MACMILLAN
CANCER SUPPORT

UNDERSTANDING CANCER OF THE LARYNX (VOICEBOX)

> ‘I’ve learned to swallow and eat again and took up running. Life has changed but I don’t see the loss of most of my voice as debilitating.’

Jacob, diagnosed with cancer of the larynx

About this booklet

This booklet is about cancer of the larynx (voicebox), which is also called laryngeal cancer. It is for anyone who is having tests for cancer of the larynx, or anyone who has been diagnosed with it. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of cancer of the larynx. It also explains how it is diagnosed and treated, and ways to cope. This includes your feelings, relationships, work and finances.

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

The booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 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 133 to 139, there are details of other organisations that can help.

Quotes

In this booklet we have included quotes from people who have been affected by 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.

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**.

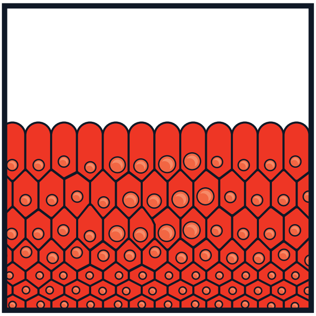
Contents

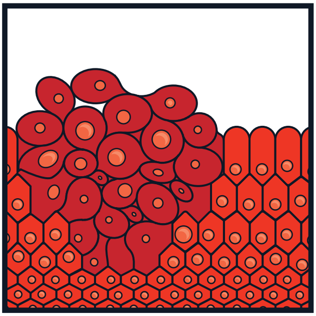
THE LARYNX AND CANCER OF THE LARYNX

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.


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. 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.

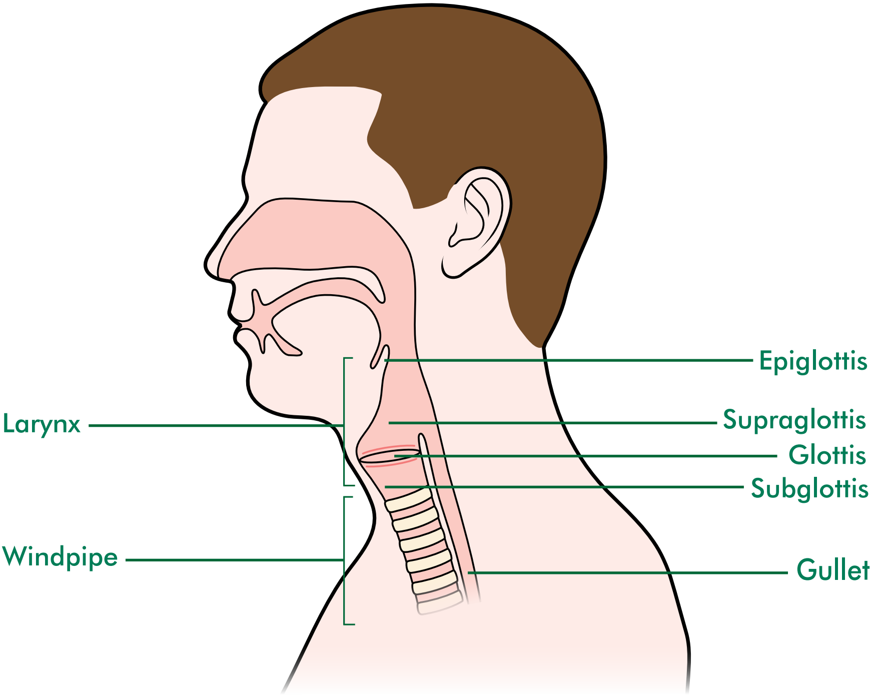
A tumour that is cancer (a malignant tumour) can grow into nearby tissue.

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 (see pages 12 to 13). 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.

The larynx

The larynx (see below) 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 (2in) long.

Parts of the larynx



The larynx allows air you breathe to reach your lungs. It has a flap of skin at the top, called the epiglottis (see the illustration opposite).

When you swallow, the epiglottis sends food and liquid down the gullet, stopping it from going into the windpipe. The larynx has two 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 your neck. This is known as the Adam's apple.

The larynx has three main parts:

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

Types of cancer of the larynx

Most cancers of the larynx are squamous cell carcinoma. This means the cancer starts in the thin, flat (squamous) cells that line the larynx. We have more information about squamous cell carcinoma on our website (see page 128).

Here are some rarer types of cancer of the larynx:

- Sarcoma – cancer of the connective tissues in the larynx.
- Lymphoma – cancer of the lymphatic tissue in the larynx.
- Adenocarcinoma – cancer that starts in the glandular (adeno) cells of the larynx.
- Neuroendocrine carcinoma – 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 covers treatment for squamous cell cancer of the larynx. For information about rarer types of cancer of the larynx, contact our cancer support specialists on **0808 808 00 00**.

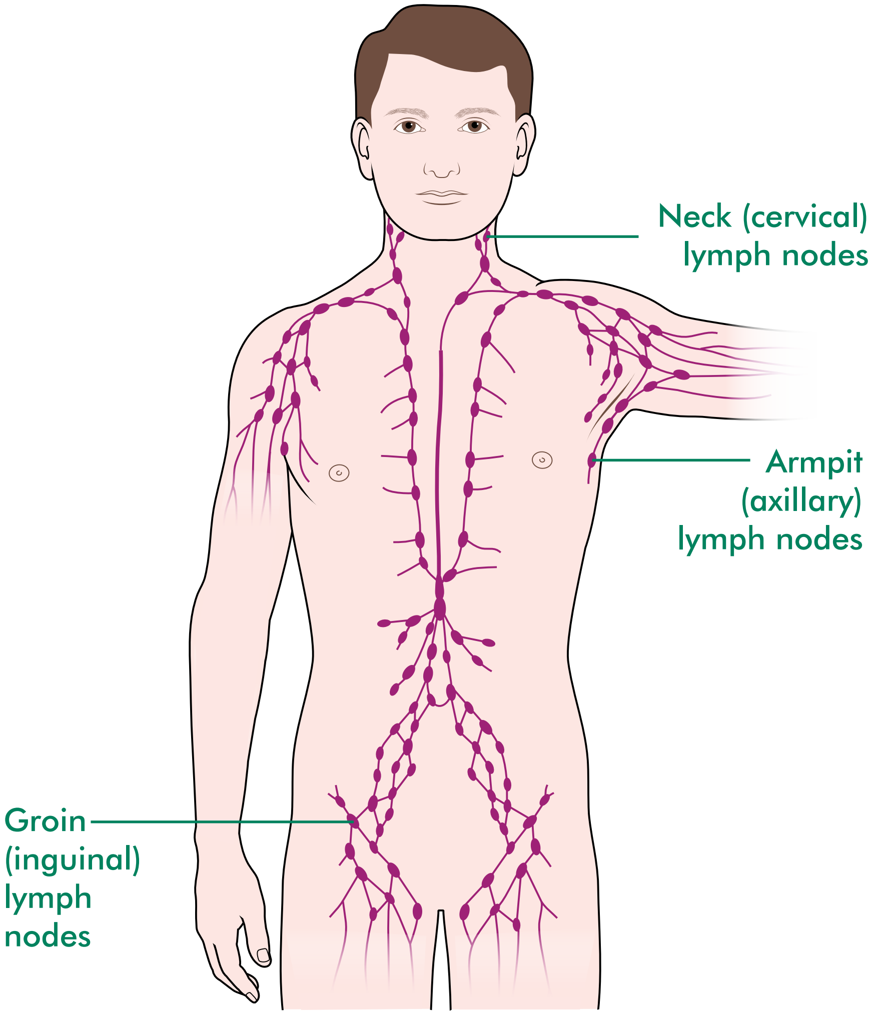
The lymphatic system

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

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

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

The lymphatic system



Risk factors and causes

We do not know 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.

