Understanding cancer of the larynx (voicebox)

> "My Macmillan nurse was with me from my second diagnosis. She was always so helpful, considerate and optimistic despite the situations and challenges."

Jacob, diagnosed with cancer of the larynx

About this booklet

This booklet is about cancer of the larynx (voicebox), also called laryngeal cancer. It is for people who have cancer of the larynx. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of cancer of the larynx and how it is diagnosed. It also talks about treatment options, side effects, and ways to cope. This includes information on feelings, relationships, and money.

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

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

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

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

On pages 139 to 148, there are details of other organisations that can help.

At the back of this booklet, you will find a leaflet **Getting help during treatment for cancer of the larynx**. It has useful questions you may want to ask your doctor or nurse during treatment. There is also space to write down your own questions, answers, and details of your healthcare team.

Quotes

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

For more information

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

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

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

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

Contents

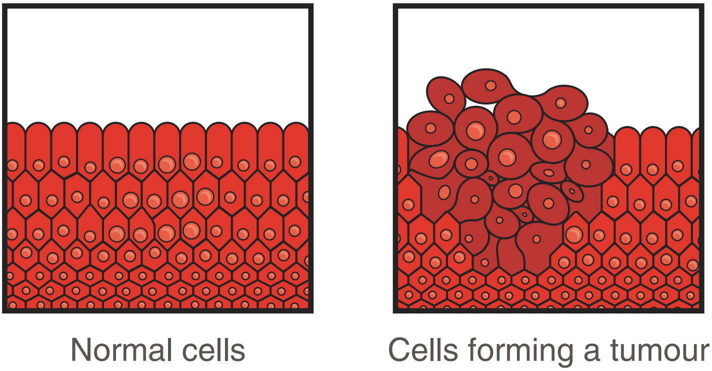
The larynx and cancer of the larynx

What is cancer?

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

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

Abnormal cells forming a tumour



Normal cells

Cells forming a tumour

Not all tumours are cancer. Doctors can tell if a tumour is cancer by taking a small sample of cells from it. This is called a biopsy (page 22). The doctors examine the sample under a microscope to look for cancer cells.

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

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

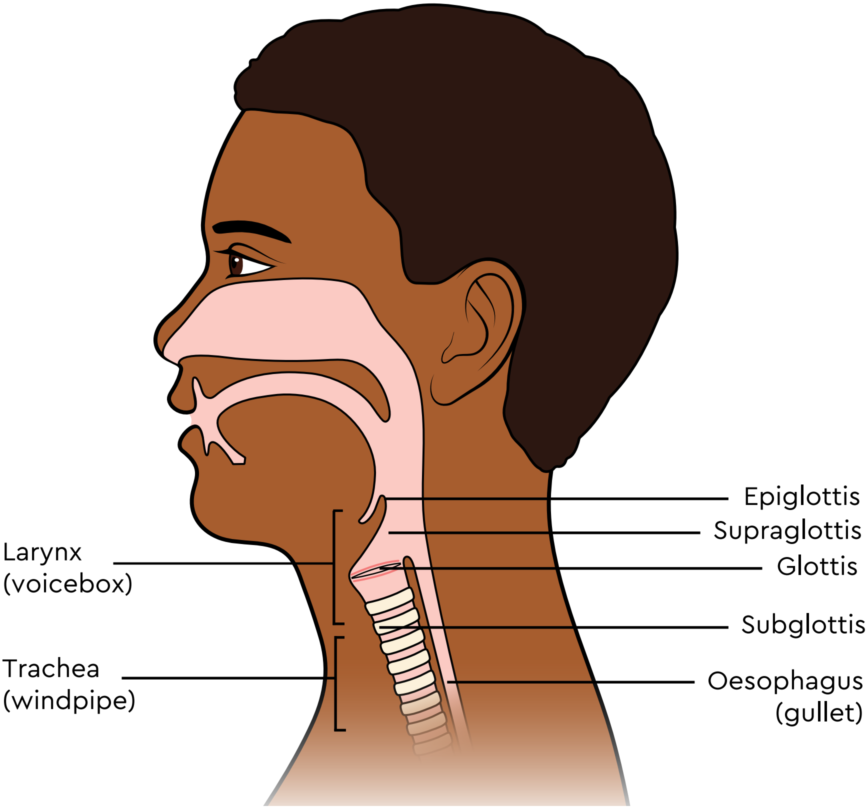
Sometimes cancer cells spread from where the cancer started (the primary site) to other parts of the body. They can travel around the body in the blood or through lymph fluid which is part of the lymphatic system. When these cancer cells reach another part of the body, they may grow and form another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

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

The larynx

The larynx is also called the voicebox. It is in the neck, above the windpipe (trachea) and in front of the gullet (oesophagus). The windpipe is the tube that carries air to and from the lungs. The gullet is the tube that food goes down when you eat. The larynx is tube-shaped, and it is about 5cm (or 2in) long.

Parts of the larynx



The larynx allows the air you breathe to reach your lungs. It has a flap of skin at the top, called the epiglottis. When you swallow, the epiglottis sends food and liquid down the gullet, stopping it from going into the windpipe.

The larynx contains the 2 vocal cords. The vocal cords vibrate together when air passes between them. This makes the sound of your voice.

The larynx is the lump you can see or feel at the front of the neck. This is called the Adam's apple.

The larynx has 3 main parts:

- supraglottis – the area above the vocal cords
- glottis – the middle area where the vocal cords are
- subglottis – the area below the vocal cords that connects to the windpipe.

Types of cancer of the larynx

Most cancers of the larynx are squamous cell carcinoma. This means the cancer starts in the thin, flat cells that line the larynx.

Some rarer types of cancer of the larynx include the following:

- Sarcoma – which is cancer of the connective tissues in the larynx.
- Lymphoma – which is cancer of the lymphatic tissue in the larynx.
- Adenocarcinoma – which is cancer that starts in the glandular (adeno) cells of the larynx.
- Neuroendocrine carcinoma – which is cancer that develops from cells similar to nerve (neuro) cells that make hormones (endocrine). Hormones control how different organs in the body work.

This information is about treatment for squamous cell cancer of the larynx. For information about rarer types of cancer of the larynx, contact our cancer information nurses on **0808 808 00 00**.


LA11
LA12
Way Out →
Staff Only

The lymphatic system

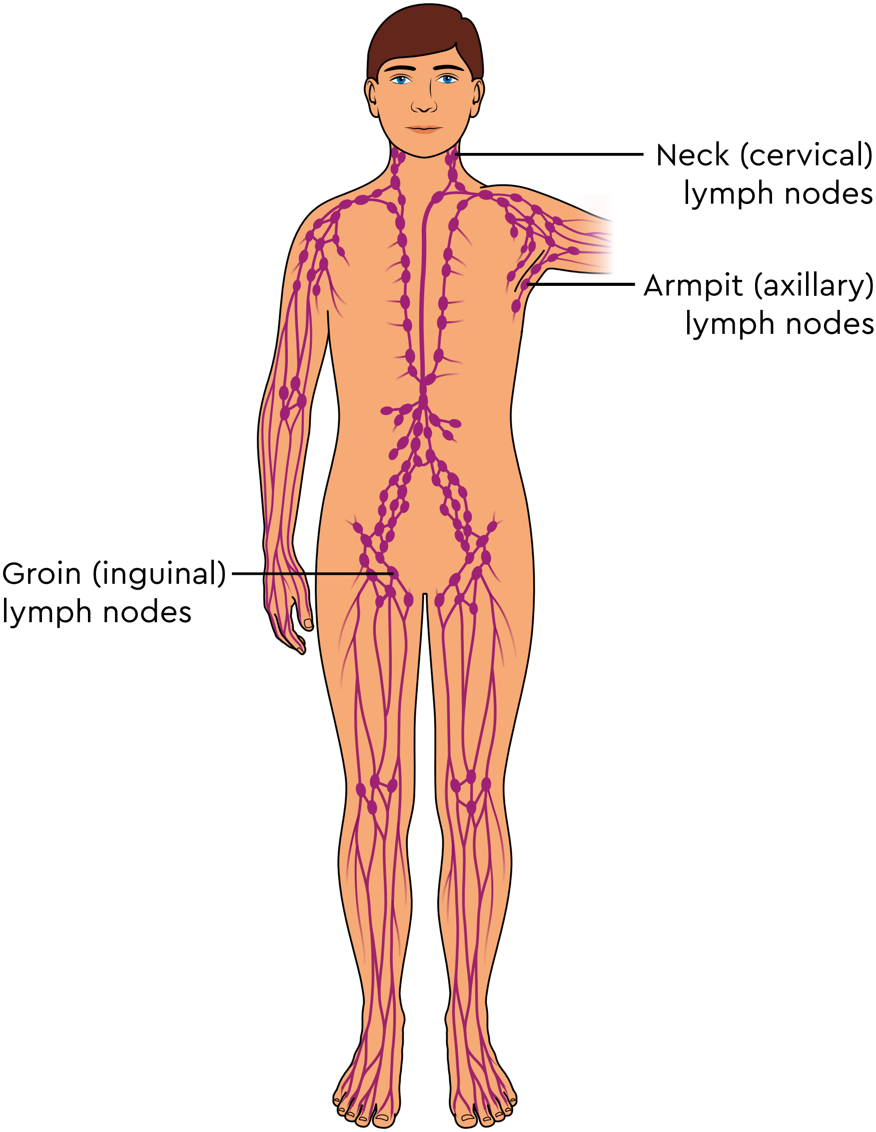
The lymphatic system helps protect us from infection and disease. It is made up of fine tubes called lymphatic vessels. These vessels connect to groups of small lymph nodes throughout the body. The lymphatic system drains lymph fluid from the tissues of the body before returning it to the blood.

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

There are lymph nodes close to the larynx. Cancer of the larynx can sometimes spread to these nearby lymph nodes.

We have more information about cancer and the lymphatic system on our website. Visit **macmillan.org.uk/lymphatic-system**

The lymphatic system



Risk factors and causes

We do not always know for sure what causes cancer of the larynx. But certain risk factors can increase your chance of developing it. Having a risk factor for cancer does not mean you will definitely get it. Some people with risk factors never get cancer. Other people can still develop cancer of the larynx without any known risk factors, although this is not common.

Around 2,360 people in the UK are diagnosed with cancer of the larynx each year. This type of cancer is rare under the age of 40. It is more common in people over 60.

As with other cancers, cancer of the larynx is not infectious. This means you cannot pass it on to other people.

Smoking

The risk of developing cancer of the larynx increases the longer you smoke for, and the more you smoke. We have information about the risks of smoking, and the support available for people giving up on our website. Visit **macmillan.org.uk/stop-smoking**

Alcohol

Drinking lots of alcohol (especially spirits) over a long time increases your risk of developing cancer of the larynx. The risk is higher for people who smoke and also drink lots of alcohol. You can find information about alcohol guidelines and how alcohol can affect your health at **drinkaware.co.uk**

Sex

Cancer of the larynx is 4 times more common in men than women.

Symptoms

Your symptoms will depend on where in the larynx the cancer is. Most cancers begin on, or near, one of the vocal cords in the glottis (page 8).

The most common symptom is changes to your voice, such as hoarseness. This may be an early sign of the cancer affecting your vocal cords. If you notice any changes to your voice, you should see your GP. If you have hoarseness for 3 to 4 weeks that does not go away, your GP should refer you to a hospital for tests.

