



Treating Mouth and Oropharyngeal Cancer - A Quick Guide

Contents

This is a brief summary of the information on 'Treating mouth and oropharyngeal cancer' from CancerHelp UK. You will find more detailed information on the website.

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Grade and stage of mouth cancers

The stage of a cancer tells the doctor how far a cancer has grown or spread. The staging information helps your doctor decide on the best treatment. The two main ways are the TNM system and number system.

TNM stages of mouth and oropharyngeal cancer

TNM stands for Tumour, Node and Metastasis. The system describes

- The size of a primary tumour (T)
- Whether the cancer has spread to the lymph nodes (N)
- Whether the cancer has spread to a different part of the body (M)

Number stages of mouth cancers

There are four main stages in this system – stages 1 to 4. Some doctors also refer to stage 0, which is an early stage before a true cancer develops. On CancerHelp UK, there is detailed information about the TNM and number stages.

Grade

The grade of a cancer tells you what the cells look like under a microscope. They are graded according to how normal or abnormal they appear. The more abnormal they look, the higher the grade. Mouth and oropharyngeal cancers are graded from 1 (low grade) to 4 (the highest grade).



Statistics and outlook for mouth cancer

Outlook means your chances of getting better. Your doctor may call this your prognosis. With mouth and oropharyngeal cancer, the likely outcome depends on how advanced the cancer is when it is diagnosed. That is, the stage and grade of your cancer. The outlook also depends on which part of the mouth or oropharynx is involved.

On CancerHelp UK, we have quite detailed information about the likely outcome of different stages of these cancers. The statistics we use are taken from a variety of sources, including the opinions and experience of the experts who check every section of CancerHelp UK. They are intended as a general guide only. For the more complete picture in your case, you'd have to speak to your own specialist.

How reliable are cancer statistics?

No statistics can tell you what will happen to you. Your cancer is unique. The same type of cancer can grow at different rates in different people. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

Treatment options for mouth cancer

Being cared for by a multi-disciplinary team

NHS guidelines state that all head and neck cancer patients should be under the care of a multi-disciplinary team. This is a team of health professionals who work together to decide on the best way forward for each patient. The MDT includes specialist head

and neck surgeons and cancer specialists, a specialist nurse, dietician, consultant restorative dentist and speech therapist. There is more about what each of these professionals do on CancerHelp UK.

How your doctor decides on your treatment

Mouth and oropharyngeal cancers can be treated with surgery, radiotherapy, chemotherapy or biological therapy. Your doctors will plan your treatment according to the type of cancer you have and the stage and grade of your cancer. They will also take into account the impact your treatment will have on your speech, and chewing and swallowing, and your general health and fitness.

You may wish to get a second opinion before you have your treatment. Most doctors are happy to refer you to another specialist for a second opinion if you want one.

Treatment by stage for mouth cancer

Stage 0

If the affected area is very small, your doctor may completely remove it during a biopsy. Or you may need to have minor surgery. If the precancerous cells continue to come back, your doctor may suggest a course of radiotherapy.

Stage 1 and 2

The treatment for early stage mouth and oropharyngeal cancers depends on where your cancer is, and the likely side effects of treatment in that area. Your doctor may recommend surgery or radiotherapy or surgery followed by radiotherapy.



Sometimes chemotherapy is given alongside the radiotherapy.

Stage 3 and 4

If you have surgery you may also have radiotherapy or chemotherapy (or both). If your cancer is too big or awkward to remove using surgery you are most likely to have radiotherapy, with or without chemotherapy. Or you may have radiotherapy combined with biological therapy.

Advanced cancer that is unlikely to get better (palliative treatment)

Palliative treatment aims to control symptoms. It won't cure your cancer, although it may slow it down a bit. For example, if your tumour is beginning to block your airway, your doctor may recommend surgery to remove all or part of the tumour to make breathing easier. They may also suggest surgery combined with radiotherapy, or chemotherapy, either alone or with radiotherapy (chemoradiation).

About mouth and oropharyngeal cancer surgery

Who will be involved in my surgery?

You are likely to have treatment from a team of specialists.

Effects of mouth and oropharyngeal surgery

The size and position of your cancer will affect the type of surgery you need. Surgery to the mouth and oropharynx may change the way you chew and swallow, the way you breathe, the way you talk, and your sense of smell. Your surgeon will always try

to avoid changing your appearance, and to keep functions such as breathing, speech, sight, chewing and swallowing as normal as possible. But sometimes this is not possible, and you will have changes to deal with. This can be very hard to come to terms with at first and take some time to get used to.

