removed is looked at under a microscope during the surgery. The surgeon continues to remove more layers until no cancer cells are seen in the tissue. This technique makes sure that all the cancer cells are removed and only a very small amount of healthy tissue is removed.

**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 is attached to a microscope so that the surgeon can see the tissue in detail when they are operating.

Transoral means the surgeon operates through the open mouth, so this surgery doesn’t cause any external cuts or scars.
Photodynamic therapy (PDT)
Photodynamic therapy uses a combination of laser light and a light-sensitive drug to destroy cancer cells.

PDT is sometimes used to treat very small, early cancers. It may also be used to shrink an advanced cancer, when the aim is to relieve symptoms rather than cure the cancer. This is called palliative treatment.

You may be offered PDT as part of a clinical research trial (see pages 101–102).

Your doctor can tell you whether PDT may be an appropriate treatment in your situation. This treatment isn’t available in all hospitals so you may have to travel to have it.

We have more information about PDT that we can send you. Call our support line on 0808 808 00 00.

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 for up to a few weeks. Your length of stay will depend on the type of surgery and whether or not you’ve had reconstructive surgery.

After your operation, you will be encouraged to start moving around as soon as possible. This is an essential part of your recovery. If you have to stay in bed, it’s important to do regular leg movements and deep-breathing exercises. A physiotherapist will explain these to you.
If you’ve had a bigger operation, you may spend some time in intensive care immediately after the operation. This is a ward where you will be closely checked and given one-to-one nursing care for as long as necessary to help you recover.

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

**Drips**
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’ll probably wake up from the operation with a tube going into a vein in your arm or your neck (an intravenous drip). The nurses will give you fluids through this tube for a few days. The drip will be removed once you’re able to drink fluids again.

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

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

When you go home, your wound and drain (if it’s still in) can be checked and dressed by a district nurse if necessary. Or you may be asked to go back to the hospital every few days to have it checked there. If you don’t have the type of stitches that dissolve, you’ll usually have your stitches or staples removed about seven days after your operation.
**Feeding tube**

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

There are two types of feeding tube:

- A **gastrostomy tube**, which is a tube that is passed through the tummy wall (abdomen) into your stomach. This is sometimes called a PEG or RIG tube.

- A **nasogastric (NG) tube**, which is a thin tube that is passed up your nose, down your throat and into your stomach.

The dietitian will talk to you about this before your operation and will provide support afterwards. They’ll prescribe high-protein, high-calorie, liquid food to be given through the tube.

Once the tissues in your mouth and throat have healed, your surgeon may arrange for you to have a swallowing assessment by a speech and language therapist (see page 117). When you can eat and swallow safely, the feeding tube can be removed.

If you’re 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, the nurses will be able to teach you and/or your carers how to look after it safely. They will also arrange community support to visit your home. A small number of people will have a gastrostomy tube for a longer period of time.

We have more information on nutritional support, which includes information on NG, PEG and RIG tubes. Call our support line on 0808 808 00 00 to order our information.

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

Tracheostomy tube
Sometimes surgery to the mouth or throat can cause temporary swelling. This can narrow your airway and make it difficult for you to breathe. If the type of surgery you’re having is likely to cause this problem, the surgeon will create a small opening into your windpipe, called a tracheostomy or stoma, for you to breathe through.
The opening is made in the lower part of the front of your neck. It’s held open by a small plastic tube that is a few centimetres long. When the swelling from your operation goes down (after about 5–7 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**
If you have a tracheostomy, usually you won’t be able to speak with the tube in place. However, you will be able to use a pen and paper, or a mobile phone or tablet computer to communicate with other people.

If you’re likely to have a tracheostomy for a short time after your operation, your surgeon will explain this to you in advance. You’ll also have time to ask the specialist nurse or speech and language therapist 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 control it. It’s important to let the staff caring for you know if you’re still in pain. If the drugs aren’t relieving your pain, the dose can be increased or the painkillers can be changed.

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

If you have an external scar after the operation, it’s common for the skin around the area to feel numb. It may take several months for normal sensation to return.

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.

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 and/or voice.

For some people this is hardly noticeable, but for others, speech and/or voice may be temporarily or permanently altered. A speech and language therapist will be able to help you adapt to any changes (see pages 120–121).
'It was a case of learning how to use the new tongue. The main thing was speech therapy. I still had feeling in the tip of my tongue, which I was lucky with. That made things a lot easier. It still took time though.'

Alison

Swallowing
When you’re ready to start taking fluids and food by mouth, you’ll see a speech and language therapist. If chewing or swallowing is difficult, they will advise you about the safest and easiest types of food to have. They will also teach you mouth and jaw exercises that will improve your swallowing. You can read more about help with swallowing on pages 116–118.

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 is usually temporary and you will be given exercises 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’s important to have a good idea of what to expect.

Operations in the mouth or throat can often cause swelling. So your face and neck may look very swollen immediately after the operation. This will gradually get better over a few months.

Whenever possible, your surgeon will plan the operation so that if you have scars they will be in less noticeable places, such as in skin creases on your face or a fold in your neck. Scars are usually red or dark to begin with, but gradually fade over time.

It can take some time to adjust to changes in how you look and it’s important to know that support is available. You can find more information about coping with changes in your appearance on pages 113–116.

Preparing to go home

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

If it’s needed, the ward nurses can arrange for district nurses to visit you at home and check that you’re managing with any wounds and dressings.
Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells. It’s an important treatment for head and neck cancers. Radiotherapy can be used on its own but is often given in combination with chemotherapy (called chemoradiation – see page 70).