Sometimes, the first symptom you notice might be a lump in the throat or neck. You may also have discomfort or pain when chewing or swallowing. These symptoms are more common when the cancer starts above the vocal cords. This is called supraglottic cancer of the larynx.

Other less common symptoms include feeling breathless or having a cough that does not go away. This may happen when the cancer affects the area below the vocal cords in the subglottis, near the windpipe. But this is quite rare.

If you have any of the symptoms above, you should tell your GP. Other conditions may be causing the symptoms, but it is important to get them checked.

Diagnosing cancer of the larynx

> “I had what I thought was laryngitis and difficulty swallowing. It got really bad on holiday. When we got home I visited the GP. He sent me straight to the hospital for some tests and referred me to see a consultant.”

Jacob, diagnosed with cancer of the larynx

How cancer of the larynx is diagnosed

Usually, you start by seeing your GP. They will ask about your symptoms and examine you. They may also arrange some tests. They might refer you to an ear, nose and throat doctor, called an ENT doctor, or a specialist clinic.

At the hospital

The specialist will:

- ask about your symptoms
- check your general health
- ask whether you take any medicines
- feel for any lumps in your neck.

Swollen lymph nodes (page 12) may be causing these lumps. But other medical conditions, such as a swollen salivary gland, can also cause lumps. After carefully examining you, they will explain what tests you need.

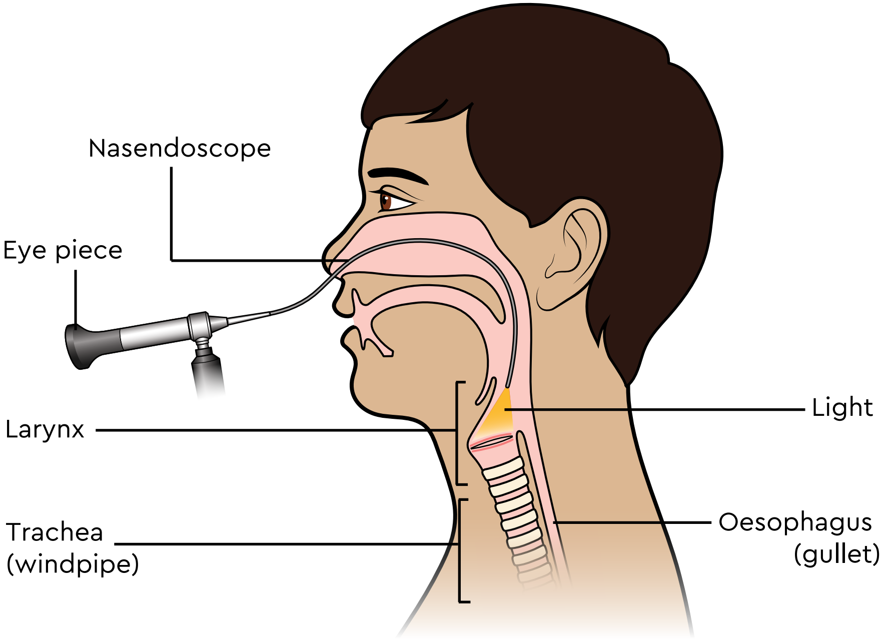
Nasendoscopy

You have this test in the outpatient clinic. Your doctor passes a thin, flexible tube up through the nose. This tube is called a nasendoscope. The tube then goes over the back of the tongue and down into the upper part of the throat. It has a light at the end to help the doctor see the back of the mouth and throat. Some nasendoscopes have a small camera at the end. The images from the camera are shown on a monitor for your doctor to see.

You may find this test a bit uncomfortable, but it only takes a few minutes. You may have an anaesthetic spray or lozenge to suck beforehand, to numb your throat.

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

Nasendoscopy



Laryngoscopy

You have this test if your doctor sees anything unusual in your throat with the nasendoscope. Or you may have it if the doctor cannot see the larynx clearly with the nasendoscope. You need to have a general anaesthetic for the test. This allows the doctor to examine the larynx using a laryngoscope. A laryngoscope is a thin metal tube with a light on the end. The doctor passes the laryngoscope down the throat to look at the larynx closely. They may also take photos using a camera that is attached to the tube.

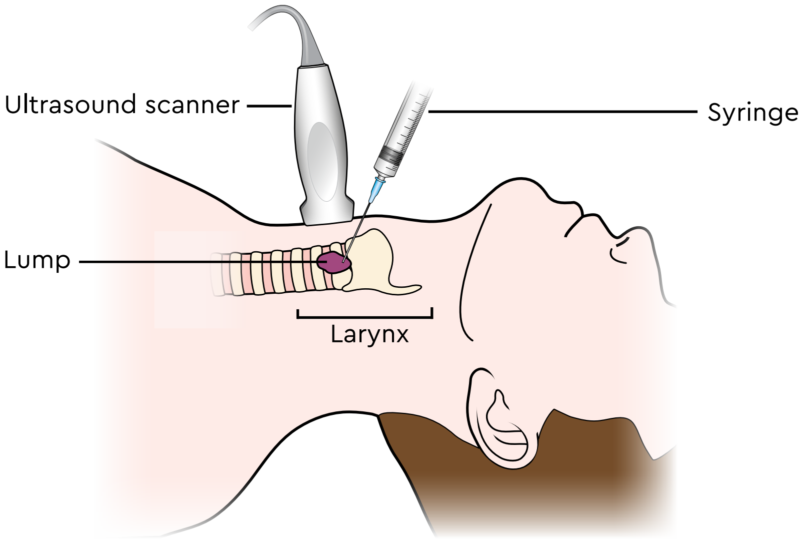
Biopsy

During the laryngoscopy, the doctor takes a sample of cells or tissue from any areas that look abnormal. This is called a biopsy. It is the most important test to diagnose cancer of the larynx. A doctor called a pathologist then looks at the sample under a microscope, to check for cancer cells. It may take about 7 to 10 days for your results to come back.

Fine needle aspirate (FNA)

You may have this test if you have a lump in your neck. You may have it in the outpatient clinic or at the x-ray department. The doctor passes a fine needle into the lump. Then they take (aspirate) some fluid or tissue using a syringe. You might have an ultrasound scan at the same time. This is to help the doctor guide the needle into the correct area. An ultrasound scan uses sound waves to build a picture of that area of the body. A pathologist then looks at the sample of fluid or tissue under a microscope, to check for cancer cells.

Fine needle aspirate



Having a CT scan

Further tests

If there are cancer cells in your larynx, your doctor will ask you to have some more tests. These will help you and your doctor make decisions about treatment.

Blood tests

You may have blood tests to check your general health and what treatments may be suitable for you.

CT scan

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

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

You may have a drink or injection of a dye. This is called a contrast. It helps show certain areas of the body more clearly. The contrast may make you feel hot all over for a few minutes. It is important to tell your doctor if you are allergic to iodine or have asthma. This is because you could have a more serious reaction.

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

We have more information about having a CT scan on our website. Visit **macmillan.org.uk/ct-scan**

MRI scan

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

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

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

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

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

We have more information about having an MRI scan on our website. Visit **macmillan.org.uk/mri-scan**

PET or PET-CT scan

A PET scan uses a low dose of radiation to check the activity of cells in different parts of the body.

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

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

About 1 hour before the scan, the radiographer will inject a radioactive substance into a vein, usually in your arm. This is called a tracer. The radiographer will encourage you to drink water. This helps move the tracer around your body.

Very rarely, some people are allergic to the tracer. This can make them feel breathless, sweaty or weak. Tell the radiographer straight away if you feel unwell.

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

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

We have more information about PET and PET-CT scans on our website. Visit **macmillan.org.uk/pet-ct-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 to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or a support organisation (pages 139 to 148) can also provide support. Or you can talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

Staging and grading

Staging

The stage of a cancer describes:

- its size
- whether it has spread from where it first started.

Knowing this helps doctors decide the best treatment for you.

TNM staging system

Doctors usually use the TNM system to stage cancer of the larynx. TNM stands for tumour, node and metastases. This system gives the complete stage of the cancer:

- T describes how much of the larynx and surrounding area is affected by the primary tumour.
- N describes whether the cancer has spread to any nearby lymph nodes.
- M describes whether the cancer has spread to other parts of the body, such as the lungs. This is called metastases or secondary cancer.

Doctors put numbers after the T, N and M. The numbers give more details about the size and spread of the cancer. Higher numbers mean the cancer is more advanced. Your doctor or nurse can give you more information about this staging system.

Number staging system

Another staging system uses numbers to describe the stage of the cancer. This is a simplified number staging system for cancer of the larynx:

- Stage 0 – sometimes called carcinoma in situ or CIS. The cancer cells are only in the lining of the larynx. There are usually no symptoms, so the cancer is not usually diagnosed at this stage. Your doctor may sometimes call this stage pre-cancerous.
- Stage 1 and stage 2 – early stage cancers that have not grown outside of the larynx.
- Stage 3 and stage 4 – more advanced tumours that may have:
    - affected the movement of the vocal cords
    - spread outside the larynx, either in the tissues around the larynx or to lymph nodes in the neck
    - spread to other areas of the body.

In this information, we use the terms early stage, locally advanced, and advanced to describe larynx cancer:

- Early stage – cancers of the larynx that are stage 0, 1 or 2.
- Locally advanced – cancers that have spread into the area surrounding the larynx, but have not spread to other areas of the body. This covers stage 3 and some stage 4 cancers.
- Advanced – cancers that have spread to other areas of the body. These are stage 4 cancers.

Staging for cancer of the larynx is complex. It depends on where in the larynx the cancer started. For example, cancer that starts in the vocal cords, also called the glottis (page 8), rarely spreads to other areas of the body. Your doctor can tell you more about your individual situation.

Grading

Grading is about how the cancer cells look under the microscope compared with normal cells. The grade helps your doctor to plan your treatment. The grades used for larynx cancer are the following:

- Grade 1 (low-grade or well-differentiated cancer) – the cancer cells look similar to normal cells. They usually grow slowly and are less likely to spread.
- Grade 2 (moderate- or intermediate-grade cancer) – the cancer cells look more abnormal and are slightly faster growing.
- Grade 3 (high-grade or poorly differentiated cancer) – the cancer cells look very different from normal cells and may grow more quickly.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically.

There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

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

You can find details of the cancer registries on page 148.

"I was diagnosed with left vocal cord cancer and had radiotherapy. When the cancer returned, I had a partial laryngectomy, meaning removal of half the voicebox."

Jacob, diagnosed with cancer of the larynx

Treating cancer of the larynx

Treatment overview

A team of healthcare professionals usually treats people with cancer of the larynx in a specialist centre.

For most people, the aim of treatment is to remove or destroy the cancer and to reduce the chances of it coming back.

Your treatment will depend on:

- where in the larynx the cancer is – page 8
- the size of the cancer and whether it has spread (its stage) – pages 28 to 30
- how fast-growing the cancer is (its grade) – pages 28 to 30
- your general health.

The main treatments for cancer of the larynx are:

- radiotherapy (pages 50 to 62)
- surgery (pages 63 to 83)
- chemotherapy (pages 84 to 93)
- targeted therapies (pages 95 to 96)
- immunotherapy (pages 97 to 98).

Treatment may affect your speech, swallowing, eating and appearance. How much your treatment affects these areas is different for everyone. Your doctor or nurse will talk to you about this. They will explain if this is likely to be short term or long term, and how they can support you.