Around 2,360 people in the UK are diagnosed with cancer of the larynx each year. This type of cancer is rare in people under the age of 40. It is more common in people in their 60s and 70s. It is four times more common in men than women. The main risk factors are smoking tobacco and drinking alcohol. There may be other factors that increase your risk of developing cancer of the larynx, but more research is needed.

Smoking

The risk of developing cancer of the larynx increases the longer you smoke for and the more you smoke. We can send you our booklet **Giving up smoking** (see page 128).

Alcohol

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

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

Symptoms

Your symptoms will depend on where in the larynx the cancer is. Most cancers begin on, or near, one of the vocal cords (see page 9).

The most common symptom is changes to your voice, such as hoarseness. Changes to your voice may be an early sign of the cancer affecting your vocal cords (glottis). 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 (subglottis), near the windpipe. But this is very 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

Diagnosing cancer of the larynx

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

At the hospital

The specialist will ask about your symptoms, your general health and whether you are taking any medicines. They will also feel for any lumps in your neck. Swollen lymph nodes may be causing these lumps (see pages 12 to 13). But other medical conditions can also cause lumps, such as a swollen salivary gland. After carefully examining you, they will explain what tests you need.

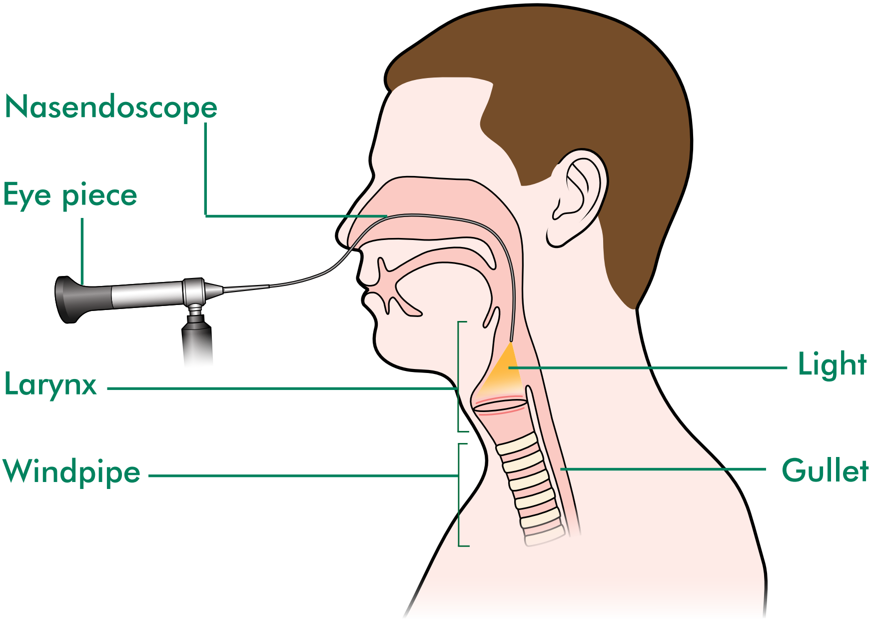
Nasendoscopy

You have this test in the outpatient clinic. Your doctor passes a thin, flexible tube up through your nose. This tube is called a nasendoscope. The nasendoscope then goes over the back of your tongue and down into the upper part of your throat. It has a light at the end to help the doctor see the back of your mouth and throat. You might find this a bit uncomfortable, but it only takes a few minutes. You may have an anaesthetic lozenge to suck beforehand, to numb your throat. Or the doctor may spray your throat with an anaesthetic. They may also spray your nose. Some people prefer to have the nasendoscopy without any anaesthetic spray to the throat or nose.

Some nasendoscopes have a small camera at the end. The images from the camera are displayed on a monitor for your doctor to see.

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 your throat, to look at the larynx closely. They may also take photos using a camera that is attached to the tube.

Biopsy

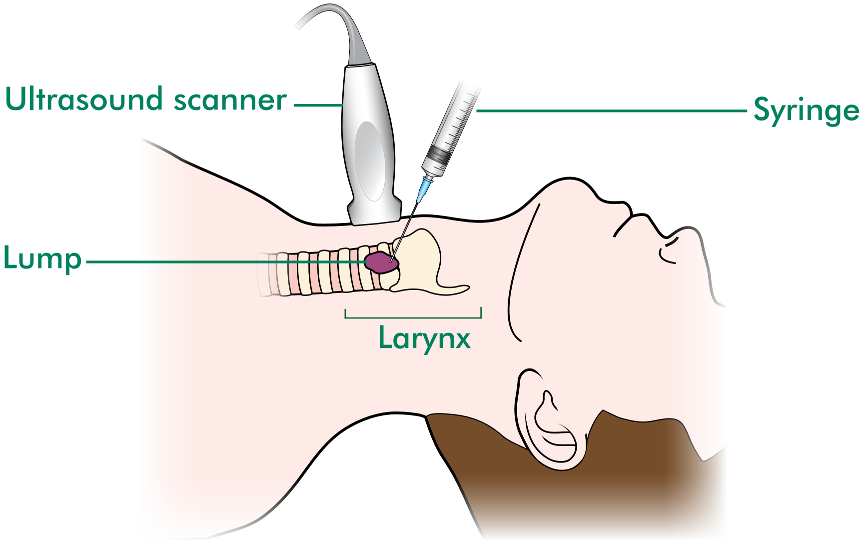
During the laryngoscopy, the doctor takes a sample of cells or tissue from any areas that look abnormal. This is called a biopsy. It is the most important test to diagnose cancer of the larynx. A doctor called a pathologist then looks at the sample under a microscope, to check for cancer cells. It may take about 7 to 10 days for your results to come back. We have more information about biopsies on our website. Visit **macmillan.org.uk**

> ‘When I was diagnosed, my consultant introduced me to Caroline, a Macmillan nurse. I can’t imagine how I would have got through my treatment without her’
>
> **Philippa**

Fine needle aspirate (FNA)

You may have this test if you have a lump in your neck. You can have it in the outpatient clinic. 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 (FNA)



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. We have listed some of the tests you may have.

Blood tests

There is no specific blood test to diagnose cancer of the larynx. But you may have blood tests to check your general health.