Radiotherapy for early-stage cancers

Radiotherapy can be used on its own to treat cancers that are small and haven’t spread. It’s 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 larger, or is affecting other tissues nearby (locally advanced cancer), radiotherapy is usually combined with other treatments. Radiotherapy may be given:

• after surgery (with or without chemotherapy) to destroy any remaining cancer and reduce the risk of cancer coming back

• in combination with chemotherapy (chemoradiation), without surgery

• in combination with the targeted therapy drug cetuximab (see page 70)

• to reduce symptoms (palliative radiotherapy).
Radiotherapy after surgery (adjuvant radiotherapy)
If you have surgery for advanced cancer, you’ll usually be given radiotherapy afterwards. This is to reduce the risk of the cancer coming back and is called adjuvant radiotherapy. Sometimes both chemotherapy and radiotherapy are given together after surgery. This 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 can’t be removed with an operation

• to treat cancers in harder-to-reach areas such as the nasopharynx or throat

• when surgery could cause unacceptable changes to speech or swallowing.

Radiotherapy and cetuximab
Combining chemotherapy and radiotherapy (chemoradiation) is a very effective treatment for head and neck cancer but it can also cause severe side effects. Some people can’t have chemoradiation because they aren’t well enough to cope with these side effects or they have other health problems that make chemotherapy too risky. Instead, they may be given radiotherapy in combination with a targeted therapy drug called cetuximab (see pages 99–100).
Palliative radiotherapy
Sometimes it’s 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 can be given in two ways:
• 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. This is the most common way of giving radiotherapy to the head and neck area.
• By putting a radioactive source into the tumour and leaving it there for a few days. This is known as internal radiotherapy, interstitial radiotherapy or brachytherapy.
External-beam radiotherapy
Treatment is given in the hospital radiotherapy department.

It can be planned in different ways. It may be given:

• Monday–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 4–7 weeks, depending on the type and size of the cancer. Your radiotherapy doctor (clinical oncologist) or specialist nurse will discuss the treatment with you.

Conformal radiotherapy (CRT) is the most common type of external-beam radiotherapy used for head and neck cancers.

A special attachment to the radiotherapy machine arranges the radiation beams to match the shape of the cancer. Shaping the radiotherapy beams reduces the radiation given to surrounding healthy cells.

Intensity-modulated radiotherapy (IMRT) is available in some hospitals. This way of giving radiotherapy shapes the beams even more accurately to the exact shape of the cancer. IMRT allows the doctors to 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.
Someone having external-beam radiotherapy
Internal radiotherapy
This involves putting a radioactive source directly into the cancer. Over a few days, this gives a high dose of radiotherapy into the tumour.

It’s sometimes used:

• to treat small tumours in the mouth or lip

• with external-beam radiotherapy to give an additional dose of radiotherapy or ‘boost’ into the tumour.

For this treatment, you will need to stay in a single room in hospital for a few days, until the doctor removes the radioactive source from your body. During this time, visitors will be restricted. It will be safe for your family and close friends to visit you for short periods. However, children and pregnant women won’t be allowed to visit. This is so they’re not exposed to even tiny amounts of radiation.

The doctors and nurses caring for you will also only be able to stay in your room for short periods of time.

Once the radioactive source is removed, the radioactivity disappears and it’s perfectly safe to be with other people.

The radioactive source causes some swelling in the tissues nearby. This swelling usually settles by the time the source is removed (generally about seven days later). The soreness may last for up to about six weeks.
Radiotherapy planning

To make sure that your radiotherapy is as effective as possible, it has to be carefully planned. Planning ensures 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 known as a clinical oncologist.

Radiotherapy planning can usually be carried out during one visit to the radiotherapy department that takes about two hours. Sometimes you may need to make more than one visit.

To start with you’ll meet the radiographers (experts in giving radiotherapy), who will answer any questions you have.

It’s important that you’re able to lie still, in exactly the same position, for each treatment. To help you do this, you’ll wear a see-through plastic mask (sometimes called an immobilisation shell) for each session of radiotherapy.

The mask holds your head and neck as still as possible. It’s designed so that you can see and breathe normally while wearing it. You’ll have it on for up to about 15 minutes at a time. Most people soon get used to it. Talk to the radiographer, mould room technician or your specialist nurse if you find it difficult to wear the mask.

You will have the radiotherapy mask made after you’ve met the radiographers. The radiographer or the mask room technician will explain the whole process to you before starting.

We can send you information about how radiotherapy masks are made. Visit be.macmillan.org.uk
Once you have your mask you will have a CT scan (see pages 33–34) of the area to be treated. The radiographers will take measurements to tailor the treatment to you. Some people also have an MRI scan (see page 35) as part of their radiotherapy planning.

The radiographer’s measurements and the information from the scans are fed into the radiotherapy planning computer so that your doctors can plan your treatment precisely.

Sometimes, marks may be drawn on your skin. These help the radiographer to position you accurately before each treatment. The marks must stay visible throughout your treatment, but they can be washed off once your course of treatment is over.

‘They measured and fitted the radiotherapy mask and did more scans to work out where exactly they wanted to shoot the radiotherapy.’

Gary

**Tracheostomy tube**

Very occasionally, radiotherapy to the mouth or throat can cause swelling in tissues around the airways, which can make breathing difficult. If this is likely to happen, your doctors will arrange for you to have a small opening made in your windpipe before you have radiotherapy. The opening is called a tracheostomy or stoma and will let you breathe comfortably. A tracheostomy is usually temporary (see pages 62–64).
Someone wearing a radiotherapy mask
Having radiotherapy

Before each treatment session, the radiographer will position you on the treatment couch and carefully fit your mask. The treatment only takes a few minutes. During this time, you will be left alone in the room, but the radiographer will be able to monitor you from the next room. If you need assistance, you can raise your arm and the radiographers will return to the room.