Treating early stage cancer

Early stage cancers of the larynx (page 28) that have not spread to nearby tissue or lymph nodes can usually be cured with radiotherapy or surgery. Your doctor will explain if these treatments are suitable for you.

Treatment might include:

- surgery using a laser to remove the cancer through your mouth – this is called transoral laser microsurgery or TLM
- surgery (non-laser)
- radiotherapy.

Treating locally advanced cancer

If a cancer of the larynx is bigger or has spread to lymph nodes in the neck (page 28), you may need more than 1 type of treatment. These treatments may be able to cure the cancer. Treatments for locally advanced cancer may include the following:

- A neck dissection (page 70) – this is when surgeons remove the cancer, but also remove nodes in the neck.
- Chemoradiation (page 94) – this is when doctors use a combination of chemotherapy and radiotherapy. It may be the main treatment.
- Chemoradiation or radiotherapy after surgery.
- Chemotherapy – you may have chemotherapy (pages 84 to 93) on its own to shrink a cancer before surgery or radiotherapy.
- Targeted therapy (pages 95 to 96) combined with radiotherapy.

Treating advanced cancer

If the cancer has come back, or is very advanced when you are diagnosed, you may have treatments to try and control the cancer and help with symptoms. These treatments may include:

- chemotherapy
- targeted therapies
- immunotherapy.

Some people may need surgery such as a tracheostomy (pages 67 to 68) to help with symptoms.

Sometimes, it may not be possible to cure the cancer. The aim of treatment may be to control the cancer for longer and manage the symptoms. This is called supportive or palliative care. You may see a specialist palliative care doctor or nurse for expert help with your symptoms.

How your treatment is planned

After your test results, you and your doctor start to talk about your treatment. Your doctor usually meets with other specialists to get their opinions too.

Multidisciplinary team (MDT) meeting

A team of specialists meet to talk about the best treatment for you. They are called a multidisciplinary team (MDT).

The MDT look at national treatment guidelines or the latest evidence for the type of cancer you have. If you have any treatment preferences, your doctor will tell them about this.

The MDT will usually include the following professionals:

- Ear, nose and throat (ENT) surgeon – a doctor who does operations (surgery) on the ears, nose and throat.
- Plastic surgeon – a doctor who does operations (surgery) to repair or reconstruct tissue and skin.
- Maxillofacial surgeon – a doctor who does operations (surgery) on the mouth, jaw, face and neck.
- Oncologist – a doctor who treats people who have cancer.
- Therapy radiographer – someone who treats certain types of cancer with radiotherapy.
- Radiologist – a doctor who looks at scans and x-rays to diagnose problems.

- Pathologist – a doctor who looks at cells or body tissue under a microscope to diagnose cancer.
- Clinical nurse specialist (CNS) – a nurse who gives information about cancer, and support during treatment.
- Speech and language therapist (SLT) – someone who gives information and support to people who have problems talking and swallowing.
- Dietitian – someone who gives information and advice about food and food supplements.
- Restorative dentist – a specialist dentist who makes sure your teeth look good and work well after treatment.

Depending on the type of cancer you have, the MDT may also include:

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


University Hospitals Coventry and Warwickshire NHS Trust
NHS

Talking about your treatment plan

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

Your specialist doctor should explain:

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

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

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

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

Our leaflet **Getting help during treatment for cancer of the larynx** has suggestions of questions to ask your healthcare team. There is also space to write your notes. You can find it at the back of this booklet.

Making treatment decisions

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

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

Decisions about advanced cancer

For advanced cancer, the aim of treatment is to control the cancer, help you live for longer and improve symptoms.

This can mean you have different treatments depending on when you need them. You may have long periods in between treatments when you feel well and can continue with everyday life. You may have ongoing treatment to control the cancer. This is sometimes called maintenance treatment.

Your doctor can often give you an idea about how well a treatment will work. You may decide to have one treatment instead of another because:

- the side effects are different
- it means you will spend less time at the hospital.

We have more information about making treatment decisions in our booklet **Making treatment decisions** (page 132).

You may need to have a treatment for a while to see if it is helping. Doctors will try to avoid you having unnecessary side effects from a treatment that is not working well.

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

We have more information on coping with advanced cancer in our booklet **Coping with advanced cancer** (page 132).

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan (page 41).

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

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

Second opinion

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

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

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

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

Before treatment starts

Before treatment starts, you will see your doctor or specialist nurse. They will give you information about the treatment and help you prepare. You may also see a:

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

You can ask your cancer doctor or specialist nurse to refer you to anyone in the multidisciplinary team (MDT) at any time. This can be before, during or after your treatment.

If you smoke or drink alcohol, your cancer doctor or specialist nurse will give you advice on stopping.

Smoking

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

- means the side effects of treatment may be less severe
- increases the chances of your treatment being effective
- may reduce the risk of cancer coming back after treatment
- reduces the risk of developing cancer in other parts of the body, such as the lungs.

It can be difficult to stop smoking, especially when you are stressed. You can ask for help and support at your hospital. NHS Stop Smoking services (page 140 to 141) can help increase your chances of stopping successfully. Research shows that people who use these services together with a stop smoking treatment are up to 4 times more likely to stop smoking for good. Speak to your cancer doctor or call a stop smoking helpline for advice and to find local NHS Stop Smoking services.

Your GP can also give advice and prescribe nicotine replacement therapies. These therapies include things like nicotine patches, gums, and inhalers.

We have more information about giving up smoking that you may find helpful, on our website. Visit **macmillan.org.uk/stop-smoking**

Alcohol

Not drinking alcohol, particularly spirits, will help make some side effects of treatment less severe. Stopping drinking alcohol can also reduce your risk of developing another head and neck cancer.

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

Dental care

Your cancer doctor may refer you to a dentist with experience in treating people who have cancer of the larynx. Or you may need to see your own dentist. This is to make sure your teeth or dentures are in good condition. This can reduce the risk of mouth problems during and after treatment. If you are going to have radiotherapy and some of your teeth are unhealthy, you may need them removed before your treatment starts.

You may also see an oral hygienist. They can give you advice on how to look after your teeth and gums. Knowing how to look after your mouth is very important. This is because cancer treatment may make it more sensitive and likely to get infections. This can happen particularly if you have radiotherapy (pages 50 to 62).

Changes to breathing and speaking

Before treatment for cancer of the larynx, you will see a speech and language therapist (SLT). Treatment can affect your breathing, speech and voice in different ways. Your SLT will talk to you about possible effects of treatment. They will also explain how to cope with these changes.

If you have radiotherapy (page 50 to 62), you will breathe and speak in the same way, but your voice may become hoarse.

If you have surgery, you may need to learn how to breathe and speak in a different way. Effects on your breathing and speech will depend on the type of surgery you have (pages 72 to 74). Your surgeon and SLT will talk to you about what changes to expect from your surgery. Remember, you will get lots of support to help you cope with any changes.

Changes to swallowing

If your team thinks treatment may affect your swallowing, you may see a dietitian and speech and language therapist (SLT). They can help with any swallowing and dietary problems you have before treatment. Your SLT can also tell you about any effects treatment is likely to have on your swallowing. They will talk to you about what can help.

Sometimes radiotherapy (pages 50 to 62) can make it very difficult to swallow. This can happen particularly if radiotherapy is combined with chemotherapy. This is called chemoradiation (page 94). Your SLT can show you exercises that may help improve swallowing after treatment. These will depend on the type of swallowing difficulties you have. Usually, swallowing improves within a few months of finishing treatment. Some people find it takes longer to improve. Rarely, some swallowing difficulties are permanent.

If your team thinks you may develop swallowing difficulties during treatment, they may suggest you are fed through a tube for a while. This is to make sure you have enough calories to maintain or gain weight.

Some different ways you can be fed by a tube include the following:

- Nasogastric (NG) feeding – this is where a thin tube is passed up the nose and down into the stomach.
- Gastrostomy feeding – this is where a tube is passed through the skin and muscle of the tummy (abdomen) into the stomach. This is called a percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) tube. You may have this if you need to be fed through a tube for a longer period of time.

If you have problems swallowing and need to be tube fed, your healthcare team will explain which type will be best for you. When your swallowing improves, and you can eat and drink enough through your mouth, the tube may be removed.

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

We have more information about nutritional support and artificial feeding on our website. Visit **macmillan.org.uk/tube-feeding**

Radiotherapy

Radiotherapy uses high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells. How and when radiotherapy is used to treat cancer of the larynx depends on the stage of the cancer.

Early stage cancers

Radiotherapy is often the first choice of treatment for early stage cancer of the larynx (pages 28 to 29). Your cancer doctor may advise you to have radiotherapy or endoscopic surgery (page 67). Both treatments help you keep your voicebox. We have more information about radiotherapy on our website at **macmillan.org.uk/radiotherapy**

The aim of radiotherapy for early cancer of the larynx is to cure the cancer. This is called radical radiotherapy.

Locally advanced cancers

If the cancer is larger, or spreads to lymph nodes or tissues nearby, it is called locally advanced (pages 28 to 29). In this case, radiotherapy may be combined with other treatments. You may have radiotherapy:

- after surgery to destroy any remaining cancer cells, and reduce the risk of it coming back
- after surgery, combined with chemotherapy (chemoradiation) (page 94)
- instead of surgery, combined with chemotherapy
- combined with a targeted therapy drug (pages 95 to 96).

If you have surgery first, you usually start chemoradiation or radiotherapy 6 or 7 weeks later.

Advanced cancers

Sometimes it is not possible to cure the cancer. In this case, the main aim of radiotherapy is to help reduce symptoms. This is sometimes called palliative radiotherapy.

You may have palliative radiotherapy to:

- help control the cancer for a period of time
- shrink a tumour that is causing problems with swallowing or breathing
- help improve symptoms, if the cancer has spread to other areas of the body
- reduce symptoms – this might happen if the cancer has spread to lymph nodes and these are causing problems such as pain, bleeding or breaking through the skin.

How radiotherapy is given

Radiotherapy is usually given from outside the body. This is called external beam radiotherapy. High-energy x-rays are directed at the cancer from a radiotherapy machine. Radiotherapy is not painful, but you do have to lie still for a few minutes while the treatment is being given.

External beam radiotherapy

You usually have external beam radiotherapy as an outpatient in the hospital radiotherapy department. It is normally given as a number of short treatments. These are called treatment sessions or fractions. You may have radiotherapy:

- Monday to Friday, with a rest at the weekend (this is the most common method)
- more than once a day (hyperfractionation).

Treatment may take 3 to 7 weeks. This is called a course of treatment. Your cancer doctor, specialist nurse or radiographer will discuss the treatment with you.

If you are having radiotherapy to help with symptoms, you may only need a short course or a single treatment session.

Intensity-modulated radiotherapy (IMRT)

IMRT is the main type of external beam radiotherapy used to treat cancer of the larynx. It shapes the radiotherapy beams and allows the radiographer to give different doses of radiotherapy to different parts of the treatment area. This means lower doses of radiotherapy are given to the healthy tissue surrounding the tumour. This can help reduce the risk of side effects (pages 56 to 62) and late effects. It may also allow the radiographer to give higher doses of radiotherapy to the tumour.

Research has shown that having IMRT may reduce some long-term side effects, including having a dry mouth. This is because radiotherapy given in this way avoids the salivary glands, where saliva (spit) is produced.

Some people may have regular scans during their treatment. This is to make sure the radiotherapy is targeting the treatment area. Sometimes the treatment may need adjusting, for example, if you lose weight during treatment.