You may need to have a part of your face or neck rebuilt (reconstructed) with tissue flaps or skin grafts. For some cancers your surgeon may need to remove some of the bones in your face and mouth. If this is the case, your doctor may suggest you have a false part called a prosthesis made to replace the part of your face that has been removed.

With some types of mouth and oropharyngeal cancers, you may need to have to have a breathing stoma. This is a hole in your neck, made so that you can breathe. You may also hear this called a tracheostomy. Usually this is only temporary.

Cancers of the mouth and oropharynx often spread to the lymph nodes in the neck. You may have an operation called a neck dissection to remove lymph nodes.

Types of mouth cancer operations

Surgery to remove the cancer

Many of the operations to remove cancer of the mouth and oropharynx are major surgery. Some will cause changes to the way you look, eat, speak and cope with life. The living with mouth and oropharyngeal cancer section of CancerHelp UK has information about how to cope with any changes that surgery can bring.



Depending on where your cancer is, surgery to remove the cancer can include removing all or part of your jawbone, your tongue or larynx (voice box), or all or part of the bones in the roof of your mouth. Or you might need to have layers of your lips removed. Your surgeon will only remove the tissue necessary to control your cancer.

Removing lymph nodes in your neck

Your surgeon may suggest removing the lymph nodes nearest your cancer. This might be a big operation. If your cancer has already spread to lymph nodes in your neck, then your surgeon is likely to remove all the nodes on one or both sides of your neck. This is called a neck dissection. It can have long term side effects.

Other operations

Some people need other operations, such as a tracheostomy (having an opening made in the front of your neck to allow you to breathe more easily), removal of teeth and replacement with dental implants, or putting in a gastrostomy tube (a tube into your stomach to give you liquid food if you can't swallow).

Before your operation for mouth cancer

When you go into hospital for your operation, your surgeon, anaesthetist, physiotherapist, nurse and dietician will come to talk to you about what will happen. Your surgeon will explain the operation and tell you what to expect when you come round from the anaesthetic. If your operation might cause problems with speech, a speech therapist will talk to you about how you can communicate afterwards.

A physiotherapist will teach breathing and leg exercises to you. It is very important that you do these exercises as instructed because they will help you to get better more quickly.

It is important to ask as many questions, as you need to. It may help to make a list of questions before you go into hospital to have your surgery.

You will also have tests before your operation to check your general health. These help to make sure you are fit enough to make a good recovery from your surgery.

After your operation for mouth cancer

When you wake up you may have several different tubes in place. You may have a breathing tube in a hole (called a stoma) in your neck. This is usually temporary. You will breathe through the tube for 3 or 4 days.

Talking after your operation

If you have had surgery to your voice box, mouth, jaw, tongue or throat you will have problems talking. You will have a call bell close by so that you can call for help, and a pen and paper to write down anything you want to say.

Coping with pain

You will almost certainly have some discomfort for the first week or so. It is very important to tell your doctor or nurse as soon as you feel any pain. With your help they can find the right type and dose of painkiller for you. Pain can usually be well controlled.



Eating and drinking

Any surgery to your mouth or oropharynx usually means that you won't be able to eat or drink for a few days. You will have fluids through your drip. If you have had major surgery you may not be able to eat or drink for some time after your surgery. You will then need to have liquid food through a tube that goes through your nose to your stomach.

Seeing yourself for the first time

It is not unusual for people who have had facial surgery to find it very difficult to look in the mirror. You may feel very angry, confused and upset for some time. You will need a lot of support from your medical team and those close to you.

What to ask your doctor about surgery for mouth cancer

- Why do I need an operation?
- Which type of operation should I have and why?
- What exactly are you going to do?
- Could you draw me a diagram to help me understand what you are planning?
- Will the operation cure my cancer?
- What are the risks and benefits of having this operation?
- What are the long term effects of this operation?
- What will I look like after the operation?
- How will my appearance change as I recover?
- Will I have pain after this operation?
- How will I breathe after my operation?
- How long will I have a drip after surgery?
- When will I be able to start eating again?

