

Oral Cancer

Information for Patients and Carers

Background

Cancer of the mouth affects approximately 3000 men and women in this country every year. It can occur anywhere in the mouth but most commonly affects the tongue, the lining of the mouth underneath the tongue and the lower gum.

It is mainly a disease of the elderly with nearly three quarters of all mouth cancers occurring in those aged between 55 & 75 years but it can and does occur in those who are younger than this.

The vast majority of mouth cancers are caused by excessive use of tobacco and alcohol. People who smoke more than 20 cigarettes or 5 cigars a day are 6 times more likely than non-smokers to get mouth cancer and those who also drink heavily are 24 times more likely than non-drinkers and non-smokers to get the disease. Pipe smoking, chewing tobacco and chewing betel nut (Pan) can also cause mouth cancer. Cancer of the mouth is very rare in people who neither drink alcohol nor use tobacco.

It is also slightly more common in people whose close relatives had a cancer of the mouth or throat

What to look out for

Early symptoms include new ulcers, lumps, white or red patches on the lining of the mouth or tongue that do not heal after 2 or 3 weeks of simple treatment. In early mouth cancers ulcers are frequently painless.

Late symptoms of mouth cancer include painful ulcers or lumps, difficulty with speaking or swallowing, earache and swollen glands in the neck.

It is extremely important that anyone who has any of the above symptoms for longer than 3 weeks visits their dentist or doctor for a professional examination and possible referral to a hospital specialist for treatment. Any patient who is suspected of having a mouth cancer who is referred by a doctor or dentist to a hospital specialist will be seen and examined by the specialist within 14 days of being referred.

What can I do to reduce my risk of getting mouth cancer?

The single most important thing to do if you are a smoker is to quit **NOW!** People who stop smoking for 10 years reduce their risk of developing mouth cancer to the same level as those who have never smoked so it is very worthwhile. Help is available to help you quit smoking in the form of nicotine replacement gum and patches as well as tablets and counselling. Your family doctor is the best person to discuss these issues with. If you are not a smoker don't start.

Drinking alcohol **in moderation** may actually be beneficial to your health but men should not drink more than 40 units of alcohol per week and women should not drink more than 20 units of alcohol per week. One unit of alcohol is equal to half a pint or beer, or a single measure of spirit, or a small glass of wine.

Eat a balanced diet including plenty of fresh fruit and vegetables as these have been shown to reduce the risk of mouth cancer.

Visit your dentist regularly even if you have dentures. As well as ensuring that your teeth and gums are healthy he or she will be able to spot anything abnormal in your mouth especially in places where it is difficult for you to see yourself.

Is mouth cancer curable?

The simple answer to this question is **YES** but as with other cancers the earlier the disease is found and treated the better the chance of cure. However, mouth cancer is a highly lethal

disease and almost 1000 people in this county die of it every year. If cancers are treated when they are small the vast majority of people will be alive and well 5 years later and most of these will be cured. But if people present for treatment late when the cancer is large or has spread to the glands in the neck or elsewhere in the body then only about half will survive more than 5 years. This is the reason why it is so important to visit your dentist regularly for check-ups and to contact your dentist or doctor immediately if you have an ulcer, lump or white or red patch that does not heal after 3 weeks.

What tests and investigations are used?

It is important to examine any suspicious non-healing ulcer or lump under the microscope as this is the only way that a cancer can be positively diagnosed. In the majority of cases a small piece of the ulcer or lump is removed for further examination. This is called a biopsy. This can often be done with a simple local anaesthetic procedure in the hospital outpatient clinic. It is painless and only takes a few minutes to do.

If patients have a lump in the neck, which *may* indicate that the cancer has spread, a small sample from the gland will be taken using a syringe and needle. This is called an FNAC (fine needle aspiration cytology). Again this can be done in the clinic and only takes a few minutes.

It will usually also be necessary to perform routine blood tests and take X-rays of the jaws and chest and to organise scans of the head and neck area. The scans are performed by specialists in the X-ray (radiology) department and have to be booked but are usually performed within a few days.

Occasionally, especially if the ulcer or lump is at the back of the mouth it will be necessary to admit patients to hospital in order that the examination and biopsies can be performed under a general anaesthetic while they are asleep. The results of investigations are usually available within 14 days. All patients are then seen at a special (multi-disciplinary) clinic, which is attended, by doctors and nurses who are specialists in treating mouth cancer. At this clinic all the results of investigations and tests will be available and all possible options for treatment will be discussed in order to ensure that a treatment plan specifically designed and optimised for each individual patient can be produced. The proposed treatment options and their side effects will be fully discussed with patients and their carers at this appointment and any questions answered fully and as honestly as possible. It may be necessary to arrange a follow-up appointment within a few days to go over things again as well answer any other questions from patients and carers that have come to mind following previous discussions.

How is it treated?

In the majority of cases and wherever possible the aim of treatment is to **CURE** patients of their cancer and enable them to live as normal a life as possible afterwards. Achieving a good quality of life after treatment is vitally important. In a small number of cases it may not be possible to cure the cancer either because the disease is too far advanced or because patients are so frail that they are unable to tolerate the treatment necessary to cure their cancer. In this situation treatment (palliation) is aimed at reducing symptoms such as pain and ulceration.

There are 3 main ways of treating mouth cancer; surgery (an operation), radiotherapy (X-ray treatment) and chemotherapy (drug treatment). These treatments can be given individually or combined together. About half of all patients are treated by a mixture of both surgery and radiotherapy. For early (smaller than 2cm) cancers of the mouth and lips

that do not involve the bone the chance of cure is equally good with either surgery or radiotherapy. For small to intermediate cancers where surgery might produce problems with speech or eating radiotherapy may be preferable as the functional results are likely to be better. For larger tumours, particularly those that involve the bone or if the cancer has spread to the neck glands then surgery is usually the treatment of choice. In the majority of cases radiotherapy will be given after the operation in an attempt to destroy any remaining cancer cells.

Surgery

The aim of surgery is to physically remove all the cancer and an area of normal tissue surrounding the cancer in order to minimise the chance of the tumour coming back (recurring). If the cancer is small it can be removed with little effect on surrounding tissues leaving a good functional and cosmetic result. Larger tumours inevitably require more tissue to be removed. This will usually leave a space where the cancer used to be that needs to be repaired. Usually, this will involve “borrowing” skin and muscle and sometimes bone from elsewhere on the body. This is called a flap. Depending on circumstances such as the size and site of the cancer the flap may be taken from the front of the chest, abdomen wrist or leg. It may involve the use of highly specialised microsurgery. If the cancer has spread to the neck glands an operation called a neck dissection will usually be needed to remove the affected glands as well as other structures in the neck depending on how many glands are involved.

These are all major operations, which are performed by highly skilled specialist surgeons frequently working in teams and may take many hours to complete. The length of hospital stay varies depending on the extent of the cancer, type and complexity of operation performed and general health of the patient but usually will be between a few days to 2 or 3 weeks.

Radiotherapy

Radiotherapy can be given either by shining a beam of X-rays at the cancer (external beam or teletherapy) or by inserting radioactive wires directly into the cancer (brachytherapy). The actual method chosen depends on the site and size of the tumour.

Radiotherapy is given by highly trained cancer specialists called oncologists or radiotherapists working in specialist cancer centres. The oncologist/radiotherapist is the principle member of the multi-disciplinary team and will have been present during the discussions regarding the best treatment to offer each patient.

Teletherapy is usually given on an out-patient basis daily Monday to Friday for 4 weeks. Brachytherapy requires the patient to be admitted to hospital for the radioactive implants to be inserted under anaesthetic and will be followed by a stay in hospital of a few days until the radioactive wires are removed.

In order to reduce the need for dental extractions after radiotherapy which can result in painful chronic infection of the jaw bone (osteoradionecrosis) all patients should have a thorough dental examination before starting treatment. Any dental work, especially extractions should be carried out before treatment starts.

Chemotherapy

This is also given by oncologists working in cancer centres and is a highly specialised form of cancer treatment. It is usually given in combination with radiotherapy for large and/or advanced tumours.

What are the side effects of treatment?

Unfortunately, it is seldom if ever possible to cure a cancer without producing some damage to normal surrounding tissues and some side effects are inevitable. However, the aim is always to minimise side effects of treatment and to achieve the best quality of life for patients compatible with curing or palliating their cancer.

Surgery

Most surgery for mouth cancer is **not** mutilating and many patients are able to return to their previous normal social and work activities. With surgery the most obvious side effects are scars, particularly on the face and neck. However, these usually heal well and after several months fade and become paler. Even quite large cancers of the tongue and mouth can be removed and repaired without causing significant problems with speech and swallowing but inevitably there is likely to be some reduction alteration in these functions. Treatment for very large tumours may severely affect speech and swallowing.

Patients who have operations to remove neck glands may develop some weakness and stiffness in their shoulder but this can be helped with physiotherapy and painkillers.

For major operations it may be necessary to insert a **temporary** tube into the windpipe during the operation (temporary tracheotomy) in order to ensure there are no breathing problems. While the tube is in place patients are unable to speak but speech is regained as soon as the tube is removed which is usually after 3 or 4 days.

If a flap has been used inside the mouth a **temporary** feeding tube (nasogastric or gastrostomy tube) may be used to ensure the flap remains clean and healthy and does not get contaminated by food and debris. While the tube is in place, which is usually, for 7 to 10 days patients are only allowed clear fluids to drink and all food is given *via* the feeding tube.

Radiotherapy

The main side effects of radiotherapy are a sore mouth, mouth ulcers, thrush, dry mouth and loss of taste. The ulceration and soreness usually starts about half way through treatment and lasts for several weeks afterwards. It usually subsides and while it is present symptoms can be controlled with painkillers and anaesthetic/soothing mouth washes.

Thrush is treated by antifungal capsules and mouth gel.

The dry mouth is due to damage to the salivary (spit) glands by the radiotherapy and while it improves with time some degree of dryness often remains. Frequent sips of water, saliva substitutes or occasionally special tablets can help to reduce the symptoms.

Loss of taste is due to damage to the taste buds by the radiotherapy. It can last several weeks after treatment has finished but usually improves with time.

The reduction in saliva following radiotherapy can lead to rapid tooth decay and it is vital that patients pay particular attention to keeping their teeth and gums clean and healthy by frequent tooth brushing and using an antibacterial mouth wash such as Corsodyl™.

Frequent (at least every 6 months) visits to the dentist for check-ups and fluoride applications are vital. Patients without any of their own natural teeth should visit their dentist twice yearly to ensure their dentures are comfortable and fitting properly.

Chemotherapy

The side effects of chemotherapy are similar to radiotherapy but vary according to the drugs given. If you are going to have chemotherapy the oncologist will warn you of the specific side effects associated with your drugs.

What happens after treatment is completed?

It is never possible to completely guarantee that the treatment has resulted in cure and so it is vital that patients are regularly reviewed by the specialist team after treatment has finished. The first 12 months following completion of treatment are the most crucial as it is during this period that cancers are most likely to recur. Recurrences after 12 months are less common and in the majority of cases, if patients are free of disease 5 years following treatment they can be considered to be cured. Patients are thus followed up very regularly in outpatient clinics for at least 5 years. In most cases they will be seen every month during the first year following treatment. If there are no signs of the cancer recurring the intervals between follow-up appointments can then be extended.

Follow-up visits usually consist of a thorough clinical examination of the mouth and neck. Any suspicious areas may be biopsied and additional X-rays or scans may be requested. In this way any recurrences are picked up very early allowing prompt treatment and so maximising the chance of cure.

Where can I get more information on mouth cancer?

- The first person to ask is the hospital specialist who is looking after you. He or she will be able to explain and discuss all aspects of your treatment with you and your carers. To help you remember the questions you want to ask it helps to write them down as and when you think of them. Most people find they forget many of the things they intended to ask the specialist when they meet him or her because they are so anxious.
- One of the members of the team helping to look after you is a cancer nurse specialist. He or she is a highly trained nurse with a special interest in cancer. As well as being able to answer questions about the medical and nursing aspects of your treatment they will also be able to give you information on accessing support from agencies such as social services. They will also liaise with the nurses in the community and your family doctors' surgery.
- Your family doctor will be informed immediately you have been diagnosed with mouth cancer. He or she will be able to offer help and support to you and your carers while you are at home before and after your hospital treatment.
- This information sheet is intended to give only a broad outline of the causes and treatment of mouth cancer. If you would like more detailed and specific information other leaflets are available from the unit – just ask.
- There is an excellent leaflet published by Cancer BACUP which is available free of charge to all patients with cancer. Copies can be obtained by writing to:
 - CancerBACUP, 3 Bath Place, Rivington Street, London EC2A 3JR
Telephone: 020 7696 9003 Fax: 020 7696 9002
- There are numerous references on the internet some good, some not so good and some that are positively bad. This is a list of internet sites that have been vetted by us as providing good quality information:
 - Cancer BACUP: <http://www.cancerbacup.org.uk>

- Cancer BACUP – understanding cancers of the mouth and throat:
<http://www.cancerbacup.org.uk/info/mouth.htm>
- Oral cancer prevention and detection:
<http://www.gla.ac.uk/Acad/Dental/OralCancer/>
- Guide to internet resources for cancer:
<http://www.cancerindex.org/clinks6.htm>
- The British Association of Oral and Maxillofacial Surgeons:
<http://www.baoms.org.uk>
- Bradford Hospitals NHS Trust Departments of Oral & Maxillofacial Surgery and Orthodontics: <http://www.maxillofacial.ws>