Chest x-ray

This uses x-rays to take a picture of your chest, to check your lungs and heart.

CT (computerised tomography) scan

A CT scan takes a series of x-rays, which build up a three-dimensional picture of the inside of the body.

The scan takes 10 to 30 minutes and is painless. It uses a small amount of radiation, which is very unlikely to harm you and will not harm anyone you come into contact with. You will be asked not to eat or drink for at least four hours before the scan.

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

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

MRI (magnetic resonance imaging) scan

This test uses magnetism to build up a detailed picture of areas of your body. The scanner is a powerful magnet so you may be asked to complete and sign a checklist to make sure it is safe for you. The checklist asks about any metal implants you may have, such as a pacemaker, surgical clips or bone pins, etc.

You should also tell your doctor if you have ever worked with metal or in the metal industry as very tiny fragments of metal can sometimes lodge in the body. If you do have any metal in your body, it is likely that you will not be able to have an MRI scan. In this situation, another type of scan can be used. Before the scan, you will be asked to remove any metal belongings including jewellery.

Some people are given an injection of dye into a vein in the arm, which does not usually cause discomfort. This is called a contrast medium and can help the images from the scan to show up more clearly. During the test, you will lie very still on a couch inside a long cylinder (tube) for about 30 minutes. It is painless but can be slightly uncomfortable, and some people feel a bit claustrophobic. It is also noisy, but you will be given earplugs or headphones. You can hear, and speak to, the person operating the scanner.

PET-CT scan

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

PET-CT scans give more detailed information about the part of the body being scanned. You may have to travel to a specialist centre to have one. You cannot eat for six hours before the scan, although you may be able to drink.

A mildly radioactive substance is injected into a vein, usually in your arm. The radiation dose used is very small. You will wait for at least an hour before you have the scan. It usually takes 30 to 90 minutes. You should be able to go home after the scan.

Waiting for test results

Waiting for test results can be a difficult time. It may take from a few days to a couple of weeks for the results of your tests to be ready. You may find it helpful to talk with your partner, your family or a close friend. Your specialist nurse or an organisation can also provide support. You can also talk things over with one of our cancer support specialists on **0808 808 00 00**.

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.

T N M staging system

Doctors often 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.

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

M describes whether the cancer has spread to other parts of thebody such as lungs (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** – This stage is sometimes called carcinoma in situ (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 precancerous.
- **Stage 1** – The cancer has grown further into the lining of the larynx. The vocal cords still move normally.
- **Stage 2** – The cancer is affecting another part of the larynx, and may affect the vocal cords moving. It has not spread outside the larynx.
- **Stage 3** – The movement of the vocal cords is affected. Or the cancer may have spread to one lymph node, which is no larger than 3cm. The cancer has spread within the larynx.
- **Stage 4** – The cancer has spread into the area surrounding the larynx. It may have spread to one or more lymph nodes, which may be larger than 3cm. It may have spread to other areas of the body.

In this information, we use the term **early-stage cancer** to describe cancers of the larynx that are stage 0, 1 or 2.

Stage 3 and 4 tumours that have spread into the area surrounding the larynx are described as **locally advanced cancer**. But they have not spread to other areas of the body.

Stage 4 tumours that have spread to other areas of the body are described as **advanced cancer**.

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 (glottis) 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.

- **Grade 1 (low-grade or well-differentiated cancer)** – the cancer cells look similar to normal cells and 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 more information at **macmillan.org.uk/cancerregistry**

TREATING CANCER OF THE LARYNX

Treatment overview

You will usually be treated in a specialist centre, by a team of healthcare professionals.

The main treatments for cancer of the larynx are:

- radiotherapy (see pages 45 to 56)
- surgery (see pages 58 to 67).

You may also have chemotherapy (see pages 76 to 85)), targeted therapies or immunotherapy. But you do not usually have these for early-stage cancer of the larynx. You may have these treatments on their own or combined.

For most people, the aim of treatment is to remove or destroy the cancer. Treatment will also try to reduce the chance of the cancer coming back.

Your doctors will plan your treatment carefully to reduce your risk of late or long-term effects (see pages 99 to 103). However, you may have some side effects during or after treatment.
For example, it could affect your:

- speech
- voice
- swallowing
- appearance.

Your cancer doctor and specialist nurse will talk to you about how the different treatment options may affect you.

Your treatment will depend on:

- where in the larynx the cancer is (see pages 8 to 9)
- the size of the cancer and whether it has spread (its stage – see pages 26 to 28)
- how fast-growing the cancer is (grade – see page 28)
- your general health.

Early stage (see pages 26 to 27) cancer of the larynx can usually be cured with radiotherapy or surgery.

To treat **locally advanced cancer** (see pages 26 to 28) of the larynx, your doctors may recommend you have chemotherapy with radiotherapy (chemoradiation) instead of surgery. There is more information about chemoradiation on page 85.

If the tumour is large, you may need surgery to remove part of, or the whole, larynx (see pages 61 to 64). If the cancer has spread to the lymph nodes, you may have an operation to remove the affected nodes. This is called a neck dissection (see page 64).

> ‘Miyuki (a Macmillan nurse) was with me when discussing surgical options and then throughout my stay at hospital.’
>
> **Jacob**

Your doctor may advise you to have treatment after surgery, to reduce the risk of the cancer coming back. This is called adjuvant treatment. It may be radiotherapy or chemoradiation.

You may have chemotherapy:

- to reduce the size of the cancer before radiotherapy
- if the cancer spreads outside the larynx
- if the cancer comes back after radiotherapy.

Some people have treatment with a targeted therapy drug combined with radiotherapy.

If the cancer has spread or comes back and chemotherapy has not worked, you may have an immunotherapy drug.

Sometimes, it may not be possible to cure the cancer. If this happens, your doctor will offer you treatment to help slow the cancer growing and control symptoms. This is called palliative treatment.

Questions to ask about treatment

You may find it helpful to use the leaflet attached to the inside of the back cover of this booklet. It suggests useful questions to ask your cancer doctor or specialist nurse about your treatment for cancer of the larynx. There is also space to write down any answers you get or other questions or notes you have.

How treatment is planned

A team of specialists meet to discuss the best treatment for you. This team is called a multidisciplinary team (MDT). It includes:

- an ear, nose and throat (ENT) surgeon – a specialist in treating cancer of the larynx
- a plastic and reconstructive surgeon – a surgeon skilled in rebuilding tissue in the head and neck
- a cancer doctor (oncologist) – a doctor who specialises in cancer treatments, such as radiotherapy, chemotherapy, targeted therapy and immunotherapy
- a therapeutic radiographer – who works closely with the doctors to plan and give radiotherapy
- a radiologist – a doctor who specialises in reading scans and x-rays
- a pathologist – a doctor who specialises in looking at cells under a microscope and diagnosing the cell type
- a specialist nurse – a nurse who gives support and information about the cancer or treatment
- a speech and language therapist (SLT) – a therapist who specialises in helping with communication and problems swallowing
- a dietitian – someone who gives advice about getting all the nutrients your body needs
- a restorative dentist – a specialist dentist who makes sure your teeth look as normal as possible, and work as naturally as they can.