- Will I be able to eat and drink normally after this operation?
- Will I get help with my diet after the operation?
- What are the possible complications of this type of operation?
- Will I need any other treatment as well as surgery?
- Is there any treatment I can have instead of surgery?
- What will happen if I don't have the operation?
- How long will it take me to get better?
- How can I help myself get over the operation?

About radiotherapy for mouth cancer

Radiotherapy uses radiation to kill cancer cells.

Radiotherapy alone

Radiotherapy may be the first choice of treatment for some types of mouth and oropharyngeal cancers. It can cure many people with early stage cancers. Your doctors will suggest it if they can, because it will not usually cause voice loss or changes in the way you look after the treatment.

Radiotherapy after surgery

Radiotherapy after surgery helps to stop your cancer from coming back. You usually have treatment daily, Monday to Friday, for 4 to 7 weeks.

Radiotherapy with chemotherapy

You may have radiotherapy and chemotherapy at the same time for some types of mouth and oropharyngeal cancers. This treatment is called chemoradiation.



Radiotherapy to relieve symptoms

Radiotherapy can relieve symptoms in advanced mouth and oropharyngeal cancer. You may hear this called palliative radiotherapy. The treatment relieves symptoms by shrinking the cancer. The cancer may grow back, but it could take a while to do so. Radiotherapy can also help to relieve pain. To control symptoms, you are most likely to have a short course of a few radiotherapy treatments over a few days.

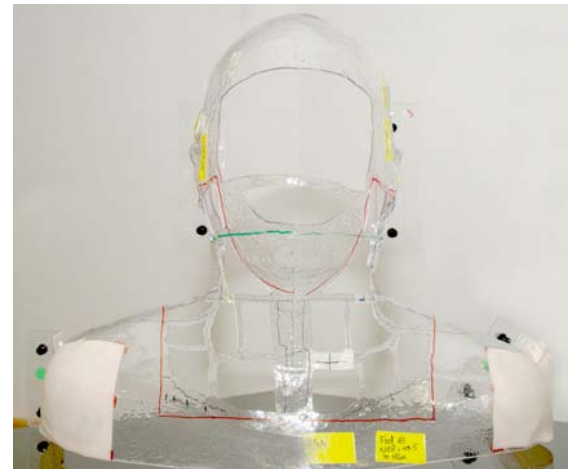
External radiotherapy for mouth cancer

This treatment directs a high dose of radiation to the area of the tumour. You have the treatment in the hospital radiotherapy department. You go for treatment once a day, from Monday to Friday, with a break at the weekends. The length of the course of treatment varies but is usually between 4 to 7 weeks.

Radiotherapy masks

If you have radiotherapy to any area of your face and neck, you will usually need to wear a treatment mask, also called a cast, mould or shell. This keeps your head and neck very still during your treatment. The mask will fit over all or part of your face and neck. The radiographer attaches it to the radiotherapy couch each time you are treated.

You have your mask made during your first planning appointment. It should feel comfortable and secure when you wear it.



Planning your treatment

Radiotherapy treatment is carefully planned. During your planning appointment, you have a CT scan or lie under a large machine called a simulator. The scans or simulator work out exactly where to give the treatment.

Internal radiotherapy for mouth cancer

Internal radiotherapy is also called brachytherapy or interstitial radiotherapy. It uses a radiation source inside your body to give radiotherapy to the cancer. The source is put within the cancer or very close to it. The tumour gets a high dose of radiation without damaging surrounding tissue. Internal radiotherapy can often cure small tumours in the lip, tongue, soft palate, cheeks, neck, tonsil or floor of the mouth. It may cause less physical changes and loss of function compared to other types of treatment.

Doctors use internal radiotherapy to treat small tumours. It can also treat cancers that have come back after earlier treatment with external radiotherapy. Or it can be used as a booster dose at the end of a course of external radiotherapy.



How you have internal radiotherapy

You have radioactive wires, tubes or seeds put into your tumour under general anaesthetic. The implants stay in place for anything from a few minutes to a few days. Implants in your mouth can be uncomfortable and make eating and talking difficult. You may need a soft or liquid diet. A speech and language therapist will help you to communicate and will make sure that you can swallow well. You will have a private room so that other people are not exposed to the radiation.

You have another general anaesthetic to have the implant taken out. You are likely to feel sore for a while afterwards.