External radiotherapy doesn’t make you radioactive, and it’s perfectly safe for you to be with other people, including children and pregnant women, throughout your treatment.

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. Side effects can be mild or more troublesome, depending on the dose of radiotherapy 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 two weeks of radiotherapy. They may continue to affect you for 7–10 days after treatment ends before gradually improving. Most people find that side effects have noticeably improved 6–8 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. Two of the most common late effects are a dry mouth and an increased risk of tooth decay. It’s very important to follow a regular mouthcare routine during and after radiotherapy (see page 83–84).

Your specialist can tell you whether your treatment may cause any late effects. You’ll also be told about things you can do to help reduce the risk of having problems.

You can find more information about late effects on page 90.

**What you can do to help reduce side effects**

**Stop smoking**
Smoking during radiotherapy is likely to make your side effects worse, and it reduces the effect of radiotherapy on the cancer. So, if you smoke, stopping will help your recovery. You can get information and support to help you stop. We have a leaflet with tips on how to stop smoking and a list of organisations that can help you (see pages 149–150).

**Cut down on alcohol**
Alcohol, especially spirits, will irritate the areas affected by your treatment. So, it’s best not to drink alcohol or use mouthwashes containing alcohol during radiotherapy.
**Look after your mouth**

It’s 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 healing and reduce the risk of problems in the future. See page 84 for more information about how to look after your mouth.

**Eat healthily**

Eating can be a struggle during treatment, but it’s important to get the nutrition you need. This will help your tissues to heal, increase your strength and can also reduce your risk of getting some long-term effects of radiotherapy.

If you’re finding it difficult to eat, tell your specialist nurse or radiographer or ask to see a dietitian, if you don’t already have one. There are lots of things that can be done to help make sure you get the nutrition you need.

Sometimes your doctor will recommend that you have a feeding tube inserted to support you through the rest of your treatment. This will usually be in place for a few weeks and can normally be removed once you start to eat and drink again.

If swallowing is a problem, a speech and language therapist can give you advice and support. We have more information about feeding tubes and how to cope with eating problems (see page 118).
Managing side effects during radiotherapy

Sore and sensitive skin
The skin over your face and neck will gradually redden or darken and may feel sore and itchy (a bit like sunburn). This starts after about two weeks of treatment and lasts for up to about four weeks after radiotherapy has finished.

The radiotherapy team will advise you on how to look after your skin. It’s very important to use only the soaps, creams and lotions that they recommend, as chemicals in some products can make the skin more sensitive to radiation. It’s 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’s 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. But don’t use sun protection creams on your head and neck while you’re having radiotherapy. The radiotherapy team can talk to you about when and how to use sun protection cream after your treatment.
Understanding head and neck cancers
Mouthcare
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’ll be much more likely to get tooth decay.

You should see your dentist every 3–6 months and a dental hygienist as suggested by your dentist. Going for regular check-ups means that if you develop any mouth problems, they can be picked up early when they’re easier to treat. Your dentist or hygienist can give you a mouthcare routine you can follow to help prevent problems.

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

Towards the end of the radiotherapy your mouth is likely to be extremely sore and you may need strong painkillers, such as morphine. Your doctor or specialist nurse can discuss this with you.

Once your course of radiotherapy has finished, your mouth will gradually heal and most people get back to eating normally after a few weeks.
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 or mouthwash daily, as prescribed by your dentist. The fluoride helps to protect and strengthen your teeth.

• Use dental floss or tape daily to clean in between your teeth (but check with your specialist doctor or nurse if you’re having chemotherapy or radiotherapy).

• If your dentures are uncomfortable, you may need to leave them out for a few weeks.

• Rinse your mouth with a non-alcohol-based mouthwash.

• 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.

• Limit sugary and acidic foods and drinks to mealtimes only.

• Don’t smoke.

• Do jaw exercises as advised by your specialist to prevent jaw stiffness.

Our booklet *Managing the late effects of head and neck cancer treatment* has more information about mouth care following radiotherapy. Call our support line on 0808 808 00 00.
Loss of taste
If you have radiotherapy to your head and neck, it will affect 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.

There is advice on coping with taste changes and other eating problems in our booklet Eating problems and cancer. Call our support line on 0808 808 00 00 to order a free copy.

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

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 – carry a bottle of water with you. Soft, moist foods with gravy and sauces will be easier to eat 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 and lozenges. You may have to try different types to find one that suits you.
Some people find that using a humidifier in their home helps as it makes the atmosphere less dry.

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

After a few months you may begin to make saliva again, but it may not be as much as before. Sometimes the salivary glands don’t recover, which leaves the mouth permanently dry.

We can send you information on coping with a dry mouth. Visit be.macmillan.ork.uk or call 0808 808 00 00 to order your free information.

‘I am now 15 months post radiotherapy. My saliva has come back slowly and taste is also coming back but nothing tastes like it used to. I can eat most things now but not chicken, steak or anything with a hint of spice in it. I go out for meals but eat so slowly due to having to chew twice as much so I can swallow food. Generally though am almost back to where I was and fortunately the scar on my neck is hardly noticeable. The biggest change to my life is the quality of sleep. Dry mouth and sore throat throughout the night means I wake up regularly needing a drink of water.’