Volumetric modulated arc therapy (VMAT)

VMAT is a type of IMRT that is used to treat many different cancers. It is sometimes used to treat larynx cancer. VMAT delivers a continuous dose of radiation as the machine rotates 360 degrees around the body. This treatment accurately shapes the radiation dose to the tumour while minimising the dose to the healthy tissue surrounding it. Giving the radiotherapy in this way makes it very accurate and shortens the treatment time.

Conformal radiotherapy (CRT)

Many types of external beam radiotherapy are conformal. This means the beams are specially shaped to fit the treatment area. It may be used to give lower doses of radiotherapy.

Planning your radiotherapy

To make sure your radiotherapy is as effective as possible, it must be carefully planned. Planning makes sure the radiotherapy is aimed directly at the cancer. This means it causes the least possible damage to surrounding healthy tissues. Your cancer doctor plans your treatment with a radiotherapy team who are experts in giving you radiotherapy.

Radiotherapy planning is usually done during a visit to the radiotherapy department. Sometimes you may need to make more than one visit. Planning can take up to 2 hours. Your team will let you know how long it is likely to take and answer any questions you may have.

Radiotherapy masks

It is important that you lie still and in the correct position during each treatment. To help you stay still, you wear a plastic mesh mask for each session of radiotherapy. The radiographer, or mask room technician, will explain how the mask is made.

The mask is designed so you can see and breathe normally while wearing it. It is sometimes called a mould, head shell or cast.

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

Marks might be drawn on your mask. These help the radiographer position you correctly before each treatment. Sometimes the marks are made on your skin. They are permanent and about the size of a pinpoint. These marks will only be made with your permission. If you are worried about them, talk to your radiographer.

We have more information about how radiotherapy masks are made on our website. Visit **macmillan.org.uk/radiotherapy-masks**

A radiotherapy mask

Planning a CT scan

After your mask is made, you have a CT scan (page 25) of the area to be treated. The radiographers take measurements to plan the treatment specifically for you. Some people also have an MRI scan as part of their radiotherapy planning.

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

Having radiotherapy

At the beginning of each session, the radiographers will make sure you are in the correct position. They will tell you how long your treatment will take. They then carefully fit you with your mask and make sure you are comfortable.

When everything is ready, they leave the room and the treatment starts. The treatment itself is not painful. It does not make you radioactive. You will not be a risk to anyone during your treatment.

The radiographers will watch you on cameras. If you need to talk to them during your treatment, you can use the intercom.

In some treatment rooms, you can listen to music to help you relax during treatment. Ask your radiographers if this is possible.

During treatment, the radiotherapy machine may stop and move into a new position. This is so you can have radiotherapy from different directions. Some radiotherapy machines make a small beeping noise to tell you when the treatment is starting and when it has finished.

Side effects of radiotherapy

Radiotherapy to the larynx can cause side effects. They can be mild or more severe. Some of the side effects occur a few days after treatment has started. Others may occur soon after treatment is finished. The exact side effects usually depend on where the tumour is and how much treatment is needed. Side effects are usually more severe if you have chemoradiation (page 94).

Many of the side effects listed below usually occur within 7 to 10 days of starting treatment and may last for several weeks before improving.

Other side effects may develop some time after treatment has finished. These are called late effects and can be temporary or permanent. You may not have any late effects, or they may be mild or more severe.

Before you start radiotherapy, someone from your healthcare team will discuss your treatment with you so you know what to expect. This could be your:

- cancer doctor
- nurse
- speech and language therapist (SLT)
- dietitian
- radiographer.

Tell them about any side effects you have during or after treatment. There are often things that can help.

Feeling tired

Radiotherapy often makes people feel tired. Tiredness may get worse as treatment goes on. If you are having radiotherapy alongside other treatments, such as surgery or chemotherapy, you may feel more tired. But there are things you can do to help, such as:

- get plenty of rest
- do some gentle exercise, such as short walks
- drink plenty of fluids
- ask others for help with everyday jobs.

After treatment finishes, you may continue to feel tired for weeks or months. If it does not get better, tell your cancer doctor or specialist nurse.

We have more information about coping with tiredness in our booklet **Coping with fatigue (tiredness)** – page 132.

Skin reactions

The skin in the area that is treated may:

- redden
- darken
- feel sore or itchy.

Your radiographer or specialist nurse will give you advice on taking care of your skin. If your skin becomes sore or itchy or changes colour, tell them straight away. They can give you advice and treatments if needed.

Skin reactions should get better within 4 weeks of treatment finishing.

During your treatment, you are usually advised to:

- wear loose-fitting clothes made from natural fibres, such as cotton
- wash your skin gently with mild, unperfumed soap and water and gently pat it dry
- avoid rubbing the skin
- avoid wet shaving
- avoid hair-removing creams or products, including wax
- follow your radiotherapy team's advice about using moisturisers
- protect the treated area from the sun.

Sore throat and difficulty swallowing

The lining of your throat may become swollen, sore and inflamed. This may affect your swallowing and make eating and drinking more difficult. Your doctor can prescribe liquid painkillers to help with this. Try to take these before meals to make eating easier.

Your SLT will talk to you about any swallowing or eating problems you may have (pages 110 to 115). It is important to try to keep eating and drinking for as long as possible during your treatment.

You may cough when you eat and drink. Sometimes this can be a sign that food and drink is going down the wrong way, into the windpipe. This can cause a chest infection. If you are coughing when you swallow, it is important to tell your SLT straight away. They can give you advice, and show you how to do exercises that will help stop food and drink going down the wrong way. It is important to follow the advice of your SLT to stop further or ongoing swallowing problems.

Your team will give you advice on foods that are easy to swallow. They may also give you nutritious or high-calorie drinks. Most people manage to eat soft, moist foods while their throat is sore. Some people can only manage a liquid diet. The soreness usually lasts for a few weeks after radiotherapy has finished. But some problems may continue for longer, depending on the area treated.

Some people find the soreness stops them eating or drinking enough. This is more common if you have chemoradiation. If this happens, your doctor might suggest you have nutritional support so that you do not lose too much weight. This means you have liquid food that contains all the nutrients you need. You will have this through a feeding tube that goes into your stomach. You can also have liquids and medicines through the tube. If doctors think you might have problems eating, they may suggest putting in a feeding tube before you start treatment.

Nutritional support can:

- prevent weight loss and make sure you get enough fluids and nutrients
- help you feel less weak or tired
- make you feel less stressed about having to eat
- allow the sore area to heal and help you recover faster
- allow you to eat smaller amounts when eating is uncomfortable
- give you enough calories to help prevent you needing any breaks in treatment.

Your SLT will assess whether you can still swallow food and fluids safely while you have a tube in. If you swallow safely, you will still be encouraged to eat and drink normally with a tube in place. This will happen even if you can only manage small amounts at a time.

When treatment has finished, you are usually encouraged to stop using the tube as soon as it is safe. It is important to follow the advice of your healthcare team when you have a feeding tube in.

Dry mouth or throat

Radiotherapy to the larynx may affect the salivary glands. This can make you produce less saliva or spit. The lining of your mouth and throat can become dry. This can make eating and speaking difficult.

Saliva helps keep your mouth clean. This means it is important to brush your teeth with a soft toothbrush twice a day. Your healthcare team will advise you on whether to use a mouthwash. It is important to follow any instructions that your specialist nurse or doctor give you.

You are less likely to get an infection if your mouth is moist. Drinking sips of water regularly can help keep your mouth moist. Your radiotherapy team can give you artificial saliva sprays and gels to help.

You may have a dry mouth (page 111) for several months after treatment has finished. Sometimes, it can be permanent. This usually depends on the size of the area being treated. Your doctor will be able to tell you what to expect.

Thick, sticky saliva (mucus)

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

You might need to spit often to get rid of the mucus, so it is a good idea to always have tissues with you. Rinsing your mouth and drinking water regularly can also help.

If you have a build-up of mucus, your cancer doctor or specialist nurse may suggest you use a nebuliser. This is a small machine that changes liquid medicine into a fine mist of fluid, which you inhale. It can help to loosen the mucus.

If your sleep is disturbed by coughing, using a nebuliser before bed may help. A nebuliser may also help if you have problems swallowing, or a dry mouth and throat.

Changes in your saliva may get better within about 8 weeks of radiotherapy ending. But sometimes they continue for several months or more. Tell your doctor or nurse if this happens. They may be able to prescribe medicines to help.

Voice changes

Your voice may already be hoarse, and this could get worse during radiotherapy. Your cancer doctor or SLT will tell you about the risk of permanent voice changes. If your voice is hoarse and weaker than before, try not to strain it. Try to make sure you are drinking enough fluids, and avoid smoky places. Your voice should slowly get better and stronger after radiotherapy has finished. This may take several weeks. Your SLT can advise you on how to look after your voice during treatment. They can also suggest voice exercises to speed up your recovery.

Loss of appetite

You may not feel like eating if your mouth is sore. The soreness may be worse towards the end of radiotherapy and in the first 2 weeks after treatment has finished. It is important to try to eat, even if you do not feel like it. Try taking smaller meals more often. If your mouth is very sore, it can help to take painkillers before you eat. You can also see a dietitian. They may suggest you have some high-calorie or nutritious drinks until your appetite returns.

Loss of taste

Your sense of taste may change or you may find everything tastes the same. This should get better, but it may take a few months. It should then slowly improve for up to a year or more after radiotherapy has finished. Sometimes, radiotherapy can affect taste permanently.

Hair loss

Radiotherapy may cause some temporary hair loss over the back of your head. If you have any facial hair, it may fall out. Sometimes, this can be permanent.

We have more information about hair loss in our booklet **Coping with hair loss** (page 132).

Breathing problems

Radiotherapy may cause swelling in your throat. Very rarely, this can cause breathing problems, which need treatment straight away.

If you develop difficulty breathing, or if your breathing sounds different, tell a doctor or contact the hospital straight away. Very rarely, you may need an operation to help you breathe. This is called a tracheostomy (pages 67 to 68).

Surgery

Your cancer doctor may advise that you have surgery. The operation you have will depend on the stage of the cancer (pages 28 to 30). You may have surgery if:

- the cancer is small enough to be removed through the mouth – this is done using an endoscope with a laser (heat) or small surgical instruments
- the cancer is locally advanced (page 29)
- the cancer comes back after radiotherapy or chemoradiation
- if the cancer is controlled by radiotherapy or chemoradiation but treatment has caused damage to the voice box.

Before your operation

The main aim of surgery is to remove the cancer completely. Your specialist surgeon will also do everything possible to reduce changes to your speech and swallowing.

Before you have the operation, your surgeon and nurse will explain what will happen before, during and after the surgery. It is important you understand what the operation involves and how it will affect you in the short and long term. You will usually meet other members of the MDT before your surgery (pages 37 to 38). This can include a specialist nurse, a speech and language therapist (SLT) and a dietitian. They can provide support and advice before and after the operation.

You will have some tests before your operation to check:

- how well you would cope with an anaesthetic, if you need one
- whether you can make a good recovery after surgery.

You may also have:

- blood tests
- a chest x-ray
- an electrocardiogram (ECG) to check your heart
- breathing tests (lung function tests).

You may have these done at a pre-assessment clinic before you go into hospital.

Types of operation

There are different types of operation that you may have to treat cancer of the larynx.