Permanent implants

Some implants (made of radioactive iodine or gold seeds) are left in place permanently. The amount of radiation they give is small and can only travel a very short distance. So the tumour gets nearly all the radiation dose, with very little effect on surrounding tissues and organs. It is not a risk to you or anyone around you.

Mouth cancer radiotherapy side effects

Most people do have side effects with radiotherapy to the mouth, oropharynx and neck area. They will usually be at their worst at the end of your course. Over the 2 to 3 weeks following your treatment they will slowly get better. Getting over a long course of treatment completely can take several months.

Generally, radiotherapy causes tiredness and sore, red skin in the area being treated. Sometimes you may also feel sick. Don't put any lotions, powders or creams on the

treated skin without checking first with your radiotherapy department.

Other side effects

Other side effects with mouth or oropharyngeal cancer radiotherapy can include

- Sore throat and pain on swallowing - Your mouth and throat may become increasingly sore with mouth ulcers. You may need strong painkillers and a liquid diet or liquid food through a tube
- A dry mouth - Radiotherapy to this area can damage the glands that make saliva. You may have a permanently dry mouth. Your doctor can prescribe artificial lubricating agents and stimulants for your salivary glands.
- Changes to your sense of taste and smell
- A hoarse or lost voice - Your voice will come back but may sound different after treatment.

If you need help with side effects, speak to your radiographer or nurse at the radiotherapy department. They can help you manage the side effects.

What to ask your doctor about radiotherapy for mouth cancer

- Why are you recommending radiotherapy for me?
- What is internal radiotherapy?
- Will I need internal or external radiotherapy or both?
- Are there any other types of treatment I could have?
- How will the treatment help me?
- What are the likely side effects?
- How long will they last?



- Is there anything I can do to help with side effects?
- Are there any long term or permanent effects?
- How often will I have to come to the hospital for treatment?
- Can I get help with fares to and from the hospital?
- Is there any transport available?
- Will I have to stay in hospital, and if so, for how long?
- Is there a number I can ring if I am worried about anything when at home?

About chemotherapy for mouth cancer

Chemotherapy means treatment using anti cancer or cytotoxic drugs.

Chemoradiation

You may have chemotherapy and radiotherapy at the same time. This is called synchronous therapy or chemoradiation. It is most commonly used for oropharyngeal cancer. You may also have it for small mouth cancers so that you can avoid surgery. Chemoradiation is quite tough treatment to get through. You will need to have tests to see if you are fit enough to withstand it.

Chemotherapy to try and control a cancer that has come back

You may have chemotherapy on its own if your cancer is advanced, or has come back after treatment with surgery or radiotherapy. This can help to relieve your symptoms and may slow the growth of your cancer.

Chemotherapy to shrink a large cancer before surgery or radiotherapy

If your cancer has not spread to other organs, but is too big to operate on, your doctor may suggest chemotherapy before surgery. The aim of the treatment is to shrink your cancer with chemotherapy before you have surgery or treatment with radiotherapy. This treatment is still being investigated.

Chemotherapy drugs for mouth cancer

It is most common to have 2 or more chemotherapy drugs together to treat cancer. You may hear this called combination chemotherapy. CancerHelp UK has information about the most commonly used drugs and their side effects.

Having chemotherapy

You have the chemotherapy drugs through a drip (intravenous infusion) into your arm or central line, usually once every 3 or 4 weeks. Each 3 or 4 week period is known as one cycle of treatment. You will probably have between 2 and 3 cycles to begin with. If the treatment is working and you are not having too many side effects you may go on to have up to 6 cycles.

Your own doctor will decide the exact amount of treatment you have. So the complete chemotherapy course can take 6 months or more.

Side effects of the drugs used in chemotherapy for mouth cancer

Drugs affect people in different ways. Not all patients have the same side effects with the same drug. Some people have very few side effects at all. It is not possible to tell



how you will react until you have had that particular drug.

Side effects that are common with many chemotherapy drugs include

- A fall in the number of blood cells, leaving you prone to infections
- Feeling sick
- Diarrhoea
- Sore mouth and mouth ulcers
- Hair loss or thinning
- Feeling tired and run down

Side effects of chemoradiation

Chemoradiation means having course of radiotherapy and chemotherapy at the same time. The side effects of this treatment are the same as for each individual treatment. But some are likely to be more severe. In particular, you are likely to get a very sore mouth and throat. For some people, the mouth is so sore that they can't swallow. If this happens you are likely to need a feeding tube so you can get enough food and drink inside you. You may also need a strong painkiller such as morphine.