Dave
Thick, sticky saliva (mucus)
Radiotherapy can change the consistency of your saliva. It may become thicker, stringy and sticky, like mucus. The mucus doesn’t flow as well as normal saliva so it may build up in your mouth and throat.

You may feel the need to spit frequently to get rid of the mucus build-up, so it’s a good idea to keep tissues handy. Rinsing your mouth regularly can help to cut through the mucus. You can make a mouth rinse with half a teaspoon of salt and half a teaspoon of baking soda mixed into a litre of water. Alternatively, your specialist nurse can give you advice on the type of mouth rinse that’s suitable for you.

Sometimes a build-up of mucus can cause coughing, especially at night. Your nurse or doctor may prescribe nebulisers (a liquid that is mixed with air to make a mist or fine 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 eight weeks of radiotherapy ending but sometimes continue for several months or longer. If the mucus continues, there are medicines that can be prescribed to reduce the amount you make. Tell your cancer specialist or nurse if you’re having difficulties.
Bad breath
This is usually caused by changes to your saliva and can be reduced by regular mouth care (see pages 83–84). It may also be caused by an infection in your mouth, which is common during radiotherapy treatment. If you have an infection, it can be treated with antibiotic or antifungal medicine.

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

Tiredness (fatigue)
You’re likely to become tired 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 increase your energy levels.

We have more information about controlling nausea and vomiting, which you may find helpful. You can download it from our website be.macmillan.org.uk. We also have a booklet Coping with fatigue that has helpful tips. Call our support line on 0808 808 00 00 to order a free copy.
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 head and neck radiotherapy.

Many treatment side effects get better over time. If you have side effects that aren’t 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’re concerned about the risk of developing particular side effects, you should speak to your cancer doctor or specialist nurse.

The most common long-term effects include:

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

These effects and others are discussed in our booklet *Managing the late effects of head and neck treatment*. Call our support line on 0808 808 00 00 to order a copy.
Chemotherapy

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

**Having chemotherapy**

Chemotherapy is usually given in combination with radiotherapy to treat locally advanced head and neck cancers. This is called chemoradiation (see page 70).

Sometimes chemotherapy is given before radiotherapy to shrink the tumour and help to make the radiotherapy more effective. Very rarely, chemotherapy is given before surgery to shrink the tumour and make it easier to remove.

Sometimes chemotherapy is given to relieve symptoms and improve quality of life if it’s 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 circulate in the bloodstream and reach cancer cells all over the body.

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 crook of your arm (PICC line) or your chest (central line).
Someone having chemotherapy
Chemotherapy drugs that are commonly used to treat head and neck cancer are:

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

We can send you more information about having chemotherapy and individual chemotherapy drugs. We also have information about PICC and central lines. Visit be.macmillan.org.uk to order your free information.
Possible side effects of chemotherapy

Risk of infection
Chemotherapy can reduce the number of white blood cells, which help fight infection. If the number of your white blood cells is low you’ll be more prone to infections. A low white blood cell count is called neutropenia.

Always contact the hospital immediately on the 24-hour contact number you’ve been given and speak to a nurse or doctor if:

- you develop a high temperature, which may be over 37.5°C (99.5°F) or over 38°C (100.4°F) depending on the hospital’s policy, follow the advice that you have been given by your chemotherapy team
- you suddenly feel unwell, even with a normal temperature
- you feel shivery and shaky
- you have any symptoms of an infection such as a cold, sore throat, cough, passing urine frequently (urine infection), or diarrhoea.

If necessary, you’ll be given antibiotics to treat any infection. You’ll have a blood test before each cycle of chemotherapy to make sure your white blood cells have recovered. Occasionally, your treatment may need to be delayed if the number of your white blood cells is still low.

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.

Sore mouth
This is a very common side effect if you’re having both chemotherapy and radiotherapy. Your mouth may become sore or dry, or you may develop mouth ulcers during treatment.

Some people find that sucking ice is soothing. Drinking plenty of fluids can help if your mouth is sore.

Tell your nurse or doctor if you have mouth problems. They can prescribe mouthwashes and medicine to relieve pain and to prevent or clear mouth infections.

We have a more information about mouthcare during chemotherapy. You can download it from be.macmillan.org.uk
Numbness or tingling in hands or feet
If you have treatment with cisplatin, fluorouracil (5FU) or docetaxel, you may have changes in sensation in your hands and feet. This is due to the effect these drugs can have on nerves and is known as peripheral neuropathy. You may also notice that you have difficulty doing up buttons or similar fiddly tasks.

Tell your doctor if you notice these symptoms. You may need to have your chemotherapy dose lowered slightly or the drugs changed.

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

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 you 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. However, tinnitus usually improves when treatment ends. Tell your doctor if you notice any loss of hearing or tinnitus. They may suggest altering the dose of your chemotherapy. See page 121 for advice on coping with hearing changes.
Tiredness
Chemotherapy affects people in different ways. Tiredness can build up over a course of treatment, and if you’ve 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 and 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.

We have a booklet called *Coping with hair loss*, which has useful tips on wigs and head coverings, and dealing with the emotional effects of hair loss. We also have a booklet *Coping with fatigue* which has more advice about dealing with fatigue. Call our support line on 0808 808 00 00 to order a copy.

Changes in the way the kidneys work
Cisplatin can affect how your 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 there are any changes in how much urine you are producing.
Targeted therapies

Targeted (biological) therapies are drugs that mimic substances that occur naturally in the body to destroy cancer cells. They work by changing the way that cells interact with or signal to each other.

Cetuximab (Erbitux®) is the most commonly used targeted therapy to treat head and neck cancer. It’s given as a drip (infusion) into a vein.