The MDT often includes a number of other healthcare professionals. These may include:

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

After the meeting, one or more of the team will explain your treatment options to you and answer any questions you have. It may help to bring a list of questions. You might also want to bring a family member or friend with you to the appointment.

Treatment decisions

Sometimes, doctors may offer you a choice of two treatments. These will be equally effective at treating the type and stage of cancer you have. If this happens, your healthcare team can discuss the options with you. They will help choose the best treatment for you.

It is important to understand what each treatment involves before you decide what is right for you. You should also know about the possible side effects of each treatment. It may help to take notes at your appointment, so you can remember what is said.

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

The benefits and disadvantages of treatment

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

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

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

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

You may find our booklet **Making treatment decisions** helpful. You can order this at **be.macmillan.org.uk**

Giving your consent

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

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

If you do not understand what you have been told, let the staff know straight away, so they can explain again. Some cancer treatments are complex, so it is not unusual to need repeated explanations. It is a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

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

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

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

Second opinion

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

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

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 multi-disciplinary team MDT at any time (see pages 35 to 36). 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 before treatment. Stopping smoking:

- means you are likely to have fewer side effects from cancer treatment
- means the side effects of treatment may be less severe.

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 (see page 134) can help increase your chances of stopping successfully. Research shows that people who use these services are twice as likely to succeed as people who try giving up on their own. Speak to your cancer doctor or call a stop smoking helpline for advice and to find local Stop Smoking Services (see page 134).

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

We have more information about giving up smoking that you may find helpful. You can order our booklet **Giving up smoking** (see page 128).

Alcohol

Not drinking alcohol, particularly spirits, may help make some side effects of treatment less severe. Stopping drinking alcohol can also reduce your risk of developing another head and neck cancer. Your specialist nurse or cancer doctor can give you support to reduce how much alcohol you drink.

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 (see pages 44 to 56).

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, 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 (see page 58). 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 think treatment may affect your swallowing, you may see a dietician and 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 can make it very difficult to swallow. This can happen particularly if radiotherapy is combined with chemotherapy (chemoradiation – see page 85). Your SLT can show you exercises to 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.

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

- **Nasogastric (NG) feeding** – a thin tube is passed up the nose and down into the stomach. It is used for shorter periods of time, for example less than 4 weeks.
- **Gastrostomy feeding** – a tube is passed through the skin and muscle of the tummy (abdomen) into the stomach. This is called a percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) tube. This depends on how the tube is put into the stomach. 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 more 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, and your family members or friends, how to use and look after it safely. 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 (see page 128).

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

You may have radiotherapy on its own if you have an early-stage cancer of the larynx (see pages 26 to 27). Your cancer doctor may advise you to have radiotherapy if surgery is likely to affect your speech or swallowing.

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 (locally advanced – see pages 26 to 28), radiotherapy is usually 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 – see page 85)
- instead of surgery, combined with chemotherapy (chemoradiation)
- combined with a targeted therapy drug (see pages 86 to 87).

The aim of radiotherapy for locally advanced cancer of the larynx is to cure the cancer (radical radiotherapy).

Advanced cancers

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

You may have radiotherapy:

- to shrink a tumour that is causing problems with swallowing or breathing
- to help improve symptoms if the cancer has spread to other areas of the body.

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.

> ‘The actual radiotherapy session does not take that long. It’s best to let the staff know if you are scared – they can talk you through it.’
>
> **Chris**

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 or specialist nurse 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 different doses of radiotherapy to be given 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 and late effects. It may also allow higher doses of radiotherapy to be given 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.

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. The treatment is planned by your cancer doctor.

Radiotherapy planning is usually done during one 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 for you.

To start with, you meet the radiographers (experts in giving radiotherapy). They can answer any questions you 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. It is important to talk to the radiographer, mask room technician or your specialist nurse if you have difficulty wearing the mask. 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.

Planning CT scan

After your mask is made, you have a CT scan of the area to be treated (see pages 22 to 23). The radiographers take measurements to plan the treatment specifically for you. Some people also have an MRI scan as part of their radiotherapy planning (see page 24).

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. We have a video on our website about radiotherapy for head and neck cancer (see page 128).

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 can see and hear you from outside the room. There is usually an intercom, so you can talk to them if you need to during your treatment.

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

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. This is just so that you know when the treatment is starting and when it has finished.

Side effects of radiotherapy

Radiotherapy can cause some side effects, such as a sore mouth, throat or skin. Side effects can be mild or more severe. This depends on the size of the area being treated and the length of your treatment. They are usually more severe if you have radiotherapy combined with chemotherapy (chemoradiation).

Side effects usually begin to develop after 2 weeks of radiotherapy. They may continue for about 2 weeks after treatment ends before starting to get better. Most people notice that their side effects have improved about 4 to 6 weeks after treatment finishes.

Radiotherapy can cause some side effects after treatment has finished. These are called late effects and can be temporary or permanent (see page 99).

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, SLT, dietician or 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
- eat a healthy diet and 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 can send you our booklet **Coping with fatigue (tiredness)** – see page 128.

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 make it difficult to swallow. Your doctor can prescribe liquid painkillers to help with this. Try to take these before meals to make eating easier.

Your speech and language therapist (SLT) will talk to you about any swallowing or eating problems you may have. 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. It is important to tell your SLT straight away if you are coughing when you swallow. 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 radiotherapy and chemotherapy at the same time (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. 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. You can also use mouthwashes, but make sure you follow any instructions from your specialist nurse or doctor.

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

You may have a dry mouth 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.

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 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. 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.

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 temporary tracheostomy (see page 61).


Consulting Rooms

Surgery

Your cancer doctor may advise that you have surgery. The operation you have will depend on the stage of the cancer (see pages 26 to 28). 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 (see pages 27 to 28)
- radiotherapy has not destroyed all of the cancer (this is rare)
- the cancer comes back after radiotherapy (see pages 44 to 56) or chemoradiation (see page 85).

Before your operation

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

Before you have the operation, your surgeon 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 (see pages 35 to 36). 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 to make sure you are well enough for the operation. These usually include:

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

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.

Endoscopic resection and transoral laser microsurgery (TLM)

If you have early-stage cancer of the larynx, your surgeon may be able to remove the cancer through your mouth. This type of surgery is called transoral surgery. You will not have a wound in your neck afterwards. You have this operation under general anaesthetic, and you only need a short stay in hospital.

The surgeon passes a thin, flexible tube with a camera at the end (endoscope) into your mouth and down into your throat. 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.

Sometimes, your surgeon uses high powered laser (heat) 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 (margin) of healthy tissue around it. This is to try to make sure they have removed all the cancer cells. They also use the laser to stop any bleeding during surgery.

Sometimes, instead of holding the surgical instruments themselves, the surgeon uses a machine (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).