Transoral resection

If you have early stage (page 29) cancer of the larynx, your surgeon may be able to remove the cancer through your open mouth. This is called transoral resection. You will not have a wound in your neck afterwards. You have it done under a general anaesthetic, and you only need a short stay in hospital. It may help to reduce the risks of certain side effects, such as swallowing difficulties. It will also help you recover faster.

The surgeon passes a thin, flexible tube with a camera at the end into the mouth and down the throat. This is called an endoscope. They use the camera to see images of the larynx. These appear on a screen in the operating theatre. This lets your surgeon see the cancer clearly. They then guide small surgical instruments through the endoscope to remove the cancer.

Transoral laser microsurgery (TLM)

Sometimes, your surgeon uses a high-powered laser to remove the cancer. This is called transoral laser microsurgery (TLM). The surgeon points the laser beam at the tumour to remove it. They also remove a small amount of healthy tissue around it, called a margin. This is to try to make sure they have removed all the cancer cells. The laser can be used to stop any bleeding during surgery.

Transoral robotic surgery (TORS)

Sometimes, instead of holding the surgical instruments themselves, the surgeon uses a machine or robot to hold them. The surgeon controls the robotic arms. These arms can move very steadily and precisely to remove the tumour through the mouth. This is called transoral robotic surgery (TORS).

TORS is not widely available in the UK. Your cancer doctor can explain if it is suitable for you.

After a transoral resection

You may have some pain in your throat and difficulty swallowing for about 2 days afterwards. Your doctor or nurse can tell you what painkillers to take until this gets better.

If the surgery involved a vocal cord, your voice may be hoarse. Your doctor might ask you to rest it for a few days. For some people, the surgery may cause a permanent change to their voice. If this happens, your SLT can give you advice and support. They may also suggest voice therapy.

Rarely, side effects of a transoral resection include:

- bleeding
- infection
- damage to your teeth.

Your cancer doctor or specialist nurse will give you more information about this before you go home.

Partial laryngectomy

You might have a partial laryngectomy to treat early stage cancer of the larynx or if you need more treatment. Your surgeon will remove the affected part of the larynx.

This may be done endoscopically. This means the surgeon passes the instrument down the throat. Or it may be done through a cut in the neck.

After a partial laryngectomy, you still have part of your larynx. You may have some difficulties with your voice or swallowing. This will depend on the type of partial laryngectomy you have. Your surgeon and SLT will discuss your specific operation, how it might affect you and ways to cope.

Tracheostomy

Sometimes, surgery or radiotherapy to the larynx causes temporary swelling around the throat. This can narrow your airway and make it difficult to breathe. If this happens, the surgeon creates a small opening at the front of the neck. This allows them to insert a tube into the windpipe (trachea) to help you breathe. This is called a tracheostomy or stoma.

The tracheostomy is held open by a small plastic tube that is a few centimetres long. The tube stays in place until the swelling improves. This usually takes a few days. After this, the tube is removed. You breathe through your nose and mouth like you did before. When the tube is removed, the opening is left to heal naturally.

If you have a tracheostomy, you cannot usually speak with the tube in place. But you can use a pen and paper to communicate. Or you can get an app for your mobile phone, laptop or tablet that reads aloud what you type into it.

If your surgeon thinks you need a tracheostomy after surgery, they will talk to you about it beforehand. You will have time to ask the specialist nurse or SLT questions before you have surgery.

Total laryngectomy

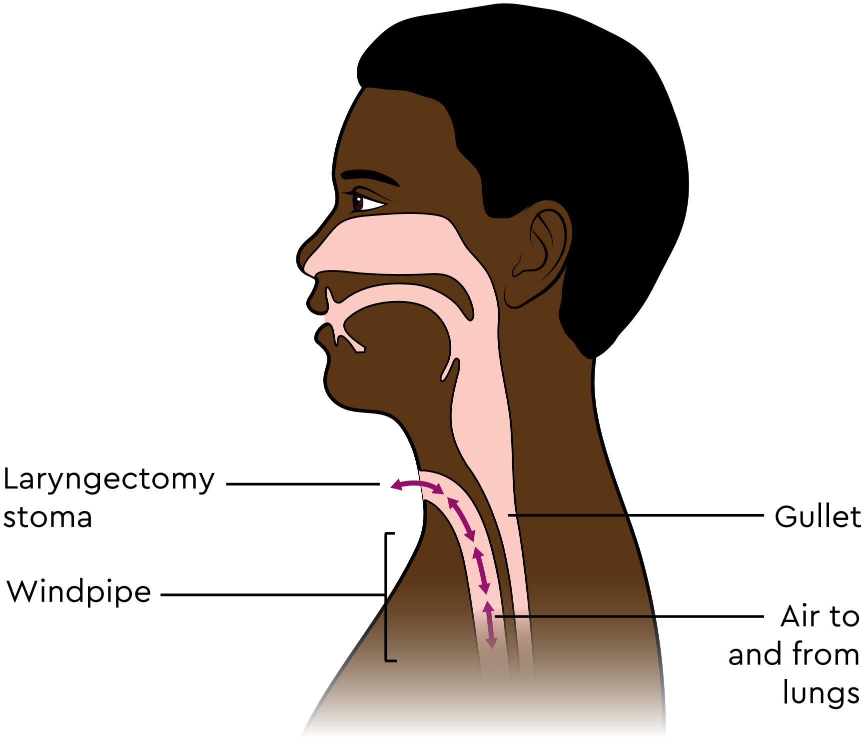
A total laryngectomy is an operation to remove all of the larynx (voicebox). You might need an operation to remove the whole larynx in order to remove all the cancer. Your doctors may offer this treatment if they think radiotherapy may not cure the cancer completely. You may also need some lymph nodes removed from your neck.

When the surgeon removes the whole larynx, there is no longer a connection between your mouth, nose and lungs. This means that after the operation you breathe and speak in a different way. You breathe through a hole (opening) in your neck, called a tracheostomy or stoma. You also no longer have vocal cords to produce a voice. But you can speak using a choice of different ways to communicate. The connection between the throat and oesophagus (gullet) is usually not affected. This means you can swallow liquids and food as you did before the operation. Sometimes you may need to eat softer foods to begin with.

Laryngectomy stoma

A laryngectomy stoma is when the surgeon makes a permanent opening in the windpipe. It is in the lower part of your neck and you breathe through it. Having a stoma is safe. It usually stays open on its own and will not close over. Some people may need a soft tube to help keep their stoma open for the first few days after surgery. Others may need the tube for longer.

Laryngectomy stoma



The thought of having a laryngectomy stoma can be frightening. But you will get lots of support and information from your healthcare team.

You have the stoma for the rest of your life and start breathing through it when you have your operation. Your surgeon, specialist nurse and SLT will talk to you about this before your operation. When you are well enough, your nurse and SLT will teach you how to clean and take care of the stoma. You can continue to get support from your healthcare team for as long as you need it.

Removing lymph nodes

Surgery to remove the cervical lymph nodes in one or both sides of the neck is called a neck dissection. It tells your doctor more about the stage of the cancer, removes any lymph nodes that contain cancer cells and reduces the risk of the cancer coming back.

A neck dissection is done under general anaesthetic. It can be done:

- at the same time as the operation to remove the cancer
- before or after chemoradiation or radiotherapy if the lymph nodes still have cancer cells in them
- if the cancer comes back in the nodes after treatment.

You have tests first to see if there are any signs of cancer in the lymph nodes. The nodes that are removed are sent to a laboratory. A pathologist checks them for cancer cells. Your surgeon will talk to you about this before your operation.

After the operation, your neck and shoulder may be stiff on the side where you had the surgery. A physiotherapist can show you exercises to help with this.

Reconstruction

Sometimes, you may need surgery to reconstruct the area where you have had the operation. The aim of reconstructive surgery is to make the area look and work as naturally as possible.

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

Reconstruction can help with your recovery from the operation. It can also help improve your speech and swallowing. Your surgeon will explain whether this is recommended for you.

After your operation

You usually go back to the ward after your operation. You may be looked after in an intensive-care or high-dependency unit for 1 or 2 days. The doctors and nurses can make sure your breathing is safe and give you pain relief.

After your operation, you are encouraged to start moving around as soon as possible. This is an important part of your recovery. It is important to do regular leg movements and deep-breathing exercises. This helps prevent a blood clot forming. A physiotherapist may explain the exercises to you.

Breathing and speaking

After a total laryngectomy, you will be able to breathe and cough through the stoma straight away. You may need extra oxygen to help you breathe for a short while. The nurses give you oxygen through a special mask, which fits over your stoma.

You might have mucus in your airway, so you may cough a lot in the beginning.

When you cough, the mucus will come out of the stoma in your neck. Your nurses and physiotherapist will show you breathing exercises to help clear the mucus. Your nurse can also use a thin, flexible suction tube to remove the mucus. They can do this until you get used to the changes in your breathing.

You will not be able to speak at first. But you can communicate by mouthing words, writing or using a communication chart. If you have a mobile phone or tablet, you could use an app that reads what you type aloud. Being unable to speak can be frustrating and difficult to cope with. It is important to remember that most people who have a laryngectomy are able to speak again. But you may speak differently to how you did before surgery. Your SLT will support you with your communication, and you will get plenty of support and information from your healthcare team.

Pain

Your doctor or nurse will talk to you about managing or preventing pain after your surgery.

You may have your painkillers as an injection, or through a syringe connected to an electronic pump. The pump gives a continuous dose of pain relief over a set time. Pain relief may be called analgesia.

You may also have a hand control with a button to press if you feel sore. This is called patient-controlled analgesia (PCA). It is designed so you cannot have too much pain relief. This means you can press it whenever you are uncomfortable.

Always tell the nurses if you are in pain. They may be able to increase the dose or change the pain relief.

Drips and drains

You may have several drips and drains in place for a few days after surgery. You are encouraged to get out of bed and move around from the first day after surgery. The nurses help you with the drips and drains when you are out of bed.

You have some thin tubes called wound drains attached to you. These drain fluid from your operation site and allow your wound to heal. Tell your doctor or nurse if these are uncomfortable. They are usually taken out 2 to 4 days after surgery.

A drip going into a vein in the arm gives you fluids for a few days. You also have a feeding tube for liquid foods and medicines. You should be able to eat and drink again once your throat has healed. This usually takes 1 to 2 weeks, but it can take longer. You will need to increase your eating gradually. Your dietitian or speech and language therapist (SLT) can give you advice you about this.

Changes to your appearance

Before your operation, your surgeons and specialist nurse can talk to you about possible changes in your appearance. It is important to have a good idea of what to expect.

Operations to the larynx often cause swelling. Your face and neck may look swollen after the operation. This slowly gets better over time.

Scars are usually red or dark to begin with, but slowly fade over time.

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

We have more information about coping with changes in your appearance in our booklet **Body image and cancer**.

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

Coping and support

It can take time to recover from surgery to the larynx. You may feel embarrassed about your stoma. This can affect your confidence and may be distressing. It can take time to adjust when you are learning how to speak in a different way and breathe through a stoma.

It can help to tell your family and close friends how you feel. Your cancer doctor, specialist nurse and speech and language therapist (SLT) can give you advice and support. They may put you in contact with someone in your area who has had a laryngectomy.

You may find it helpful to use our Online Community. Visit our website **macmillan.org.uk/community**. You can share your experience, ask questions and get support online. You could also ask your specialist nurse or SLT if there are any local support groups. These can help support you and give practical advice.

Living with a laryngectomy stoma

Before you leave hospital, you will get information about your stoma and advice on how to care for it. Try not to worry if you do not understand it all straight away. It will get easier with time.

Some people find it helps if a family member is also shown how to care for the stoma. You will also have contact details of people you can contact if you have any problems at home. Your SLT or nurse specialist will explain how you can get supplies for your stoma. These are usually available on prescription from your GP.

Caring for a laryngectomy stoma

Before you leave hospital, your specialist nurse or SLT will show you how to:

- clean the skin around the stoma
- cough and clear your mucus
- use a suction tube to remove mucus if you need to.

They will tell you what to use to clean the skin around the stoma, and how often to do this. They will also show you how to protect the skin around the stoma, especially in hot weather. This is to stop the area becoming sunburnt.

Stoma filters

When you breathe in, air goes down into your lungs through your stoma. The air is no longer warmed and moistened by your mouth and nose. The cooler, drier air can irritate your lungs. You may produce more mucus or phlegm. You will not be able to clear the mucus by sniffing or blowing your nose. When you cough, the mucus is coughed out through your stoma, not your mouth.

It is important to keep your stoma covered with a stoma cover or filter. These are also called heat and moisture exchangers (HMEs). Your cancer doctor, specialist nurse or SLT can show you how to use them. The HME makes sure that the air you breathe is warmed and filtered. This will help reduce the amount of mucus, and reduce the risk of chest infections. You can get HMEs on prescription. Your specialist team will talk to you about this.

Swallowing

When your throat has healed, you can start taking fluids and food in by mouth. If chewing or swallowing is difficult, your SLT will give you advice on foods that are easy to swallow. They will also show you exercises to help with swallowing. Most people are able to eat a normal diet after a total laryngectomy.

Showering and bathing

When you have a bath or shower, you need to protect your stoma so that water does not get into your lungs. To do this, you need to cover the stoma with an aid or shield. Your specialist nurse or SLT can give you information about showering aids or shields and how to use them.

After surgery, your neck may feel numb. To avoid cutting yourself when shaving, try using an electric razor.

Chest infections

Breathing through a stoma may make you more likely to get chest infections. Signs of an infection include:

- feeling unwell
- feeling cold, shivery, hot or sweaty
- a change in the colour of your mucus to green or dark yellow
- having a cough that does not go away
- coughing up more mucus than usual.

It is normal to cough up some mucus after a laryngectomy. You will get used to what is normal for you. If you have any signs of an infection it is important to tell your cancer doctor straight away. You may need antibiotics.

Changes to smell and taste

Your senses of smell and taste are affected because you no longer breathe through your nose and mouth. This can improve after a few months, but some people might have long-term problems. There are ways to try and improve your sense of taste and smell. Your SLT may be able to teach you these.

Swimming

If you swim, you will need special equipment to stop water going into the stoma. Your SLT can talk to you about this. The National Association of Laryngectomee Clubs has information and training on using the equipment safely (page 140).

Speaking after a laryngectomy

Most people who have had a laryngectomy are able to speak afterwards. But this will be in a different way to before surgery.

Some people cope well with learning to speak again. For others, it can be practically and emotionally difficult. But there are other ways to communicate. The type of communication you use depends on your situation, the type of surgery you had, and your preferences.

You will see a speech and language therapist (SLT) before your operation to talk about different ways of communicating. You may be able to watch videos of people talking after a laryngectomy. Or you may be able to meet someone who has had similar surgery. Some people find this very helpful. Others prefer written information.

The video at **macmillan.org.uk/speech-therapy** shows an SLT and someone who has had a laryngectomy. They talk about different ways to communicate, including using a voice prosthesis valve (pages 81 to 82).

There are other ways to help you communicate if you do not have a valve. These include:

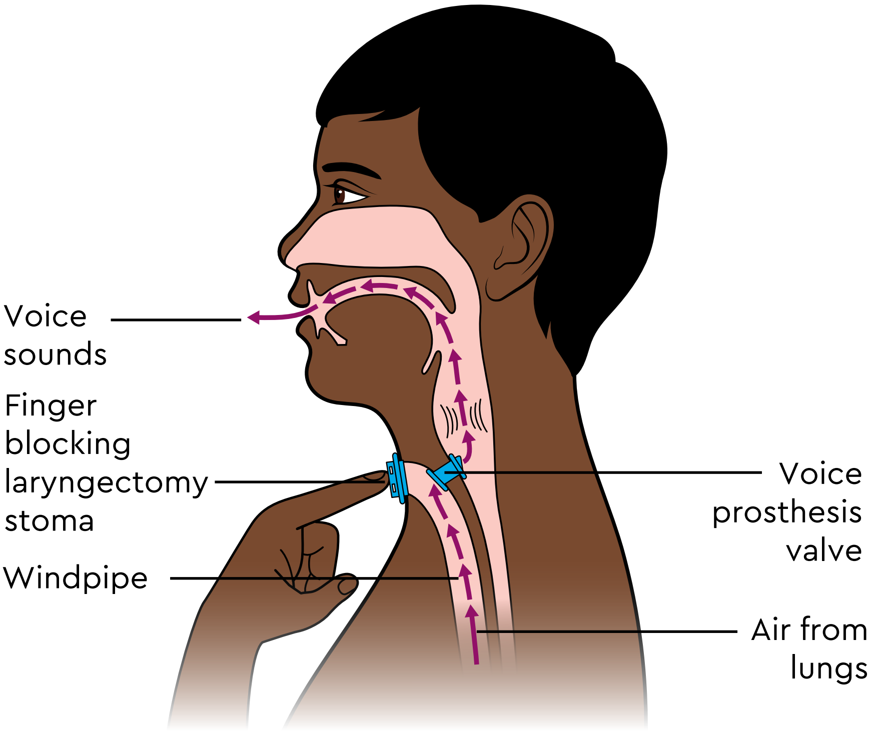
- oesophageal speech (page 82)
- an electrolarynx (page 83)
- a combination of oesophageal voice and electrolarynx
- an electronic keyboard (page 83)
- an app on a smart phone or tablet
- mouthing or writing.

Voice prosthesis valve

This operation can be done at the same time as a laryngectomy or at a later time. It involves a hole (fistula) being made through the wall between your windpipe and gullet (the trachea and oesophagus).

A small valve called a voice prosthesis is put into the opening to connect the windpipe to the gullet. The valve is one-way. This stops food and fluids passing into the windpipe. When the stoma is covered with a finger or thumb and you breathe out, air from the lungs is pushed through the valve to make a voice by vibrating the muscles in the gullet.

Voice prosthesis valve



After your valve has been fitted, you will be seen regularly by the SLT. They will support you as you adjust to living with your voice prothesis valve and caring for it. It can take time to learn how to speak with a voice prosthesis. The voice can sound quite natural and you will speak with your usual accent. It is usually a lower pitch than before.

Some people may be able to use a hands-free valve. This allows them to speak without using their finger to cover the stoma. These are not suitable for everyone, but you can ask your cancer doctor or SLT about it.

Oesophageal speech

Sometimes, people choose to learn a technique called oesophageal speech. You can learn this as you recover from your laryngectomy (page 67).

In oesophageal speech, air is squeezed down into the oesophagus (gullet) from the mouth. As the air moves back up from the oesophagus, your throat muscles vibrate and make a sound. As with normal speech, movements of your lips, cheeks and tongue shape the sound into words.

Oesophageal speech has the advantage of not needing any equipment. Some people find it easy to do, but others find it more difficult. It is usually best to practise little and often. Your SLT can help you develop the best speech possible. They can talk to you about other ways of communicating if this technique does not work for you. They will also help you use your new way of talking for social situations and on the telephone.

Electrolarynx

There are different types of electronic aids available to help you produce an artificial voice. You may be given one to use while you practise developing your new voice. You hold them next to your neck under the chin. They make sound vibrations in the mouth that you can form into speech. Your SLT will help you choose the type that works for you. They will show you how to use it and look after it.

Electronic keyboards

Some people like to use electronic keyboards to communicate. These are like small typewriters. Mini-laptops, tablets or text messaging on your mobile phone can also be good. There are also different types of writing device available. Your SLT can tell you about these.

Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. They are also called cytotoxic drugs. This means toxic to cells. These drugs disrupt the way cancer cells grow and divide. But this means they also affect normal cells. The drugs travel around the bloodstream and can reach cancer cells anywhere in the body.

Chemotherapy can be used to treat cancer of the larynx:

- at the same time as radiotherapy – called chemoradiation (page 94)
- before radiotherapy – to shrink larger tumours and make radiotherapy more effective
- before surgery – to shrink larger tumours, but this is rare
- to help control the cancer and improve symptoms – this is called palliative chemotherapy.

The most common chemotherapy drugs for treating cancer of the larynx are:

- cisplatin
- 5-fluorouracil (also known as 5FU).

Other drugs include:

- carboplatin
- docetaxel
- paclitaxel.

We have more information about chemotherapy in our booklet **Understanding chemotherapy** (page 132).

How chemotherapy is given

A nurse will give you chemotherapy intravenously. That means it goes directly into a vein. You can have it through a:

- short, thin tube put into a vein in your arm or hand, called a cannula
- fine tube that goes into a vein in your arm and up into a vein in your chest, called a PICC line
- fine tube that goes under the skin of your chest and into a vein close by, called a central line.

A PICC line and central line can be put in for you as a day patient. They will stay in until you have finished all your treatment sessions. A cannula is taken out after each treatment.

If you have a PICC or central line, you may have 5FU through a small pump. You can carry the pump in a bag and take it home with you. Your nurse will show you how to take care of it. They will also show you how to look after your line when you are at home.

While having chemotherapy, you may need to stay in hospital for a few days. Or you may be treated as a day patient. You usually have chemotherapy as several sessions or cycles of treatment. Your doctors will explain how often you will have treatment.

We have more information about chemotherapy drugs and the different ways chemotherapy is given on our website **macmillan.org.uk/chemotherapy**

Side effects

Chemotherapy may cause side effects, but these can usually be well controlled with medicines. Side effects will usually get better once treatment has finished. Not all drugs cause the same side effects and some people may have very few. You can talk to your doctor or nurse about what to expect.

You may get some of the side effects we mention, but you are unlikely to get all of them. If you are also having treatment with other cancer drugs, you may have some side effects that we have not listed here. Always tell your doctor, nurse or pharmacist about any side effects you have.

Risk of infection

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

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

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection
- your temperature goes below 36°C (96.8°F).

Symptoms of an infection include:

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

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

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

Anaemia (reduced number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red blood cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Bruising and bleeding

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

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

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

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

Feeling sick

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

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

Tiredness (fatigue)

Feeling tired is a common side effect of this treatment. It is often worse towards the end of treatment and for some weeks after it has finished. Try to pace yourself and plan your day so you have time to rest. Gentle exercise, like short walks, can give you more energy. If you feel sleepy, do not drive or operate machinery.

We have more information about tiredness (fatigue) in our booklet **Coping with fatigue (tiredness)** – page 132.

Sore mouth

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

If your mouth or throat is sore:

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

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

Loss of appetite

Some people find they lose their appetite during chemotherapy, especially if they are also having swallowing difficulties. Your doctor can arrange for you to see a dietitian. They can give you advice and might give you high-calorie drinks until your appetite comes back. Your doctor can also arrange for you to see a speech and language therapist (SLT) about any swallowing difficulties you may have.

Hair loss

Some chemotherapy drugs may cause hair loss. Some people may have complete hair loss, including eyelashes and eyebrows. Others may only have partial hair loss or thinning. It depends on the chemotherapy drugs you have. Your cancer doctor or specialist nurse can tell you more about what to expect.

Scalp cooling is a way of lowering the temperature of your scalp to help reduce hair loss. Your nurse can tell you if this is an option for you.

Hair loss is almost always temporary, and your hair will usually grow back after treatment finishes. Your nurse can give you advice about coping with hair loss and how to look after your scalp.

We have more information about hair loss in our booklet **Coping with hair loss** (page 132).

Numb or tingling hands or feet (peripheral neuropathy)

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

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

Diarrhoea

Some chemotherapy may cause diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

- If you have diarrhoea:
- try to drink at least 2 litres (3½ pints) of fluids each day
- avoid alcohol, caffeine, milk products, high-fat foods and high-fibre foods
- contact the hospital for advice.

Sore and red palms of hands and soles of feet

You may get sore and red palms of hands and soles of feet. The skin may also begin to peel. This is called palmar-plantar or hand-foot syndrome. It usually gets better after treatment ends.

Tell your doctor or nurse about any changes to your hands or feet. They can give you advice and prescribe creams to improve any symptoms you have. It can help to:

- keep your hands and feet cool
- moisturise your hands and feet regularly
- avoid tight-fitting socks, shoes and gloves.

Changes in hearing

Some chemotherapy drugs can cause changes in your hearing. You may have ringing in the ears. This is called tinnitus. Or 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 rarely, treatment may affect your sense of balance.

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

Effects on the heart

This treatment can affect how the heart works. You may have tests to see how well your heart is working. These may be done before, during and after treatment.

If the treatment is causing heart problems, your doctor may change the type of treatment you are having.

Contact your doctor straight away on the 24-hour number the hospital has given you if you have any of these symptoms during or after treatment:

- pain or tightness in your chest
- breathlessness
- dizziness
- changes to your heartbeat.

Other conditions can cause these symptoms, but it is important to get them checked by a doctor. If you cannot get through to your doctor, call the **NHS urgent advice number** on **111**.

Changes in the way the kidneys work

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

We have more information about chemotherapy in our booklet **Understanding chemotherapy** (page 132).

Chemoradiation

Certain chemotherapy drugs, such as cisplatin, may make radiotherapy work better. Having chemotherapy at the same time as radiotherapy is called chemoradiation.

Chemoradiation may be used:

- as your main treatment, if the cancer is locally advanced
- for cancers that cannot be removed with surgery
- as adjuvant treatment, to reduce the risk of the cancer coming back after surgery.

Having chemotherapy and radiotherapy at the same time increases side effects. It also increases your risk of developing late effects (pages 110 to 115).

Targeted therapies

Targeted therapy uses drugs to find and attack cancer cells. There are many different types of targeted therapy. Each type of therapy targets something in or around the cancer cell that is helping it grow and survive.

We have more information about different targeted therapies on our website. Visit **macmillan.org.uk/targeted-therapies**

Cetuximab

Cetuximab (Erbitux®) is a targeted therapy drug used to treat cancer of the larynx. It belongs to a group of cancer drugs called monoclonal antibodies. They work by targeting specific proteins called receptors on the surface of cells.

Cetuximab may sometimes be given with radiotherapy if chemotherapy cannot be given. Or it may be given with chemotherapy drugs (page 84) such as cisplatin and 5FU. You have the drug through a drip or infusion into a vein.

How cetuximab works

Most squamous cell cancers of the larynx (page 10) have proteins on their surface called epidermal growth factor receptors (EGFRs). Activating them causes the cancer cells to divide and grow. Cetuximab locks on to the EGFRs and stops the cancer cells growing. It may also make the cancer more sensitive to the effects of radiotherapy (pages 50 to 62).

Side effects of cetuximab

Some people have flu-like symptoms when having the infusion.
These include:

- a headache
- fever
- chills
- dizziness.

Your nurse will give you medication before the infusion to reduce the risk of this happening.

The most common side effect is a skin rash. It usually starts within 2 weeks of having the first treatment. But the rash usually goes away once treatment is finished. Your nurse will give you advice on how to look after your skin while you are having cetuximab.

Other common side effects of cetuximab include:

- diarrhoea
- nausea
- vomiting
- irritation and redness of the eye, called conjunctivitis.

Immunotherapies

The immune system protects the body against illness and infection. Immunotherapies are treatments that use the body's immune system to find and attack cancer cells.

The immunotherapy drugs used to treat cancer of the larynx are nivolumab and pembrolizumab. They are also called checkpoint inhibitors.

T-cells are part of the body's immune system. They help your immune system attack cancer. A protein called a PD-1 receptor switches off T-cells. Nivolumab and pembrolizumab attach to the PD-1 receptor so it cannot switch off the T-cells. This means the T-cells stay active and may help shrink a cancer, or stop it growing.

Nivolumab and pembrolizumab are both given as an infusion, through a drip into the vein. A chemotherapy nurse gives it to you in the chemotherapy day unit. Your cancer doctor will explain if one of these drugs are suitable for you.

We have more information about both of these immunotherapy drugs on our website **macmillan.org.uk**

Side effects

Some of the common side effects of immunotherapy drugs are:

- diarrhoea
- tiredness
- a skin rash
- thyroid problems
- breathlessness and cough.

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

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

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

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

Clinical trials

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

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

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

Taking part in a trial

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

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

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

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

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

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

Blood and tumour samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

After your treatment

Follow-up

Once your treatment has finished, you will have regular check-ups at the hospital. These continue for several years. You may also have scans. It is important to tell your specialist about any new symptoms you have, or any symptoms that are not improving. Do not wait until your next appointment to tell them.

If you cannot attend a follow-up appointment, contact your cancer doctor or hospital to arrange another one.

Well-being and recovery

You may feel that the cancer and its treatment have taken over your life. This can be one of the hardest feelings to cope with. It is a common feeling, but there are things you can do to help.

It can take time to recover from treatment. There might also be physical changes in the way you look. Or you may have to cope with changes to your daily life, such as speaking and eating. There will also be emotional changes to deal with, so it is important to give yourself time to adjust. There may be days when you feel too tired to even think about what could help. You will have good and bad days. But if these feelings are too much for you, talk to your cancer doctor or specialist nurse.

You may want to make positive changes to your lifestyle and find out more about living healthily. You may have followed a healthy lifestyle before your cancer and want to continue focusing on your health. There are things you can do to help your body recover. These can also improve your sense of well-being and lower your risk of getting other illnesses and cancers.

The Cancer Laryngectomee Trust, the National Association of Laryngectomee Clubs and Changing Faces can also provide support to help you adjust after treatment. You can find contact details for these organisations on pages 139 to 148.

Stop smoking

If you smoke, giving up is one of the healthiest decisions you can make.

Smoking:

- increases the risk of the cancer coming back
- increases your risk of developing a second cancer in your head or neck area
- can make some late effects worse, such as mouth problems
- is a major risk factor for other smoking-related cancers and heart disease.

Giving up smoking can be difficult, but there is lots of support available. Speak to your cancer doctor or specialist nurse, or call a stop-smoking helpline for further advice (pages 140 to 141). They can help you find your local stop-smoking service.

Drink less alcohol

Drinking alcohol will greatly increase your risk of developing another head and neck cancer. You can reduce this risk if you stop drinking alcohol or reduce the amount you drink.

NHS guidelines suggest that you should:

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

A unit of alcohol is half a pint of ordinary-strength beer, lager or cider, one small glass (125ml) of wine, or a single measure (25ml) of spirits. There is more information about alcohol and drinking guidelines at **drinkaware.co.uk**

For many people, this positive choice helps them get back a sense of control. It can also make you feel that you are doing the best thing for your health. If you are finding it difficult to stop drinking alcohol or reduce the amount you drink, talk to your GP. There is support available.

Eat a healthy diet

It is important to have a healthy and well-balanced diet. This should include plenty of fresh fruit and vegetables, even if your appetite has changed. You may find it easier to eat small meals often.

We have more information about eating a well-balanced diet in our booklet **Healthy eating and cancer** (page 132).

A dietitian may continue supporting you until you reach a healthy weight and can eat a well-balanced diet. Your dietitian can advise you on ways to eat well and help with any problems you may have. They may prescribe high-calorie drinks to help build up your weight. You may also need support from a speech and language therapist (SLT) if you are having difficulty with swallowing.

We have more information about building up your weight in our booklet **The building-up diet** (page 132).

Keep physically active

Keeping active helps increase your energy levels. It also reduces stress. Gentle exercise, such as going for a short walk, may be all you need. Your cancer doctor, specialist nurse or physiotherapist can advise how much and which type of exercise would be helpful for you. Start slowly and increase your activity over time.

We have more information about keeping active in our booklet **Physical activity and cancer** (page 132).

Complementary therapies

Some people find complementary therapies can help them feel better and reduce stress and anxiety.

You can find out more about complementary therapies in our booklet **Complementary therapies** (page 132).

Relaxation, counselling and psychological support are available at many hospitals. Some hospitals also offer:

- visualisation
- massage
- reflexology
- aromatherapy
- hypnotherapy.

Remember it is important not to have massage directly over a tumour or lymph nodes affected by cancer. Therapies are sometimes available through cancer support groups or your GP. Many complementary therapists also have private practices.

Not all complementary therapies are suitable for people who have just finished radiotherapy. If you are thinking of having one, it is important to check with your healthcare team first.

We have more information about complementary therapies on our website. Visit **macmillan.org.uk/complementary-therapies**

> "Life has changed but I don't see the loss of most of my voice as an overly debilitating one. I have just had to adjust and adapt. But in general I am continually moved by people's response when I explain."

Jacob, diagnosed with cancer of the larynx

Late or long-term effects of treatment

Some side effects of treatment can take time to get better. Sometimes side effects may become permanent. Other side effects may develop some time after treatment has finished. These are called late effects. You may not have any late effects, or they may range from being mild to more severe.

Always tell your cancer doctor or specialist nurse about any problems you have. There may be things they can do to help.

Problems with swallowing

Treatments for cancer of the larynx can cause the wall of the gullet or oesophagus to become thicker. This makes the gullet narrower, which can cause problems with swallowing. The muscles used for swallowing can also be affected by the treatment. Treatments can also cause a loss of sensation when swallowing.

If you notice any problems when eating and drinking, tell your cancer doctor or specialist nurse straight away. They can refer you to a speech and language therapist (SLT). Your SLT can help with any feeding and swallowing problems. They can talk to you about swallowing exercises that help keep your muscles working. They can also suggest foods that may be easier for you to swallow.

Dry mouth

Radiotherapy can damage your salivary glands, causing a dry mouth. This may be temporary, but sometimes it can be permanent. Sometimes, having a dry mouth can make eating and speaking difficult. It can help to:

- carry water with you and keep some beside your bed to sip when you wake up
- eat softer foods with plenty of sauce or gravy, which are easier to swallow
- keep a humidifier by your bed to help stop your mouth and throat getting dry
- use mouthwashes and protective gels to coat the lining of your mouth – your cancer team or GP can give you these.

You can talk to your radiotherapy team about ways to cope with a dry mouth. We also have more information about dry mouth in our booklet **Eating problems and cancer** (page 132).

> **"I have some difficulties eating. It helps to cut food into small pieces and chew them for a long time."**
>
> Ann, diagnosed with cancer of the larynx

Dental problems

If you have a dry mouth, you are at more risk of problems with your teeth. This is because saliva protects your teeth from decay. It is important to have regular check-ups every 3 to 6 months with your dentist and oral hygienist. You should also follow a daily mouth care routine to prevent tooth decay. Your dentist may give you fluoride products and advise you on brushing your teeth and keeping your gums healthy.

Underactive thyroid

The thyroid is a small gland in the front of the neck, just below the larynx. It makes hormones, including thyroxine. These help keep the body working at the correct speed. Surgery (page 63) or radiotherapy (page 50) to the larynx can affect the thyroid gland so it produces less thyroxine. When this happens, it is called an underactive thyroid or hypothyroidism.

You will have blood tests to monitor your thyroid hormone levels. Symptoms of hypothyroidism include:

- tiredness
- weight gain
- dry skin and hair
- feeling cold.

If you develop this condition, your cancer doctor may give you thyroid hormone replacement tablets.

Lymphoedema

Lymphoedema happens when a fluid called lymph causes swelling in the neck, face or under the chin. It can develop when lymph nodes (page 12) have been removed or damaged by surgery or radiotherapy. The earlier lymphoedema is diagnosed, the easier it is to treat. It is important to tell your cancer doctor or specialist nurse if you have any swelling. They may refer you to a lymphoedema specialist.

We have more information about lymphoedema in our booklet **Understanding lymphoedema** (page 132).

Changes in how you look and talk

Cancer of the larynx and its treatments can cause changes to how you look and talk. These changes can sometimes affect your body image. This is the picture you have of yourself in your mind and how you feel about your body. If your voice sounds different to how it did before treatment, it can affect your confidence.

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 how you look and talk. But there is no set time or way of doing this. For some people it may take weeks, for others it may take months or even years. This experience will be individual to you. But you may meet other people who have similar thoughts and feelings.

As well as getting support from your healthcare team, you can get more information about changes in your appearance and how you talk from organisations such as the National Association of Laryngectomee Clubs (page 140). We have more information about body image in our booklet **Body image and cancer** (page 132).

Meeting other people

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

Be prepared for mixed reactions. You may find that people take far less notice of you than you expected. But some people may make insensitive comments or unhelpful suggestions. Children are often openly curious and may ask why you look or sound different. You may want to decide in advance how to answer. Share as much as you feel comfortable with. But saying that you have had an operation should be enough. You do not have to go into detail.

Coping successfully with social situations will help build your confidence.

You can get more information about how to manage people's reactions from organisations such as Changing Faces (page 139).

Eating and socialising

Many social activities involve eating and drinking. If you have difficulty chewing or swallowing, you may feel anxious or unsure about eating in front of other people. Everyone has their own way of dealing with these issues.

If you feel self-conscious about eating with others, it may help to get used to eating at home with people you know first. When you feel ready to try eating away from home, do something simple to start with. For example, you could go for an ice cream. You can start to do other things as your confidence grows.

Your SLT can give you more advice about eating out.

We have more information about eating and socialising in our booklet **Managing the late effects of head and neck cancer treatment**.

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

Your feelings and relationships

Your feelings

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

We have more information about emotions on our website and in our booklet **How are you feeling? The emotional effects of cancer** (page 132).

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

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

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups** Or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on page 135 about other ways we can help you.

Talking about your feelings

Cancer of the larynx can affect people both emotionally and practically. If treatment has affected the way you breathe or speak, it can affect the way you feel about yourself and how you live your life.

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.

If you have a mobile phone or tablet, this might help you communicate if your voice is not strong enough. You can download programs that read aloud text that you have type in. It is also possible to get a textphone landline. Your specialist nurse, speech and language therapist (SLT) or one of the laryngectomy organisations can advise you on what programs are most helpful.

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 the people around you.

Not everyone finds talking in a group easy, especially if you are adjusting to new ways of communicating. Try going along to see what the group is like before you decide whether or not to take part. The National Association of Laryngectomee Clubs may be able to find a group local to your area (page 140).

You can call us on **0808 808 00 00** or visit **macmillan.org.uk/supportgroups** for more information about groups across the UK.

Online support

Even though each person's experience is very individual, some people find online support a useful way to ask questions and share experiences. You may find this a helpful way to communicate after your treatment if your voice has been affected.

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

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 anti-depressant drug.

Relationships

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

We have more information online about relationships and in our booklet **Talking about cancer** (page 132).

Family and friends

Your family and friends may not always understand if you are not feeling positive about things you usually enjoy. They may not realise how much treatment is affecting your life. Telling them how you feel will help them give you the support you need.

Your partner

Some couples become closer through a cancer experience. For others, cancer puts a lot of strain on the relationship. Problems sometimes develop, even between couples who have a very strong relationship. If a relationship was already difficult, the stress of a major illness can make things worse.

Even couples that are close may not always know how each other are feeling. Talking openly about your feelings and listening can help. If your voice is healing, this might mean writing down how you feel.

Your sex life

The physical and emotional effects of cancer and its treatment may affect your sexual confidence. We have more information about sexual confidence in our booklet **Cancer and your sex life** (page 132).

After treatment, some people have problems with their body image. Cancer of the larynx and its treatment can change how you feel about kissing and having sex. This usually improves over time.

We have more information about body image in our booklet **Body image and cancer** (page 132).

If you have a partner, they may also have concerns. Being honest with each other can have a positive effect on your relationship. It can make you feel more comfortable with each other.

Even if you do not feel like having sex, you may still want to be close to your partner. It may help to try and be intimate in other ways. This could include spending more time together, holding hands, hugging or giving each other a massage.

If you are not in a relationship, you may be unsure of what to tell a new partner. It is your decision how, when and what you tell a new partner.

If you are having difficulty with your sex life, talk to your GP. They may be able to refer you to a counsellor or psychologist. The College of Sexual and Relationship Therapists has a nationwide list of counsellors or therapists (page 147).

If you are a family member or friend

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

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

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

Talking to children and teenagers

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

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

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

You can order our booklets and leaflets for free.
Some of our information is also available in audio format.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Work and financial support

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 132).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (page 144 to 145).

Our booklet **Help with the cost of cancer** has lots more information (page 132).

Macmillan Grants

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

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

To find out more, or to apply, call on **0808 808 00 00** or visit **macmillan.org.uk/grants**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer**.
Our Online Community forum on **Travel insurance** may also be helpful – visit **macmillan.org.uk/community**

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer**.

There is also lots more information online at **macmillan.org.uk/work**

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


CANCER TYPE
TREATMENT
UNDERSTANDING LUNG CANCER
UNDERSTANDING PROSTATE CANCER
UNDERSTANDING CHEMOTHERAPY
ASK ABOUT YOUR CANCER TREATMENT
CANCER AND YOUR SEX LIFE
MAKING TREATMENT DECISIONS
DIABETES AND CANCER TREATMENT
VOLUNTEER

Further information

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

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

The language we use

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

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

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

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

Information centres

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Help with energy costs

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

Macmillan Grants

Macmillan 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 find out more about Macmillan Grants.

Help with work and cancer

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

Work support

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

Talk to others

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

Support groups

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

Online Community

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

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

Macmillan healthcare professionals

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

Other useful organisations

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

Cancer of the larynx support organisations

British Association of Skin Camouflage

Tel **0125 470 3107**
www.skin-camouflage.net
Shows people how to use make-up as skin camouflage. Holds camouflage awareness presentations and demonstrations for patient support groups.

Cancer Laryngectomee Trust

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

Changing Faces

Support line **0300 012 0275**
www.changingfaces.org.uk
Offers support and information for people who have any condition or injury that affects their appearance, and their families.

National Association of Laryngectomee Clubs

Tel **020 7730 8585**
www.laryngectomy.org.uk
Aims to promote the welfare of people who have had a laryngectomy, and their families. Produces videos, DVDs and a range of booklets, including a handbook for people who have had a laryngectomy.

Skin camouflage service

Tel **0300 012 0276**
www.changingfaces.org.uk/skin-camouflage
Changing Faces has a skin camouflage service. It has skin camouflage practitioners, who can teach people how to self-apply specialist cover creams.

Stop smoking services

Help Me Quit (Wales)

Tel **0800 085 2219**
www.helpmequit.wales

Quit

Quitline **0800 00 22 00**
www.quit.org.uk

Quit Your Way Scotland

Tel **0800 84 84 84**
www.nhsinform.scot/healthy-living/stopping-smoking

Smokefree (England)

Helpline **0300 123 1044**
www.nhs.uk/smokefree

Stop Smoking Northern Ireland

www.stopsmokingni.info

General cancer support organisations

Cancer Black Care

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

Cancer Focus Northern Ireland

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

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's

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

Penny Brohn UK

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

Riprap

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

Tenovus

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

General health information

Health and Social Care in Northern Ireland

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

NHS.UK

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

NHS 111 Wales

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

NHS Inform

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

Emotional and mental health support

Mind

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

Samaritans

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

Financial support or legal advice and information

Advice NI

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

Benefit Enquiry Line Northern Ireland

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

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

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

England

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

Scotland

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

Wales

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

GOV.UK

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

Support for older people

Age UK

Helpline **0800 678 1602**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

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

Live Through This

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

Help with sexual difficulties

College of Sexual and Relationship Therapists

Tel **0208 106 9635**
www.cosrt.org.uk
A national specialist charity for sex and relationship therapy. Provides information about sexual and relationship issues.

Support for carers

Carers Trust

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

Carers UK

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

Bereavement support

Cruse Bereavement Care

Helpline **0808 808 1677**
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **0207 654 8000**
www.ndrs.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Northern Ireland Cancer Registry

Tel **0289 097 6028**
www.qub.ac.uk/nicr

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **02920 104278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu

Disclaimer

Thanks

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

With thanks to: Laura Askins, Senior Specialist Dietitian; Dr Ashoke Biswas, Consultant Clinical Oncologist; Jeanette Collings, Macmillan Information and Support Radiographer; Lesley Dempsey, Clinical Nurse Specialist; Jodie McCord, Macmillan Clinical Lead Speech and Language Therapist; Maria Smith, Clinical Nurse Specialist; and Professor Francis Vas, Consultant Head and Neck Surgeon.

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

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

Sources

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

ESMO Annals of Oncology. Squamous cell carcinoma of the oral cavity, larynx, oropharynx and hypopharynx. EHNS-ESMO-ESTRO Clinical Practice Guidelines for diagnosis, treatment and follow up. 2020. Available from www.esmo.org/guidelines/head-and-neck-cancers/squamous-cell-carcinoma-of-the-head-and-neck [accessed Jan 2022].
NICE Guideline NG36. Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over. 2018. Available from www.nice.org.uk/guidance/ng36 [accessed Jan 2022].
NICE Technology Appraisal TA736. Nivolumab for treating recurrent of metastatic squamous cell carcinoma of the head and neck after platinum-based chemotherapy. 2021. Available from www.nice.org.uk/guidance/ta736 [accessed Jan 2022].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

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

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

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

FR Registered with FUNDRAISING REGULATOR

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

This booklet is about cancer of the larynx (voicebox), also called laryngeal cancer. It is for people who have cancer of the larynx. There is also information for carers, family members and friends.

The booklet talks about signs and symptoms of cancer of the larynx. It explains how it is diagnosed and how it may be treated. It also has information about feelings, practical issues and money.

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

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

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

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