It may be used:

• in combination with radiotherapy for people who aren’t fit enough to cope with the side effects of chemoradiation

• as part of a clinical trial in combination with chemoradiation

• with palliative chemotherapy.

How cetuximab works

Most squamous cell cancers of the head and neck have proteins called epidermal growth factor receptors (EGFRs) on their surface. When chemical messengers in the body (called growth factors) attach to these receptors, it stimulates the cancer to grow.

Cetuximab stops the growth factors from attaching to receptors on the cancer and so may stop it growing. It may also make the cancer more sensitive to the effects of radiotherapy.
Side effects

The side effects of cetuximab are generally mild. Some people have flu-like symptoms such as a headache, fever, chills or dizziness when the infusion is being given. You’ll be given medication before the infusion to reduce the risk of this happening.

The most common side effect is a skin rash. It usually starts within two weeks of having the first treatment but goes away once treatment is over. You’ll be given advice on how to look after your skin while you’re having cetuximab.

We have more information about cetuximab. You can see it on our website macmillan.org.uk or call our support line on 0808 808 00 00.
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). We can send you a free copy. Call our support line on 0808 808 00 00.

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.
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After treatment

Follow-up

Once your treatment is completed, you will have regular check-ups. These will continue for several years, and will happen often at first, then less so.

You may have scans from time to time, but the most important part of your follow-up will be your specialist’s examination of your head and neck. Tell your specialist about any new symptoms you have or ongoing symptoms that aren’t improving.

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

If you can’t attend a follow-up appointment, contact your doctor or clinic to arrange another appointment.

Well-being and recovery

Coming to the end of your cancer treatment can be a time of mixed emotions. You’ll probably feel relieved but there can also be feelings of anxiety and uncertainty about the future. It can take time to rebuild confidence and to come to terms with what you’ve been through.

You may be keen to get back to doing all the things you did before your cancer. But it may take time to recover from treatment.
There may be physical changes in the way you look, and possibly changes in some areas of your daily life, such as the way you speak or what you can eat. There will also be emotional changes to deal with so it’s important to give yourself time to adjust.

Support is available from the organisations listed on pages 145–153 or you can speak to one of our cancer support specialists on 0808 808 00 00. You may also find it helpful to read our booklets *Life after cancer treatment* and *Body image and cancer*.

Gradually after treatment, you’ll find that day-to-day things that occupied you before cancer will start to fit back into your life. Going back to work (page 136) and getting back to the interests you had before can be important steps forward.

Some people feel that although they wouldn’t have chosen to go through this experience, it’s changed them in positive ways and helped them to think about their priorities. They may decide to focus more on relationships with family and friends or on doing the things they’ve 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 you may now want to be more focused on making the most of your health. There are things you can do to help your body recover. These can also help improve your sense of well-being and lower your risk of getting other illnesses and some cancers.
Eating well
It’s important to have a nutritious and well-balanced diet with plenty of fresh fruit and vegetables, even if your appetite and interest in food have been reduced. Your dietitian will be able to tell you about ways to eat well.

‘The dietitian encouraged me to experiment with different types of food to find out which foods worked best for me. He advised me on what exercise I should do along with my eating plan to ensure that I was gaining muscle as opposed to just putting fat on.’

Sandra

Smoking
If you’re a smoker, it’s important to try to give up. Smoking is the main cause of head and neck cancers and continuing to smoke puts you at greater risk of developing a second cancer.

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 and to find out where your local stop smoking service is.

Our booklet Giving up smoking has more advice and tips to help you succeed. Other organisations that can help, such as Quit, are listed on pages 148–149.
Alcohol
Cutting back on alcohol can also help. Drinking alcohol and smoking will greatly increase your risk of developing another head and neck cancer.

Physical activity
This can be an important part of your recovery after treatment. It can improve your sense of well-being and build up your energy levels. It also reduces the risk of heart disease, stroke and diabetes. You should talk to your cancer specialist or GP before you make changes to your activity levels. Start slowly and increase your activity over time.

You can read more about exercise and its benefits in our booklet Physical activity and cancer treatment.
Complementary therapies

Complementary therapies may help you to feel better, reduce stress and anxiety, and improve some treatment side effects.

Relaxation, counselling and psychological support are available at many cancer treatment hospitals. Some hospitals also offer visualisation, massage, reflexology, aromatherapy and hypnotherapy. Therapies are sometimes available through cancer support groups or your GP. Many complementary therapists have private practices.

Our booklet Cancer and complementary therapies tells you about different therapies and gives advice on choosing a therapist. You can order a free copy on our website be.macmillan.org.uk

Talking to someone or sharing your experience

Talking about your feelings can help reduce feelings of stress, anxiety and isolation. There are lots of different ways to do this.

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

Talking about your feelings isn’t always easy. You can read some helpful tips about this in our booklet Talking about your cancer.

Support groups
Self-help or support groups offer a chance to talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone, or don’t 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.

You can call us on 0808 808 00 00 or visit macmillan.org.uk for information about cancer support groups across the UK.

**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 (macmillan.org.uk/community) is a social networking site where you can talk to people in our chat rooms, blog your journey, make friends and join support groups.

‘During my treatment, I felt like I was on a treadmill, going to and from hospital, and then when it came to an end you’re left wondering, “what next?” The turning point for me was when Amanda, my Macmillan head and neck cancer nurse, told me about a course run by Macmillan. It was for people like me who had finished their treatment. That was marvellous because I could talk to people who had faced the same situation as I had. I also felt like I had a better understanding of what cancer is.’