After an endoscopic 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 an endoscopic 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

Your surgeon makes a cut in your neck and removes the affected part of the larynx. This operation is rare, as people are usually offered radiotherapy or chemoradiation instead (see page 85).

After a partial laryngectomy, you still have part of your larynx. This means you should be able to speak. But your voice is likely to be weak or hoarse. Swallowing may also be affected. Your SLT can give you more information about how to cope with this.

Temporary tracheostomy

Sometimes, surgery to the larynx causes temporary swelling around the throat. This can narrow your airway and make it difficult for you to breathe. If this happens, the surgeon creates a small opening into your windpipe for you to breathe through. This is called a tracheostomy or stoma.

The opening is made in the lower part of the front of your neck. It is held open by a small plastic tube that is a few centimetres long. The tube is taken out when the swelling from your operation goes down and you can breathe easily. The swelling might take about 5 to 7 days to go down but can sometimes take longer. 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 temporary tracheostomy after surgery, they will talk to you about it beforehand. You will also have time to ask the specialist nurse or SLT questions before you have surgery.

Total laryngectomy

You might need an operation to remove the whole larynx 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 (see page 64).

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 stoma. You also no longer have vocal cords to produce a voice. But you can speak using a choice of different ways to communicate (see pages 72 to 75).

Laryngectomy stoma

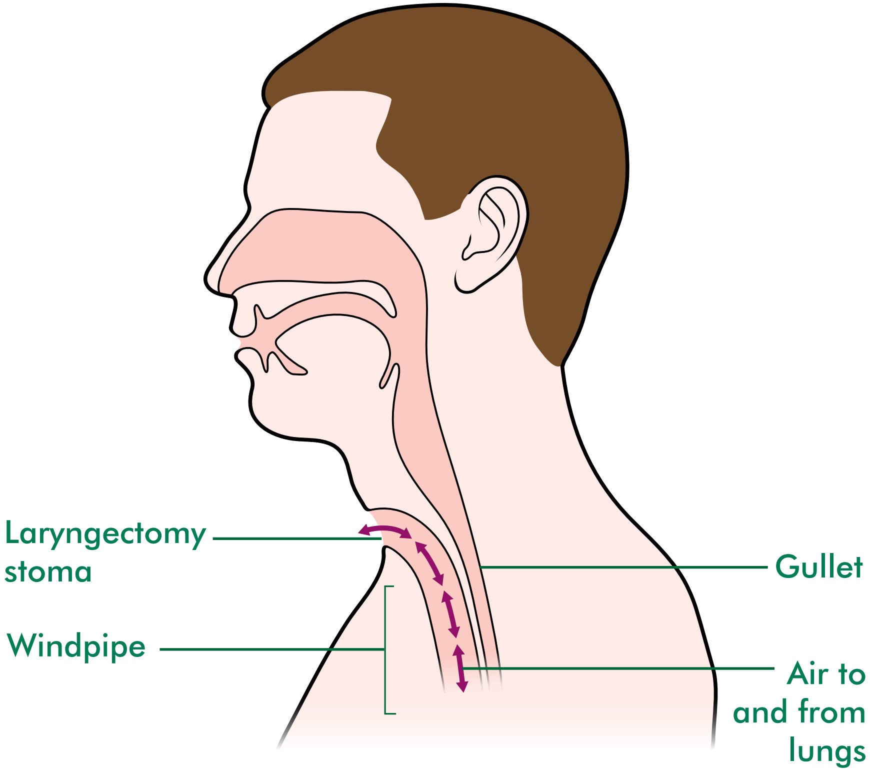
A laryngectomy stoma is when the surgeon makes a permanent opening in the windpipe. It is in the lower part of your neck and you breathe through it. The stoma stays open on its own. Some people may need a soft tube to help keep their stoma open for the first few days after surgery. Others may need the tube for longer.

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 breathe through it from 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 will teach you how to clean and take care of the stoma (see page 69). You can continue to get support from your healthcare team for as long as you need it.

Laryngectomy stoma



Removing lymph nodes

During your operation, the surgeon may also remove some lymph nodes to check for cancer cells. Or they may need to remove affected lymph nodes. This is called a neck dissection. Your surgeon will talk to you about this before your operation. The nodes that are removed are sent to a laboratory to be checked for cancer cells.

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 and uses it to replace tissue taken from the neck. They may take the tissue from areas such as the forearm, thigh or chest. This is known as a flap.

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 will explain the exercises to you.

Breathing and speaking

After a total laryngectomy, you start breathing 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, there are apps that can read aloud whatever you type in.

Being unable to speak can be frustrating and difficult to cope with. But it is important to remember that most people who have a laryngectomy are able to speak again (see pages 72 to 75). But you may speak differently to how you did before surgery. 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. We have more information about managing pain on our website (see page 128).

You may have pain relief through a syringe, connected to an electronic pump. The pump gives a continuous dose of pain relief (analgesia) over a set time.

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 that drain fluid from your operation site. This allows 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 your arm gives you fluids for a few days. You also have a feeding tube for liquid foods and medicines (see page 43). You should be able to eat and drink again once your throat has healed. This usually takes 1 to 2 weeks but can be longer. You will need to increase your eating gradually. Your dietitian or 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 straight 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.
We have a booklet called **Body image and cancer**. You can order it at **be.macmillan.org.uk**

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 (see page 131). 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 (see page 131). 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 look after 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 look after the stoma. This can give you support at home. You will also be given contact details of people you can contact if you have any problems at home. Your SLT will explain how you can get supplies for your stoma. These are usually available on prescription from your GP.

Looking after a laryngectomy stoma

Before you leave hospital, your specialist nurse or SLT will show you how to look after the laryngectomy stoma. They will show you how to:

- clean the skin around the stoma
- cough and clear your mucus
- use a suction tube (if needed) to remove mucus.

They will tell you what to use to clean the skin around the stoma, and how often to do this.

> ‘After my laryngectomy, all I thought was “When am I going to feel like a normal person again?” With my speech therapist’s help, and everyone who gave me support at the hospital, I learned to speak again.’
>
> **Stewart**

Stoma filters

When you breathe in, air goes down into your lungs through your stoma. The air is not warmed and moistened by your mouth and nose. This means the cooler, drier air can irritate your lungs. You may produce more mucus (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 known as heat and moisture exchangers (HMEs). You attach them over the stoma to warm and moisten the air. They help reduce the amount of mucus you produce. This can help reduce coughing and prevent chest infections. Your cancer doctor, specialist nurse or SLT can show you how to use them.

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. We have more information about eating problems and cancer (see page 128).

You may cough when you eat and drink. This can sometimes be a sign that food is going down the wrong way (into the airway). Your SLT can show you exercises to help with swallowing and stop you coughing.

Showering and bathing

You need to stop water going into your stoma when you shower or bathe. 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.

Your neck can sometimes feel numb after surgery. Try using an electric razor when shaving to avoid cutting yourself.

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. It is important to tell your cancer doctor straight away if you have any signs of an infection. You may need antibiotics.