What to ask your doctor about chemotherapy for mouth cancer

- Why do you think I need to have chemotherapy?
- What will the chemotherapy do for me?
- How will the chemotherapy be given to me?
- Will I need a general anaesthetic?
- What will the side effects be?
- How long will the treatments last?
- How often will I have to come to the hospital?

- Is it possible to get help with fares or transport to and from the hospital?
- Is there anything I will have to do at home (for example change the chemotherapy bags in a pump)?
- What if I cannot manage?
- Are there any long term side effects of this treatment?
- Is there a clinical trial that is suitable for me?

Biological therapy for mouth cancer

Biological therapy is treatment that changes the activity of cells. It uses substances made naturally in the body or drugs that change how the substances work. These therapies can control or destroy cancer cells. The most common biological therapy used for mouth or oropharyngeal cancer is cetuximab.

Biological therapies used for mouth or oropharyngeal cancer

Cetuximab (Erbix) blocks areas on the surface of cancer cells that can trigger growth. Cetuximab combined with radiotherapy is used for people with locally advanced mouth or oropharyngeal cancer if chemotherapy is not working or can't be used. Cetuximab is also sometimes combined with platinum based chemotherapy for people with squamous cell head and neck cancer that has come back or has spread.

Newer biological therapies are being used in clinical trials for mouth and oropharyngeal cancer. The therapies include gefitinib (Iressa), zalutumumab, everolimus and a modified virus called Reolysin.



Possible side effects

The side effects depend on which biological therapy you have but may include tiredness, diarrhoea, skin changes, a sore mouth, weakness, loss of appetite, low blood counts, and fluid build up in parts of the body.

For more information, look in the biological therapy section on CancerHelp UK.

Follow up for mouth cancer

After your treatment has finished, you will have regular check ups. This is to make sure that the cancer has not come back or that a new cancer has not developed.

At the check up your doctor will examine you. They will ask how you are feeling, and whether you have had any new symptoms or are worried about anything. Check ups may also include blood tests, X-rays, scans and dental check ups. You won't have all these tests at every visit though.

How often will I have check ups?

At first, you will need check ups every month. If all is well they will become less frequent. After 5 years you might be able to stop check ups. But this is only a general guide. If you are worried or notice any new symptoms between appointments, let your doctor know as soon as possible. You don't have to wait until your next appointment.

You may need to come back to hospital to see the speech therapist if you have had any changes to your speech or difficulty in swallowing.

Worrying about check ups

Many people find their check ups quite worrying. A hospital appointment can bring

all the worry about your cancer back to you. You may find it helpful to tell someone close to you how you are feeling. It is quite common nowadays for people to have counselling after cancer treatment. Look in the coping with cancer section of CancerHelp UK for more information about counselling.

Mouth cancer research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know that the treatments are safe.

First of all, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe are they tested in people in clinical trials.

For mouth and oropharyngeal cancer, researchers are looking into surgery, radiotherapy, chemotherapy, biological therapy, light therapy and ways of reducing the side effects of treatment.

What to ask your doctor about mouth cancer treatment

- What can you tell me about the stage of my cancer?
- What type of treatment do I need?
- If you are not sure about the stage, when will you know?
- How do you tell the stage of the cancer?
- What written information can you give me about these treatments?
- Is there any choice of treatments?
- Should I have any treatment before surgery?



- Should I have any other treatment after surgery?
- What are the risks and benefits of these treatments?
- What are the side effects?
- How can I help to reduce the side effects?
- How often will I have to come to the hospital for treatment?
- Is there any transport available?
- Is it possible to have any help with the cost of fares to the hospital?
- How long will the treatment last?
- How long will I be off work?
- Can I have a second opinion?
- Are there any experimental treatments or trials that might help me?
- Is there a counsellor here I could talk things through with?
- How often will you see me when my treatment is finished?
- What will happen at my follow up appointments?
- What should I do if I am worried between appointments?
- What pain control can you offer me?
- Do I have to have morphine, or are there other ways of controlling pain?

More information

For more information about mouth and oropharyngeal cancer, visit our website <http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on **0808 800 4040**
9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in October 2011. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2011. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666).