Catherine
Specialist help

Sometimes it’s easier to talk to someone who’s not directly involved with your illness. You can ask your hospital consultant, nurse specialist or GP to refer you to a doctor or counsellor who is a specialist in the emotional problems of people with cancer.

Our cancer support specialists on freephone 0808 808 00 00 can tell you more about counselling and let you know about services in your area.

Our booklet How are you feeling? The emotional effects of cancer has more detailed information about feelings and emotions, and helpful tips on how to deal with them. Visit our website be.macmillan.org.uk to order your free copy.
Coping with physical changes

Some side effects that develop during treatment may take a long time to improve, or may sometimes become permanent (long-term effects). Other effects can develop many years after treatment has finished (late effects). You may not experience any after effects at all or they may range from being mild to more serious.

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

Changes in how you look

Head and neck cancer and its treatments can cause changes to your appearance. The changes can sometimes affect your body image. This is the picture you have in your mind of how you look (your size, shape and form), and how you feel about your body. Changes can also be a constant reminder of your cancer diagnosis 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 adjust to a change in appearance. There’s no set time or method for this process of adapting. Everyone does it 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 (see pages 148–149), which help people to cope with a changed appearance. You will also get support from the hospital staff.

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

**Camouflage make-up**

If parts of the skin on your face or neck have been replaced with skin from another part of the body, the skin colour may not match the surrounding skin. You may also have visible scars. It’s possible to reduce the differences of skin colour and disguise the appearance of scar tissue by using camouflage make-up. It can be matched to all skin types and colours in both men and women. Some head and neck clinical nurse specialists and organisations offer camouflage make-up services with advice on how to apply it (see pages 148–149).

Some types of camouflage make-up can be applied to facial prostheses to improve the colour match to the skin. This can be useful in the summer when skin tone changes. If you have a prosthesis that needs colouring, you should take it back to the person or organisation that supplied it.
Meeting other people
As you and the people close to you become more familiar with your changed appearance, you may want to think about seeing other people and going back to work. If you avoid social situations, you may find that you want to go out less and less. The longer you leave it, the harder it may be. It’s best to start by going somewhere familiar and 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. On the other hand, some people may seem interfering and may make remarks. Small children are often openly curious and may ask why you look different. Decide in advance how you will answer. Saying that you have had an operation should be enough. You don’t have to go into the details.

Other people will soon respond to you and not to your appearance. Coping successfully with social situations will help to build up your self-confidence, and this will increase as you gradually take up your normal activities. You can get more information about learning how to manage people’s reactions from Changing Faces or Let’s Face It (see pages 148–149). These skills aren’t difficult to learn, but do need practice. In time, you will gain the confidence to manage social situations in an effective way.
Sexual relationships

Treatment for head and neck cancers can also affect the way that you feel about yourself sexually. If you have a partner, they may also need time to adjust. Talking about how you both feel is essential to overcoming any fears or worries that you may have.

We can send you more information about how cancer and its treatment can affect sexuality, and what can help. Contact our support line on 0808 808 00 00.

Changes to eating

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

Some of these changes are temporary and are caused by swelling in the mouth or throat immediately after treatment. As the swelling goes down, eating and drinking gradually improve. Although for some people, it may never be quite the same as before.

Some people find that after their treatment, they take longer to eat and can only manage certain foods. These changes may make you feel embarrassed and frustrated, and you may find it hard to eat with others.

It’s important to talk with your family and friends about how you’re feeling so that they can help. You can also talk to your specialist nurse. They will understand what you’re going through and may be able to offer help or put you in touch with other people who have experienced similar difficulties.
Your speech and language therapist 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.

**Swallowing test (videofluoroscopy)**

If you’re having swallowing difficulties, you may be asked to have a special x-ray test of your swallowing called a videofluoroscopy. It gives a moving picture of what is happening in your mouth and throat when you swallow. It can show if anything gets stuck in your throat or if any food or drink goes down the wrong way. This helps the speech and language therapist see the best ways to make swallowing safer and easier for you.

This test is carried out in the radiotherapy department by a radiologist and the speech therapist. You will be asked to swallow different types of food, from liquid to semi-solid (like yoghurt) and solid (like a biscuit). A special substance is added to the food to make it show up on the x-ray. You may also be asked to try different techniques to see if they help when you swallow. The test takes about 30 minutes and is painless. The x-rays will be recorded on video or DVD.

The speech therapist will meet with you to discuss the results of the test. You’ll also be given advice on the type of food to eat – for example, drinks can be thickened to allow them to be swallowed safely.

If the results of the videofluoroscopy show that food or liquid is getting into the lungs, you may need to be fed directly into the stomach through a tube. Usually, this is only temporary until your swallowing recovers with the help of exercises and techniques taught by the speech and language therapist. Sometimes the feeding tube will be permanent.
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 meat, fish or cheese).

• Cook with butter or oil.

• If your mouth is sore, or swallowing is difficult, try soft foods such as milkshakes, custards, scrambled eggs or mashed vegetables. Avoid foods that may irritate your mouth, such as spicy/salty foods, citrus fruit or drinks (orange, lemon and lime) and tomato sauces.

• If you have taste changes after radiotherapy, once your mouth is no longer sore you can increase the flavour of food by using marinades or strongly flavoured seasonings and herbs.

• Choose foods that look and smell appealing to you.

• Mix food with sauces to make them easier to swallow.

• Eating several small meals or snacks during the day may work better for you than having three large meals.