Changes to smell and taste

Your sense 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

You are not able to swim without using special equipment to stop water going into the stoma. Your SLT can talk to you about this. The National Association of Laryngectomee Clubs can give you information and training so you use the equipment safely (see page 134).

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 hard and difficult to deal with. But there are other ways to communicate. The type of communication you use depends on your individual situation, the type of surgery you had and your preferences.

You will see a SLT before your operation to talk to you 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.

We have a video on our website of a SLT and someone who has had a laryngectomy. They talk about different ways to communicate, including using a voice prosthesis valve. Watch the video at **macmillan.org.uk**

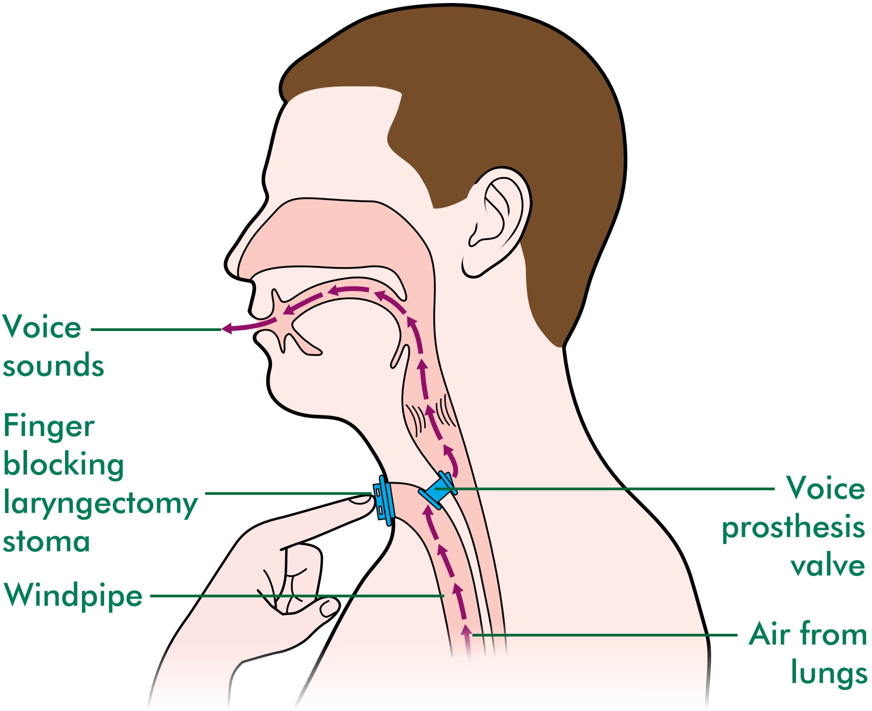
There are other ways to help you communicate if you do not have a valve. These include:

- an oesophageal voice
- an electrolarynx
- a combination of oesophageal voice and electrolarynx.

Voice prosthesis valve

During the laryngectomy, or at a later time the surgeon makes a channel between the windpipe (trachea) and the gullet (oesophagus). This is called a trache-oesophageal puncture (TOP). A small valve (voice prosthesis) is put into the channel. This connects the windpipe to the gullet. The valve is one-way, which stops food and fluids passing into the windpipe. Air can pass from your windpipe into your gullet through the valve. This allows you to develop a new voice after your operation.

Voice prosthesis valve



Covering your stoma with a thumb or finger and breathing out lets air pass from the lungs through the valve. This causes your throat muscles to vibrate and make a sound. As with normal speech, you shape the sound into words by moving your lips, cheeks and tongue. 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.

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 a voice. You may be given one to use while you practise developing your new voice. You hold them against a soft part of your neck. They make sound vibrations 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 (like small typewriters) to communicate. 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 (cytotoxic) drugs to destroy cancer cells. Cytotoxic 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 (see page 85)
- before radiotherapy – to shrink larger tumours and make radiotherapy more effective
- rarely, before surgery – to shrink larger tumours
- to help control the cancer and improve symptoms (palliative chemotherapy).

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

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

Other drugs include:

- carboplatin
- paclitaxel.

We have more information about these chemotherapy drugs on our website (see page 128).

How chemotherapy is given

A nurse will give you chemotherapy directly into a vein (intravenously). You can have it through a:

- short, thin tube put into a vein in your arm or hand (cannula)
- fine tube that goes into a vein in your arm and up into a vein in your chest (PICC line)
- fine tube that goes under the skin of your chest and into a vein close by (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 (cycles) of treatment. Your doctors will explain how often you will have treatment.

Side effects

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well controlled with medicines and will usually go away 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 from the treatment that is planned for you.

Risk of infection

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

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

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

Symptoms of an infection include:

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

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

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

Anaemia (reduced number of red blood cells)

This treatment can reduce the number of red blood cells in your blood. These cells carry oxygen around the body. If the number of red blood cells is low, you may be tired and breathless. Tell your doctor or nurse if you feel like this. 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. Tell your doctor if you have any bruising or bleeding that you cannot explain. This includes:

- nosebleeds
- bleeding gums
- tiny red or purple spots on the skin that may look like a rash.

Some people may need a drip to give them extra platelets. This is called a platelet transfusion.

Feeling sick

You may feel sick in the first few days after treatment. Your doctor will give you anti-sickness drugs to help prevent or control sickness. 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 and eat small amounts often. If you continue to feel sick, or if you vomit more than once in 24 hours, contact the hospital as soon as possible. They will give you advice and may change the anti-sickness drug to one that works better for you.

Tiredness (fatigue)

Feeling tired is a common side effect. 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.

> ‘The chemo does make you tired and fatigued. If you can, ask questions – they honestly won’t mind. I found it easier to take each day as it came.’
>
> **Chris**

Sore mouth

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

If your mouth 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.

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 to have until your appetite comes back. Your doctor can also arrange for you to see an 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.

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 or delay treatment for a short time. 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 drugs can cause diarrhoea. This often starts several days after treatment. If you have diarrhoea, contact the hospital for advice. Try to drink at least 2 litres (3½ pints) of fluid every day. It can help to avoid:

- alcohol
- caffeine
- milk products
- high-fat foods
- high-fibre foods.

Sore and red hands and feet

You may get soreness and redness that affects the palms of your hands and soles of your feet. This is called palmar-plantar or hand-foot syndrome. It gets better when treatment ends. Your cancer doctor or specialist nurse can give you advice and give you creams to improve the symptoms. It can help to keep your hands and feet cool and to avoid tight-fitting socks, shoes and gloves. Tell your nurse about any changes in your hands or feet.

Changes in hearing

If you have treatment with cisplatin, you may have changes in your hearing. You may have ringing in the ears (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

Chemotherapy can affect the way the heart works. You may have tests to see how well your heart is working. These may be done before, during, and sometimes after treatment. If the treatment is causing heart problems, your doctor can change the type of chemotherapy you are having.

Contact a doctor straight away if you:

- have pain or tightness in your chest
- feel breathless or dizzy
- feel your heart is beating too fast or too slowly.

Other conditions can cause these symptoms, but it is important to get them checked by a doctor.

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 peeing (passing urine) much.

We have more information about chemotherapy in our booklet **Understanding chemotherapy** (see page 128).

Chemoradiation

Certain chemotherapy drugs, such as cisplatin, may make radiotherapy work better. Having chemotherapy at the same time as radiotherapy is called chemoradiation. You may have it instead of surgery. Or you may have it after surgery, to reduce the risk of the cancer coming back.

Having chemotherapy and radiotherapy at the same time increases side effects. It also increases your risk of developing late effects (see pages 99 to 103).

Other treatments

Targeted therapy

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.

Cetuximab

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

Cetuximab is used to treat people with cancer of the larynx that has started spreading (locally advanced and metastatic cancer – see pages 26 to 28). You have the drug through as a drip (infusion) into a vein.

We have more information about monoclonal antibodies and cetuximab on our website (see page 128).

How cetuximab works

Most squamous cell cancers of the larynx 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.

Side effects of cetuximab

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

- a headache
- a 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.

Immunotherapy

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.

Nivolumab

Nivolumab is an immunotherapy that is sometimes used to treat cancer of the larynx. It belongs to a group of cancer drugs called monoclonal antibodies. It is also called an immune checkpoint inhibitor. We have more information about monoclonal antibodies on our website (see page 128).

It is used to treat cancer of the larynx that has spread or come back, and chemotherapy has not worked. You have it as a drip into a vein (intravenously).

How nivolumab works

T cells are part of the body's immune system. They help your immune system attack cancer. Nivolumab targets a protein called a PD-1 receptor. This protein switches off T cells. Nivolumab attaches 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.

Side effects of nivolumab

Some common side effects of nivolumab are:

- skin changes
- tiredness
- feeling sick
- diarrhoea
- high blood pressure.

It is important to tell your doctor or nurse about any side effects you have. You should tell them even after you have stopped taking nivolumab. We have more information about nivolumab on our website (see page 128).

Availability of cetuximab and nivolumab

Cetuximab and nivolumab might only be available in some situations. Your cancer doctor can tell you if one of these drugs is suitable for your situation. Other targeted therapy or immunotherapy drugs may be used as part of a cancer research trial (see pages 90 to 91).

If a drug is not available on the NHS, there may be different ways you can have it. Your cancer doctor can give you advice. They may be able to apply for funding to get it. We have more information on what to do if a treatment is not available. Visit our website or call us on **0808 808 00 00**.

Research – clinical trials

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

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

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

Taking part in a trial

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

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

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

Clinical trials are described in more detail in our booklet **Understanding cancer research trials (clinical trials)**. See page 128 for more information.

Blood and tumour samples

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

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

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.

> ‘The care lasted beyond the end of treatment. I remember my Macmillan nurse turning up to see how I was while waiting at an outpatient’s department, because of something that was worrying me.’
>
> **Philippa**

After treatment

Making positive choices after treatment

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.

You may have mixed emotions when you finish your cancer treatment. You will probably feel relieved, but may also feel anxious and uncertain. You may need to slowly come to terms with what you have been through and become confident again.

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. We have more information about these organisations on pages 133 to 139.

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 (see pages 99 to 103)
- 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 (see page 134). Speak to your cancer doctor or specialist nurse, or call a stop-smoking helpline for further advice. They can help you find your local stop-smoking service.

We have a booklet called **Giving up smoking**, which you may find helpful. You can order it by calling **0808 808 00 00**.

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 both men and women should:

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

A unit of alcohol is:

- half a pint of ordinary strength beer, lager or cider
- a single measure (25ml) of spirits
- one small glass of wine (125ml) is 1.5 units.

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.

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 and interest in food has reduced. You may find it easier to eat small meals often. 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 diet. You may also need support from a speech and language therapist (SLT) if you are having difficulty with swallowing.

You may find our booklet **Healthy eating and cancer** helpful. You can order it at **be.macmillan.org.uk**

Keep physically active

Keeping active helps increase your energy levels and 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 is our booklet **Physical activity and cancer** (see page 128).

Complementary therapies

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

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 (see pages 12 to 13). 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. It is important to check with your healthcare team first if you are thinking of having one. We can send you our booklet **Cancer and complementary therapies** (see page 128).

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 (oesophagus) to become thicker. This makes the gullet narrower, which can cause problems with swallowing. 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 suggest foods that may be easier for you to swallow.

Dry mouth

Radiotherapy can damage your salivary glands, causing a dry mouth. This effect may be temporary, but sometimes it can be permanent. Sometimes, having a dry mouth can make eating and speaking difficult. You may need to carry water with you, or eat softer foods with plenty of sauce or gravy. These will be easier to swallow. Some people keep a humidifier by their bed at night to help stop their mouth and throat getting dry. Others keep a glass of water by the bed to sip if they wake up. You can also use mouthwashes and protective gels to coat the lining of your mouth. Your cancer doctor or GP can give you these. You can talk to staff at the radiotherapy outpatient department about ways to cope with a dry mouth.

We have a booklet called **Recipes for people affected by cancer** (see page 128).

Dental problems

If you have a dry mouth, you are more at 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 regular 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, that help keep the body working at the correct speed. Surgery (see pages 58 to 67) or radiotherapy (see pages 44 to 56) 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 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 a booklet called **Understanding lymphoedema**, which you may find helpful (see page 128).

Changes in your appearance and how you 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. 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.

You can get advice and support from organisations. You will also get support from your healthcare team.

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 or Let's Face It (see page 133).

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.

> 'I have adjusted to my new voice, and in close proximity can enjoy excellent communication. Loud environments can be challenging, but family and friends are understanding.'
>
> **Jacob**

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

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

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

Shock and disbelief

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

Fear and anxiety

People can be very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control.

You may want to find out more about the cancer, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

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

Avoidance

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

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

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

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

Guilt and blame

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

Feeling alone

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

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists (see page 130). Our website can help you find out about local support groups – visit **macmillan.org.uk/supportgroups**

You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

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

Talking about your feelings

Talking about your feelings can help reduce stress, anxiety and isolation. There are lots of different ways to do this. Try to let your family and friends know how you are feeling. This means they can help and support you.

If your voice is not strong enough to communicate, using a mobile phone or tablet might help. You can download apps that convert text to speech, so they speak out whatever you type in. It is also possible to get a textphone landline. Your specialist nurse, speech and language therapist (SLT) or a support organisations may be able to tell you about helpful apps.

Support groups

Self-help or support groups let you talk to others who may be in a similar situation and facing the same challenges. Joining a group can be helpful if you live alone. Or if you do not 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 help you find a local group (see page 134).

> ‘I made friends with another patient who was having similar treatment. I was so grateful for them sharing their experiences with me and giving me advice and support.’
>
> **Sarah**

Online support

Each person's experience is different, but some people find online support groups useful to ask questions and share experiences. If your voice has been affected after treatment, you may find this a helpful way to communicate.

Our Online Community is a social networking site. You can talk to people in our chat rooms, blog about your journey, make friends and join support groups (see page 131).

If you need more help

The feelings you have after treatment can be very difficult to cope with, and sometimes people need more help. This happens to lots of people and does not mean you are not coping.

You may feel anxious, panicky or sad a lot of the time. Or you might think you could be depressed. If this happens, talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor or counsellor who can help. They may also prescribe medicine to help with anxiety, or an anti-depressant drug.

We have a booklet called **How are you feeling? The emotional effects of cancer**, which you may find helpful (see page 128).

Who can help?

Many people are available to help you and your family.

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

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

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

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

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area (see page 130).

If you are a relative or friend

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

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

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

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with cancer.

If you're looking after a family member or friend with cancer, you may find our booklet Looking after someone with cancer helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with cancer at **macmillan.org.uk/carers**

Talking to children

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

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

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

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

We can send you our booklet **Talking to children and teenagers when an adult has cancer** (see page 128).

Sex and relationships

Having cancer might have improved your relationships with people close to you. The support of family and friends may have helped you cope. But cancer is stressful, and this can affect relationships. Any problems usually improve over time, especially if you can communicate honestly about them.

Family and friends

Your family and friends may not always understand if you are not feeling positive about getting on with things. 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. Communicating 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. 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.

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.

Your cancer doctor or specialist nurse can give information and advice.

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working. We have more information about finances (see page 128).

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

On the opposite page are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under state pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA.
- Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

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, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £380, but this may change. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** – see page 128. Our Online Community forum Travel insurance may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisors and financial guides. You can speak to one 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 – see page 139.

Our booklet **Help with the cost of cancer** has lots more information – see page 128.

> ‘I could contact Atif at Macmillan and he would take care of it for me. It took all my worry away, and I could concentrate on treatment and getting better.’
>
> **Alan**

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful – see page 128. There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information – see page 128.

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

Find out more at **macmillan.org.uk/otherformats** If you'd like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Help us improve our information

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

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

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

Other ways we can help you

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

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. Our cancer support specialists can:

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

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

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

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

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

Talk to others

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

Support groups

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

Online Community

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

The Macmillan healthcare team

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

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

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

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

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

Help with work and cancer

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

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, 9am to 5pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

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

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. Most creams used by the British Association of Skin Camouflage can be prescribed by GPs.

Cancer Laryngectomee Trust
Tel 0142 220 5522
Email info@cancerlt.org
www.cancerlt.org
Provides support to people who are about to have, or have had, a laryngectomy.

Changing Faces
Tel 0300 012 0275 (Mon to Fri, 10am to 4pm)
www.changingfaces.org.uk
Offers support and information for people who have any condition or injury that affects their appearance, and their families.

Let's Face It
Tel 01843 491291
Email chrisletsfaceit@aol.com
www.lets-face-it.org.uk
An international network for people with facial disfigurement. Links together patients and their families, friends and professionals for self-help, information and mutual support.

National Association of Laryngectomee Clubs

Tel 020 7730 8585
Email
info@laryngectomy.org.uk
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

Quit

Tel 0207 553 2132
Quitline 0800 00 22 00
www.quit.org.uk

Smokefree (England)

Tel 0300 123 1044
(Mon to Fri, 9am to 8pm,
Sat and Sun, 11am to 4pm)
www.nhs.uk/smokefree

Smokeline (Scotland)

Tel 0800 84 84 84
(Mon to Fri, 8am to10pm,
Sat and Sun, 9am to 5pm)
www.canstopsmoking.com

Stop Smoking Wales

Tel 0808 252 8216
(Mon to Thu, 8am to 8pm,
Fri, 8am to 5pm,
Sat, 9am to 4pm)
www.helpmequit.wales

Want2stop (Northern Ireland)

www.want2stop.info

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

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

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service

General health information

Health and Social Care in Northern Ireland

www.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 Direct Wales

www.nhsdirect.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline 0800 22 44 88
(Daily, 8am to 10pm)
www.nhsinform.scot
NHS health information site for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Emotional and mental health support

Mind

Helpline 0300 123 3393
Text 86463
Email info@mind.org.uk
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
Samaritans branches are located across England, Ireland, Scotland and Wales. Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
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.

Support for carers

Carer's Allowance Unit

Tel 0345 608 4321
Textphone 0345 604 5312
(Mon to Thu, 8.30am to 5pm, and Fri, 8.30am to 4.30pm)
www.gov.uk/browse/benefits

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

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales)
0808 808 7777
(Mon to Wed, 10am to 4pm)
Helpline (Northern Ireland)
028 9043 9843
Email advice@carersuk.org
www.carersuk.org

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

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 220 674
(Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
Textphone 028 9031 1092
www.nidirect.gov.uk/money-tax-and-benefits

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

GOV.UK

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

Help with sexual difficulties

College of Sexual and Relationship Therapists

Tel 0208 543 2707
www.cosrt.org.uk
Email info@cosrt.org.uk
A national specialist charity for sex and relationship therapy. Provides information about sexual and relationship issues.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 10pm, and Sat 10am to 6pm)
Email helpline@lgbt.foundation
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.

YOUR NOTES AND QUESTIONS

Disclaimer

Thanks

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

With thanks to: Miss Safina Ali, Consultant ENT Head and Neck Surgeon; Laura Askins, Senior Specialist Dietician; Dr Ashoke Biswas, Consultant Clinical Oncologist; Jeanette Collings, Macmillan Information and Support Radiographer; Lesley Dempsey, Clinical Nurse Specialist; Jane Dunton, Acting Clinical Lead Speech and Language Therapist; Dr Martin Forster, Consultant Medical Oncologist; Eileen Gilmartin, Speech and Language Therapist; Jodie McCord, Macmillan Clinical Lead Speech and Language Therapist; Andrea Nelson, Senior Macmillan Head and Neck Clinical Nurse Specialist; Dr Ioanna Nixon, Consultant Clinical Oncologist; and Maria Smith, Clinical Nurse Specialist.

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

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Head and neck cancer: United Kingdom national multidisciplinary guidelines. The journal of laryngology and otology. March 2016, Volume 130, Number S2.
National Institute for Health and Care Excellence (NICE). Cancer of the upper aerodigestive tract: assessment and management in people aged 16 and over. NG36. February 2016 (updated June 2018).
National Institute for Health and Care Excellence (NICE). Suspected cancer: recognition and referral. June 2015 (updated July 2017), NG12.

Can you do something to help?

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

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

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

Share your cancer experience

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

Campaign for change

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

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

This booklet is about cancer of the larynx (voicebox), which is also called laryngeal cancer. It is for anyone who has been diagnosed with 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. It also explains how it is diagnosed and treated, and ways to cope. This includes your feelings, relationships, work and finances.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. 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.

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

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU

What's this logo? Visit **macmillan.org.uk/ourinformation**

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don’t let the taxman keep your money

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

☐ I am a UK 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.

Registered with FUNDRAISING REGULATOR

If you’d rather donate online go to macmillan.org.uk/donate

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

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