Our booklet Eating problems and cancer has helpful tips on how to eat well when you have a sore or dry mouth. You can order a free copy online. Visit be.macmillan.org.uk
Changes to speech

Any change to your lips, teeth, tongue, soft palate or voicebox is likely to make your speech and/or voice sound different. This may mean that you have difficulty making one or two specific sounds or saying some words. It may sometimes be more severe, so people can’t easily understand what you’re trying to say, or they can’t hear you.

For some people, a change in their speech and/or voice will only be a minor problem and it will return to normal, or near normal, as the tissues heal. For others, it will be more of a problem and will cause 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. That will allow you to let people know what you need. A speech and language therapist will be involved in your recovery from an early stage and will be able to give support and helpful advice.

Speech therapy

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

There are also special aids that your speech and language therapist will discuss with you, if necessary.
It will take time for you, and your family and friends to adjust to your changed speech or voice. The reactions of strangers may be harder to get used to, but will get easier. It often helps if you can put people at ease by simply explaining that you have had an operation that has made it difficult for you to talk.

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 can be due to the effects of the cancer itself or a side effect of treatment. If you have a problem with hearing after your cancer and treatment, you may be referred to a clinic that specialises in hearing problems. Appropriate treatment will then be recommended for you.

Hearing loss may be helped with hearing aids or cochlear implants (digital hearing aids that can recognise speech).

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

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.

There is more information about coping with these and other physical changes in our booklet Managing the late effects of head and neck cancer treatment.
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, such as meals on wheels, a home helper or hospital 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 can’t 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.
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 to find out more.

Our booklet Lost for words – how to talk to someone with cancer has more suggestions if you have a friend or relative with cancer.

If you’re looking after a family member or friend with cancer, you may find our booklet Looking after someone with cancer helpful. 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
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 a negative 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’ve 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.

Family and friends

Your family and friends may not always understand if you aren’t 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.

We can send you more information about the influence of cancer on your relationships. You may find our booklets Cancer, you and your partner and Sexuality and cancer helpful. Our booklet Talking about your cancer also has useful tips.
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 will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

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 overburdened. It’s important that they can go 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, 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 which has been developed especially for teenagers who have a parent with cancer.
Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It’s important to do what’s right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It’s important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets Work and cancer, Working while caring for someone with cancer as well as Self-employment and cancer have more information that may be helpful. There’s also lots more information at macmillan.org.uk/work
Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:
- contributory – you can get this if you have made enough national insurance contributions
- income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income.

Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance (DLA) in England, Scotland and Wales.
Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don’t need to have a carer, but you must have needed care for at least six months.

If you are terminally ill, you can apply for PIP, DLA or AA under the ‘special rules’. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

Carer’s Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don’t qualify for it, you can apply for Carer’s Credit. This helps you to build up qualifying years for a State Pension.

More information

The benefits system can be hard to understand, so it’s a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on 0808 808 00 00. We’ve just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at [gov.uk](http://gov.uk) (England, Wales and Scotland) and [nidirect.gov.uk](http://nidirect.gov.uk) (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 153) or Citizens Advice (see page 153). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on 0800 220 674.
Our booklet *Help with the cost of cancer* has more detailed information. You might also find our video at [macmillan.org.uk/gettingfinancialhelp](http://macmillan.org.uk/gettingfinancialhelp) useful.

‘I contacted a Macmillan benefits adviser through the Citizens Advice bureau in Taunton to see if there was anything I could do to help financially. Because even the parking fees at the hospital are immense when you start being treated.’

Gary

**Insurance**

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 153.

Our booklets *Insurance* and *Getting travel insurance* may also be helpful. You can order them on our website [be.macmillan.org.uk](http://be.macmillan.org.uk)
Understanding head and neck cancers
FURTHER INFORMATION

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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 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.

All of our information is also available online at macmillan.org.uk/cancerinformation. 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. If you’d like us to produce information in a different format for you, email us at 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 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. No one should face cancer alone.

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–Friday, 9am–8pm. Our cancer support specialists can:

• help with any medical questions you have about your cancer or treatment

• help you access benefits and give you financial advice

• 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

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 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

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

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.’

Mal
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 advice
Our financial guidance team can give you advice 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 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

Macmillan’s My Organiser app
This 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.

**British Association of Skin Camouflage**  
PO Box 3671,  
Chester CH1 9QH  
**Tel** 0125 470 3107  
[www.skin-camouflage.net](http://www.skin-camouflage.net)  
Members are trained by the association in all aspects of camouflage. Services are sometimes available through NHS clinics, and creams can be prescribed by GPs.

**Cancer Laryngectomee Trust**  
PO Box 618,  
Halifax HX3 8WX  
**Tel** 0142 220 5522  
**Email** info@cancerlt.org  
[www.cancerlt.org](http://www.cancerlt.org)  
Provides support to people who are about to have, or have had, a laryngectomy. They can send you a free copy of the book *Laryngectomy is not a tragedy*, suitable for patients, their families and healthcare professionals.

**Changing Faces**  
The Squire Centre,  
33–37 University Street,  
London WC1E 6JN  
**Tel** 0300 012 0275  
**Email** support@changingfaces.org.uk  
[www.changingfaces.org.uk](http://www.changingfaces.org.uk)  
**Skin camouflage service**  
**Tel** 0300 012 0276  
**Email** skin-cam@changingfaces.org.uk  
Changing Faces is now the official home of skin camouflage. Skin camouflage practitioners, who provide this service on a voluntary basis, can teach people how to self-apply specialist cover creams.
Let’s Face It
72 Victoria Avenue,
Westgate-on-Sea,
Kent CT8 8BH
Tel 01843 833 3724
Email chrisletsfaceit@aol.com
www.lets-face-it.org.uk
Organisation for people with facial disfigurement providing telephone support, social activities, dietary and medical advice, and information on camouflage make-up.

NHS Smoking Helpline
Tel 0800 022 4 332
(Mon–Fri, 9am–8pm,
Sat–Sun, 11am–5pm)
www.smokefree.nhs.uk
Offers free information, advice and support to people who are giving up smoking, and those who have given up and don’t want to start again.

Oracle Cancer Trust
c/o Head and Neck Unit, Royal Marsden Hospital, Fulham Road, London SW3 6JJ
Tel 0207 352 8171
www.oraclecancertrust.org
Provides support for patients with head and neck cancer and their families.

NHS Asian Tobacco Helpline
(Mon–Fri, 9am–8pm,
Sat–Sun, 11am–5pm)
Bengali 0800 169 0885
Gujarati 0800 169 0884
Hindi 0800 169 0883
Punjabi 0800 169 0882
Urdu 0800 169 0881

Quit
20 Curtain Road,
London EC2A 3NF
Tel 0207 539 1700
Quitline 0800 00 22 00
www.quit.org.uk
A national organisation that provides information and support to people who want to stop smoking.

Saving Faces
St Bartholomew’s Hospital,
West Smithfield,
London EC1A 7BE
Helpline 0779 235 7972
(Mon–Fri, 9am–5pm)
Email helpline@
savingfaces.co.uk
www.savingfaces.co.uk
Gives information about facial surgery research.
General cancer support organisations

**Cancer Black Care**  
79 Acton Lane,  
London NW10 8UT  
**Tel** 0208 961 4151  
**Email** info@cancerblackcare.org.uk  
[www.cancerblackcare.org.uk](http://www.cancerblackcare.org.uk)  
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

**Cancer Focus Northern Ireland**  
40–44 Eglantine Avenue,  
Belfast BT9 6DX  
**Tel** 0800 783 3339  
(Mon–Fri, 9am–1pm)  
**Email** hello@cancerfocusni.org  
[www.cancerfocusni.org](http://www.cancerfocusni.org)  
Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

**Cancer Support Scotland**  
Calman Centre,  
Gartnaval Complex,  
75 Shelley Road,  
Glasgow G12 0ZE  
**Tel** 0141 211 0122  
**Email** info@cancersupportscotland.org  
[www.cancersupportscotland.org](http://www.cancersupportscotland.org)  
Offers information and support to people affected by cancer. Also runs support groups, and provides counselling and complementary therapies.
Irish Cancer Society
43–45 Northumberland Road, Dublin 4, Ireland
Tel 1800 200 700 (Mon–Thurs, 9am–7pm, Fri, 9am–5pm)
Email helpline@irishcancer.ie
www.cancer.ie
Has a freephone cancer helpline staffed by nurses trained in cancer care. You can also chat to a nurse online and use the site’s message board.

Maggie’s Centres
1st Floor, One Waterloo Street, Glasgow G2 6AY
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Maggie’s Centres provide information about cancer, benefits advice, and emotional or psychological support.

Tenovus
Head Office, Gleider House, Ty Glas Road, Cardiff CF14 5BD
Tel 0808 808 1010
www.tenovus.org.uk
Provides a range of services to people with cancer and their families, including counselling and a freephone helpline.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
BACP House, 15 St John’s Business Park, Lutterworth LE17 4HB
Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at www.itsgoodtotalk.org.uk
Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)
32–36 Loman Street, London SE1 0EH
Tel (England) 0844 800 4361
Tel (Scotland) 0300 123 2008
Tel (Wales) 0292 009 0087
Email info@carers.org
www.carers.org and www.youngcarers.net
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
20 Great Dover Street, London SE1 4LX
Tel (England, Scotland, Wales) 0808 808 7777
Tel (Northern Ireland) 028 9043 9843
(Wed–Thu, 10am–12pm and 2–4pm)
Email adviceline@carersuk.org
www.carersuk.org
Offers information and support to carers across the UK. 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. Details for your local office can be found in the phone book or on one of the following websites:

**England and Wales**
www.citizensadvice.org.uk

**Scotland**
www.cas.org.uk

**Northern Ireland**
www.citizensadvice.co.uk

You can also find advice online in a variety of languages at adviceguide.org.uk

Department for Work and Pensions (DWP)
Disability Living Allowance Helpline 0345 712 3456
Textphone 0345 722 4433
Personal Independence Payment Helpline 0345 850 3322
Textphone 0345 601 6677
Carer’s Allowance Unit 0345 608 4321
Textphone 0345 604 5312

www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

**GOV.UK**
www.gov.uk
Has comprehensive information about social security benefits and public services.
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.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by our medical editor, Dr Tim Iveson, Consultant Medical Oncologist and our senior medical editor Dr Chris Alcock, Consultant in Medical Oncology.

With thanks to: Kathleen Mais, Nurse Clinician Head & Neck Oncology; Miss Carrie Newlands, Oral Maxillofacial Surgeon; Cherith Semple, CNS Head and Neck Cancer; Dr Amen Sibtain, Clinical Oncologist; Dr Anne Taylor, Research Fellow; Professor Mary Wells, Professor of Cancer Nursing Research & Practice; Annette Zuydam, Speech and Language Therapist; and the people affected by cancer who reviewed this edition.

Sources

We’ve listed a sample of the sources used in this publication below. If you’d like further information about the sources we use, please contact us at bookletfeedback@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.

**5 WAYS YOU CAN HELP SOMEONE WITH CANCER**

**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
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

Valid from

Expiry date

Issue no

Security number

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 taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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

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

27530
More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don’t have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you’re entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk