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# **Oesophageal Cancer**

# JASCAP

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS MUMBAI, INDIA

#### JASCAP

#### JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS c/o. Abhay Bhagat & Co., Office No.4, "Shilpa", 7<sup>th</sup>.Road, Prabhat Colony, Santacruz (East), Mumbai – 400 055 Tel.: 2617 7543, 2616 0007. Fax: 91-22-2618 6162 E-mail :pkrjascap@gmail.com & abhay@abhaybhagat.com

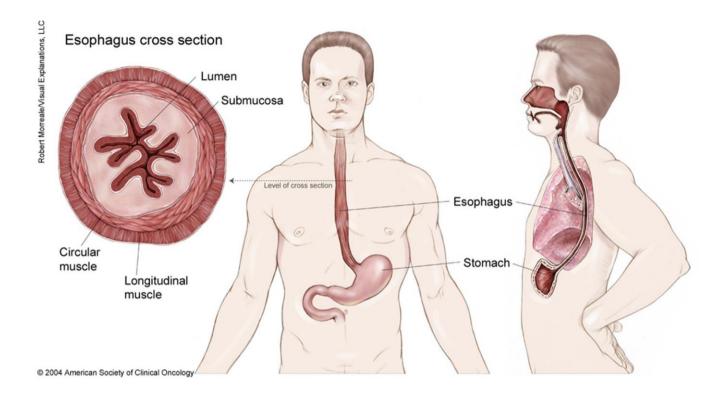
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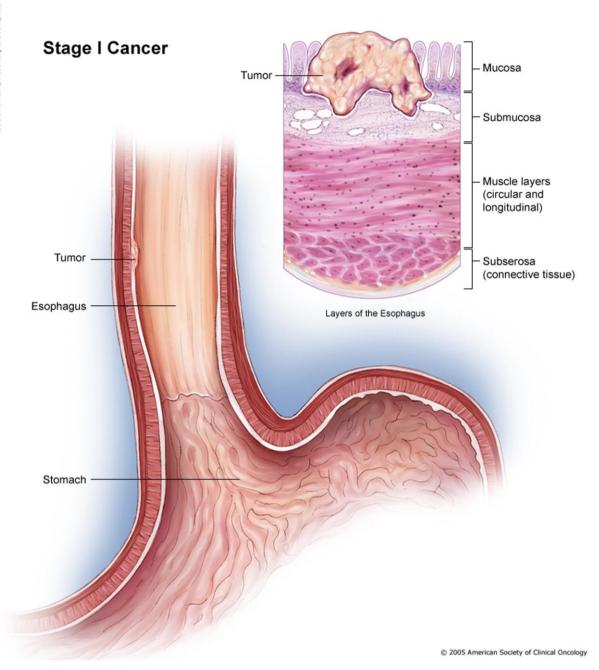
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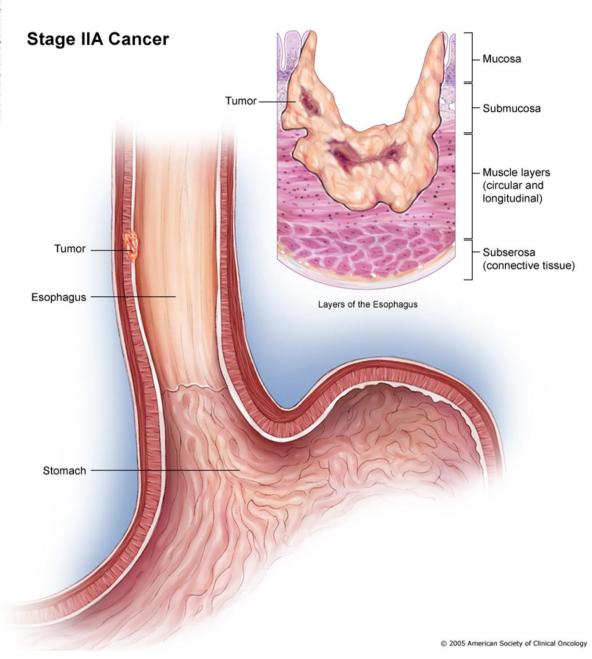
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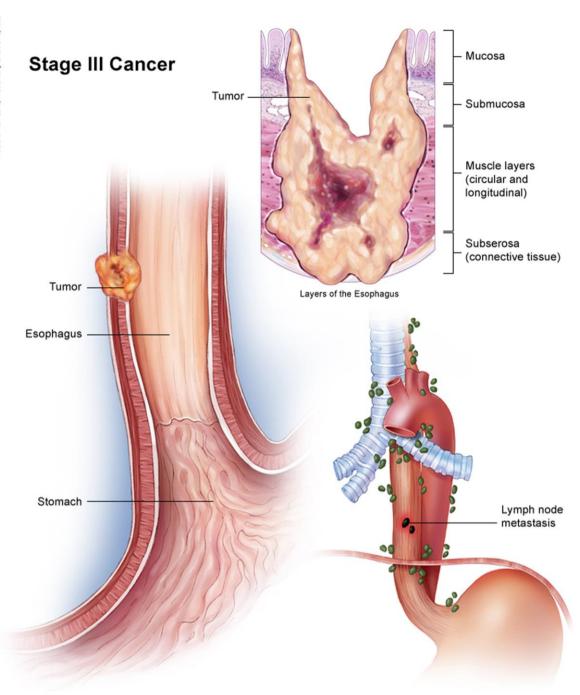
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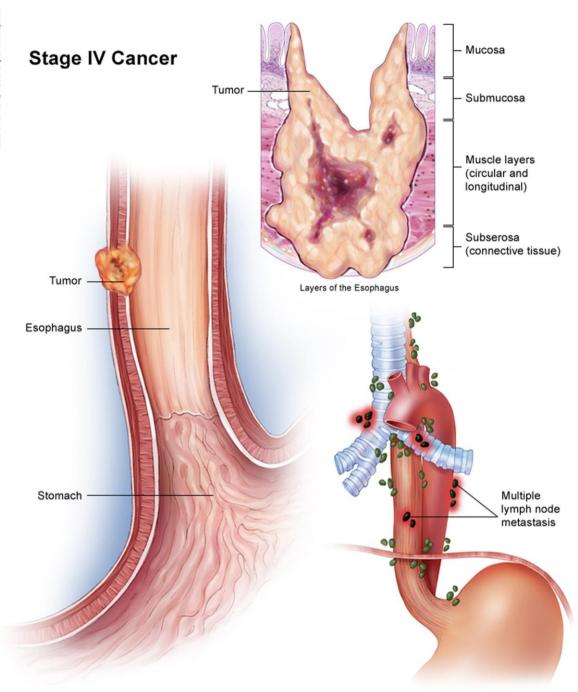
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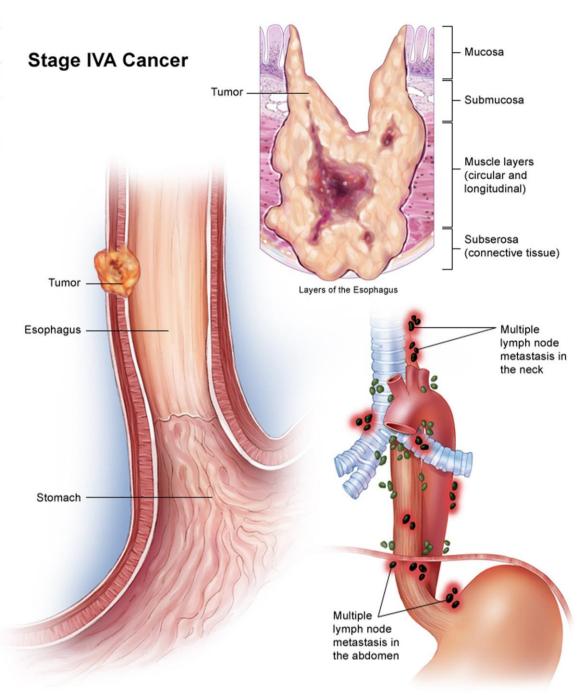


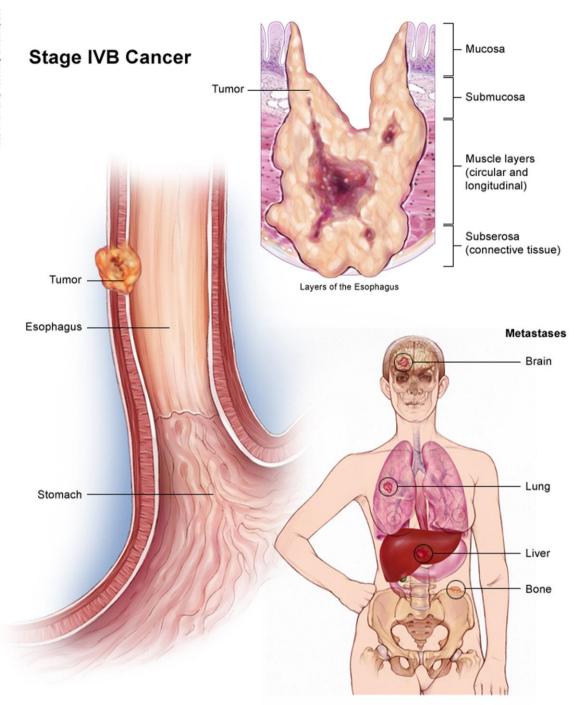












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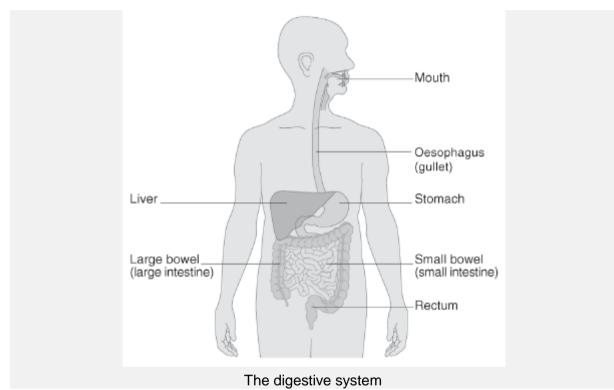
JASCAP Resources

\*\* JASCAP has a factsheet on this subject – Barrett's Oesophagus.

# The gullet (oesophagus)

The oesophagus (pronounced *e-sof-fa-gus*), is also known as the gullet. It is a long, muscular tube that connects your throat to your stomach. It is at least 12 inches (30cm) long in adults. When you swallow food it is carried down the oesophagus to the stomach, and the walls of the oesophagus contract to move the food down.

At the upper part of the oesophagus it runs behind, but is separate from, the windpipe (trachea). The windpipe connects your mouth and nose with your lungs, enabling you to breathe.

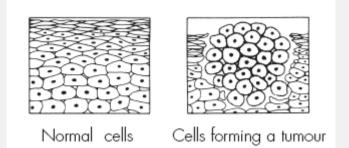


Various lymph nodes (which filter fluid and can trap bacteria, viruses and cancer cells) are near the oesophagus; in your neck, in the middle of your chest and near the area where the oesophagus joins the stomach. A tumour can occur anywhere along the length of the oesophagus.

# What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells.

Cells in different parts of the body may look and work differently but most reproduce themselves in the same way. Cells are constantly becoming old and dying, and new cells are produced to replace them. Normally, cells divide in an orderly and controlled manner. If for some reason the process gets out of control, the cells carry on dividing, developing into a lump which is called a tumour.



Tumours can be either benign or malignant. Cancer is the name given to a malignant tumour. Doctors can tell if a tumour is benign or malignant by examining a small sample of cells under a microscope. This is called a biopsy.

In a benign tumour the cells do not spread to other parts of the body and so are not cancerous. However, if they continue to grow at the original site, they may cause a problem by pressing on the surrounding organs.

A malignant tumour consists of cancer cells that have the ability to spread beyond the original area. If the tumour is left untreated, it may spread into and destroy surrounding tissue. Sometimes cells break away from the original (primary) cancer. They may spread to other organs in the body through the bloodstream or lymphatic system.

The lymphatic system is part of the immune system - the body's natural defence against infection and disease. It is a complex system made up of organs, such as bone marrow, the thymus, the spleen, and lymph nodes. The lymph nodes (or glands) throughout the body are connected by a network of tiny lymphatic ducts.

When the cancer cells reach a new area they may go on dividing and form a new tumour. This is known as a secondary cancer or metastasis.

It is important to realise that cancer is not a single disease with a single type of treatment. There are more than 200 different kinds of cancer, each with its own name and treatment.

# Types of cancer

#### Carcinomas

The majority of cancers, about 85% (85 in a 100), are carcinomas. They start in the epithelium, which is the covering (or lining) of organs and of the body (the skin). The common forms of breast, lung, prostate and bowel cancer are all carcinomas.

Carcinomas are named after the type of epithelial cell that they started in and the part of the body that is affected. There are four different types of epithelial cells:

- squamous cells that line different parts of the body, such as the mouth, gullet (oesophagus), and the airways
- adeno cells form the lining of all the glands in the body and can be found in organs such as the stomach, ovaries, kidneys and prostate
- transitional cells are only found in the lining of the bladder and parts of the urinary system

basal cells - that are found in one of the layers of the skin.

A cancer that starts in squamous cells is called a squamous cell carcinoma. A cancer that starts in glandular cells is called an adenocarcinoma. Cancers that start in transitional cells are transitional cell carcinomas, and those that start in basal cells are basal cell carcinomas.

# Leukaemias and lymphomas

These occur in the tissues where white blood cells (which fight infection in the body) are formed, i.e. the bone marrow and lymphatic system. Leukaemia and lymphoma are quite rare and make up about 6.5% (6.5 in 100) of all cancers.

## Sarcomas

Sarcomas are very rare. They are a group of cancers that form in the connective or supportive tissues of the body such as muscle, bone and fatty tissue. They account for less than 1% (1 in 100) of cancers.

Sarcomas are split into two main types:

- bone sarcomas that are found in the bones
- soft tissue sarcomas that develop in the other supportive tissues of the body.

### Others forms of cancer

Brain tumours and other very rare forms of cancer make up the remainder of cancers.

# Causes of oesophageal cancer

Each year, nearly 7600 people in the UK are diagnosed with cancer of the oesophagus. It is becoming more common in Europe and North America. Men are affected more than women and it occurs generally in older people.

There are two types: squamous cell carcinoma and oesophageal cancer (which is known as adenocarcinoma). The causes are unknown, but cancer of the oesophagus would appear to be more common in people who have long-term acid reflux (backflow of stomach acid into the oesophagus). Damage to the oesophagus caused by acid reflux is known as Barrett's oesophagus.

Barrett's oesophagus is a condition where abnormal cells develop in the lining of the lower end of the oesophagus. It is not a cancer, but over a long period of time a small number of people with this condition (around 1 in 100) may develop a cancer of the oesophagus.

Cancer of the oesophagus is more commonly seen in some populations in the Far East and Central Asia, which suggests that diet, or the environment, may affect its development. Squamous cell carcinoma is more common among smokers and people who drink a lot of alcohol (especially spirits) or have a poor diet. Other conditions affecting the oesophagus, such as achalasia, may also very occasionally lead to cancer. Achalasia is where the muscle that controls the opening between the oesophagus and the stomach does not relax properly. This makes food build up in the oesophagus and stops it emptying into the stomach.

In most people, cancer of the oesophagus is not caused by an inherited faulty gene, and so other members of your family are not likely to be at risk of developing it. However, a very small number of people who have a rare inherited skin condition known as tylosis may develop oesophageal cancer.

# Symptoms and Diagnosis

# Symptoms of oesophageal cancer

Difficulty in swallowing (dysphagia) is the most common symptom of oesophageal cancer. Usually, there is a feeling that food is sticking on its way down to the stomach, although liquids may be swallowed easily at first.

There may also be some weight loss, and possibly some pain or discomfort behind the breastbone or in the back. There may be indigestion or a cough.

These symptoms can be caused by many things other than cancer, but you should always tell your doctor, particularly if they do not go away after a couple of weeks.

# How oesophageal cancer is diagnosed

Your GP will examine you, and will arrange for you to go to hospital for tests and to see a specialist. At the hospital the specialist will ask you about your general health and any previous medical problems before examining you. You may have blood tests and a chest x-ray taken to check your general health. The following tests are commonly used to diagnose cancer of the oesophagus:

## Upper gastrointestinal endoscopy (oesophagoscopy)

This procedure enables the doctor to look directly at the oesophagus through a thin flexible tube called an endoscope. The endoscope has a tiny camera and a light on the end. If necessary, the doctor can take a small sample of the cells (a biopsy) to be examined under a microscope. This can usually confirm whether or not there is a cancer.

You can usually have an endoscopy as an outpatient, but occasionally an overnight stay in hospital is needed. Once you are lying on your side on the couch you may be given a sedative, usually injected into a vein in your arm, to make you feel sleepy and reduce any discomfort during the test.

Alternatively, a local anaesthetic may be sprayed on to the back of your throat before the doctor passes an endoscope down into your oesophagus. Sometimes both an injection and the spray are used. The doctor then looks through the endoscope and examines the inside of the oesophagus.

Endoscopy can be uncomfortable but should not be painful. After a few hours, the effect of the sedative will wear off and you will be able to go home. You should not drive for several hours after the test and if possible you should arrange for someone to travel home with you.

If you have had the local anaesthetic spray to the back of your throat you may need to stay in the hospital until the anaesthetic has worn off. This usually takes about four hours and you should not try to swallow anything during this time. Some people have a sore throat afterwards; this is normal and should disappear after a couple of days. If it doesn't, let your doctor at the hospital know. You should also tell your doctor if you have any chest pain.

Occasionally, the doctor may want to carry out treatment such as stretching (dilatation) of the oesophagus at the same time as an endoscopy. This can help you to swallow food more easily.

#### **Barium swallow**

A liquid barium solution is swallowed, which shows up on x-ray. Using an x-ray machine, the doctor can watch the barium as it flows down the oesophagus towards your stomach. At the same time x-ray pictures are taken of your oesophagus. A barium swallow takes about 15 minutes and should not be painful.

# Further tests for oesophageal cancer

If the tests show that you have cancer of the oesophagus, your doctor may want to carry out further tests. These help the doctor to see the extent (or stage) of the cancer and decide on the best type of treatment. You will probably have a chest x-ray (if one has not already been done) and other tests, which may include any of the following:

#### CT scan

A CT (computerised tomography) scan takes a series of x-rays which build up a threedimensional picture of the inside of the body. The scan is painless but takes from 10 to 30 minutes. CT scans use a small amount of radiation, which will be 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. For a few minutes, this may make you feel hot all over. If you are allergic to iodine or have asthma you could have a more serious reaction to the injection, so it is important to let your doctor know beforehand. You will probably be able to go home as soon as the scan is over.

# Endoscopic ultrasound (EUS)

The involves the same procedure as the upper gastrointestinal endoscopy, but a tiny ultrasound probe is connected to the end of the endoscope tube and passed along the oesophagus.

Ultrasound uses sound waves to build up a picture of the area. It allows the doctors to get a deeper view of the wall of the oesophagus and surrounding areas. This may give them a clearer idea of the size and depth of the tumour. It also allows them to see whether lymph nodes nearby are enlarged, and possibly, whether this enlargement is due to cancer or simply an inflammation caused by infection.

## Laparoscopy

This test involves a small operation done under a general anaesthetic and will mean a short stay in hospital. It allows the doctor to look at the upper part of the abdomen (tummy) from the inside. This is to see whether the cancer has spread into the abdomen.

The doctor makes a small cut (about 2cm) in the skin and muscle near the tummy button (navel) and carefully inserts a thin, flexible fibre-optic tube (laparoscope) into your abdomen. The doctor can then examine the area and may take samples of tissue (biopsies) to be examined under the microscope. Whether or not a laparoscopy is needed depends on the position of the tumour within the oesophagus.

#### PET scan

Positron emission tomography scans (PET scans) can be used to find whether the cancer has spread beyond the oesophagus, or to examine any lumps that remain after treatment to see whether they are scar tissue or whether cancer cells are still present.

A PET scan uses low-dose radioactive glucose (a type of sugar) to measure the activity of cells in different parts of the body. A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. A scan is then taken a couple of hours later. Areas of cancer are usually more active than surrounding tissue and show up on the scan.

PET scans are a new type of scan and you may have to travel to a specialist centre to have one. They are not always necessary but you can discuss with your doctor whether one would be useful in your case.

### Waiting for your test results

It will probably take from one to two weeks for the results of your tests to be ready, and a follow-up appointment should be arranged for you before you go home. This waiting period will be an anxious time for you and it may help to talk things over with the hospital's specialist nurse, a close friend, a relative.

# Staging of oesophageal cancer

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

A commonly used staging system for cancer of the oesophagus is described below:

Stage 0 or carcinoma in situ (CIS) – This is a very early stage of oesophageal cancer. There are cancer cells in the lining of the oesophagus, but they are contained entirely within the lining. Oesophageal cancer is not often diagnosed this early, as there are usually no symptoms at this stage.

Stage 1 – The cancer is found only in the surface layers of the lining of the oesophagus or in a small part of the oesophagus. It has not spread to nearby tissues, lymph nodes or other organs.

Stage 2 – This means that the cancer has either grown into the muscle layer of the oesophageal wall or spread to nearby lymph nodes, but has not spread to any other organs. If the cancer has not spread to nearby lymph nodes, it is stage 2A. If the cancer has spread to nearby lymph nodes, it is stage 2B.

Stage 3 – The cancer has grown through the wall of the oesophagus. It may also have spread to nearby lymph nodes and other body tissues close to the oesophagus, but there is no spread to other parts of the body.

Stage 4 – The cancer has spread to lymph nodes and other parts of the body, such as the liver, lungs or stomach and is known as secondary or metastatic cancer.

Your doctors may also describe your cancer using the TNM staging system.

- T describes the size of the tumour. There are five different stages ranging from T0–T4.
- N describes whether the cancer has spread to the lymph nodes. There are four stages depending upon the number of lymph nodes that are involved, ranging from N0–N3.
- M describes whether the cancer has spread to another part of the body, such as the liver or the lungs (secondary or metastatic cancer). There are two stages: M0 is where there are no metastases; M1 is where there are metastases.

The TNM staging system is more complex, and it can give more precise information about the stage of your tumour.

# Treating gullet cancer

# Treatment for oesophageal cancer

# **Treatment types**

Cancer of the oesophagus can be treated using surgery, chemotherapy or radiotherapy. The choice of treatment will depend upon the exact type of oesophageal cancer, its stage, position and size, as well as your age and general health. The treatments can be used alone or in combination. When diagnosing and treating cancer doctors consider the oesophagus in three sections: upper, middle and lower.

Other treatments may be used to ease any swallowing difficulties you may have. These include: intubation or stenting (inserting a tube into the oesophagus to keep it open), dilatation (stretching the oesophagus), laser treatment and photodynamic therapy. You may be offered one or more of these treatments, which are described in greater detail on the difficulty in swallowing section.

## Treatment planning

In most hospitals a team of specialists will discuss with you the treatment that they feel is best for your situation. This multidisciplinary team (MDT) will include a surgeon who specialises in oesophageal cancers, a medical oncologist (chemotherapy specialist), a clinical oncologist (radiotherapy specialist and chemotherapy specialist) and may include a number of other healthcare professionals such as a:

- nurse specialist
- dietitian

- physiotherapist
- occupational therapist
- psychologist or counsellor.

#### **Treatment choices**

If two treatments are equally effective for your type and stage of cancer, your doctors may offer you a choice of treatments. Sometimes people find it very hard to make a decision. If you are asked to make a choice, make sure that you have enough information about the different treatment options, what is involved and the side effects you might have, so that you can decide which is the right treatment for you.

# Talking about treatment

Remember to ask questions about any aspects that you don't understand or feel worried about. You may find it helpful to discuss the benefits and disadvantages of each option with your cancer specialist, nurse specialist or with our cancer support specialists.

If you have any questions about your treatment, don't be afraid to ask your doctor or nurse. It often helps to make a list of questions and to take a close friend or relative with you.

## Giving your consent

Before you have any treatment your doctor will explain the aims of the treatment to you and you will usually be asked to sign a form saying that you give your 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 have been given full information about:

- the type and extent of the treatment you are advised to have
- the advantages and disadvantages of the treatment
- any other treatments that may be available
- any significant risks or side effects of the treatment.

If you do not understand what you have been told, let the staff know straight away so that they can explain again. Some cancer treatments are complex, so it is not unusual for people to need their treatment to be explained more than once.

It is often a good idea to have a friend or relative with you when the treatment is explained, to help you remember the discussion more fully. You may also find it useful to write down a list of questions before you go for your appointment.

People often feel that the hospital staff are too busy to answer their questions, but it is important for you to be aware of how the treatment is likely to affect you and the staff should be willing to make time for you to ask questions.

If you feel unable to make a decision about the treatment when it is first explained to you, you can always ask for more time. You are also free to choose not to have the treatment, and the staff can explain what may happen if you do not have it.

## Benefits and disadvantages of treatment

Many people are frightened at the thought of having cancer treatments, particularly because of the potential side effects that can occur.

Although many of the treatments can cause side effects, knowledge about how treatments affect people – and improved ways of reducing or avoiding many of these problems – have made most of the treatments easier to cope with.

Treatment can be given for different reasons and the potential benefits will vary depending upon the individual situation.

#### Early-stage oesophageal cancer

In people with early-stage cancer of the oesophagus, treatment may be given with the aim of curing the cancer. Occasionally additional treatments are given to reduce the risk of it coming back.

#### Advanced-stage oesophageal cancer

If the cancer is at a more advanced stage, treatment may only be able to control it, leading to an improvement in symptoms and a better quality of life. Unfortunately, for some people the treatment will have little effect upon the cancer and they will get the side effects without many of the benefits.

### **Treatment decisions**

If you have been offered treatment that aims to cure your cancer, deciding whether or not to accept the treatment may be simple. However, if a cure is not possible and the treatment is being given to control the cancer for a period of time, it may be more difficult to decide whether or not 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 or not you wish to have treatment. If you choose not to, you can still be given supportive (palliative) care, with medicines to help control any symptoms.

# Second opinion

A number of cancer specialists work together as a team to decide the most suitable treatment for each person. Even so, you may want to have another medical opinion. Most doctors will be pleased to refer you to another specialist for a second opinion, if you feel that this will be helpful. The second opinion may cause a delay in the start of your treatment, so you and your doctor need to be confident that it will provide useful information.

If you go for a second opinion, it may be a good idea to take a friend or relative with you, and to have a list of questions ready, so that all your concerns are covered during the discussion.

# Surgery for oesophageal cancer

Your doctor will discuss with you the most appropriate type of surgery. This will depend on the size and position of the tumour, and whether or not it has spread. It is important to discuss any operation fully with your doctor before it happens. You may find it helpful to make a list of any questions you have ahead of the discussion.

Remember, no operation or procedure will be done without your consent. Some types of surgery may mean that you need to stay in hospital for a few weeks.

## The operation

The most common type of operation is where the section of the oesophagus containing the tumour is removed and the remaining length of oesophagus is re-attached to the stomach.

There are two main ways of doing this:

- Trans-thoracic oesophagectomy cuts are made in the abdomen and the chest so that the affected part of the oesophagus can be removed.
- Trans-hiatal oesophagectomy cuts are made in the abdomen and neck to remove the affected part of the oesophagus.

During these operations the top part of the stomach is often also removed. You will still be able to eat in the same way as before, but as the stomach will be higher than before (above the sheet of muscle which divides the chest from the abdomen instead of below) you will need to have smaller meals, more often. You may also find that you feel sick if you eat too quickly.

If it is not possible to join your stomach to the remaining part of the oesophagus, it may be possible to remove a section of your large bowel (colon) to replace the part of the oesophagus that has been removed. If your doctor suggests this type of surgery, they will explain in more detail what is involved.

During your operation the surgeon will check the area around the oesophagus. They will also remove some of the lymph nodes. This is called lymphadenectomy and is done because the nodes may contain cancer. The lymph nodes will be examined under a microscope. Removing them helps to reduce the risk of the cancer coming back as well as helping the doctors to know the stage of your cancer.

Occasionally, the surgeon discovers that the tumour cannot be removed, after a planned operation to remove the cancer has begun. This may be because the tumour has spread or gone through the wall of the oesophagus, or because many lymph nodes are affected. If this happens, the surgeon may insert a tube (stent) instead, to make eating and swallowing easier for you.

## After your operation

Most people will be nursed in the intensive care or high-dependency unit for a day or two. This is purely routine and does not mean your operation has gone badly or that there are complications. A machine called a ventilator may be used to help you to breathe – again, this is routine in some hospitals.

#### Pain

It is likely that you will have some pain and discomfort after the operation. You will be given regular painkillers, but should let your nurse or doctor know if you are still in pain. You may have your pain controlled using an epidural. This is a fine plastic tube that is inserted into the space around your spinal cord so that a drug can be given to numb the nerves. Your doctor or nurse will explain this procedure to you.

#### Drips and drains

A drip will be used to give you fluids until you are able to eat and drink again. You may also have a naso-gastric (NG) tube. This is a fine tube that passes down your nose into your stomach or small intestine and allows any fluids to be removed so that you don't feel sick. This helps the area of the operation to recover. You will have chest drains in place for a few days. These are tubes that are inserted into your chest during the operation to drain away any fluid that may have collected around the lungs. The fluid drains into a bottle beside your bed. The chest drains can be uncomfortable; if they are, let your doctor or nurse know.

A physiotherapist will help you to clear your lungs of any fluid that may have built up as a result of your operation.

After your operation, you will be encouraged to start moving around as soon as possible. This is an essential part of your recovery. Even if you have to stay in bed, it is important to do regular leg movements to prevent blood clots forming in your legs, and deep breathing exercises to help keep your lungs clear. A physiotherapist and the ward nurses will help you with this.

#### Eating and drinking

At first you will not be able to drink fluids, and will only be allowed sips of liquid, until your doctor is satisfied that the join in the oesophagus is healing. It will be a few days before you are able to drink. Some surgeons will put a small feeding tube directly into the small bowel during surgery so that you can be fed through this while you are not able to eat or drink. The tube is put into the middle part of the small bowel (the jejunum) through a small cut made in the wall of the abdomen (tummy). It is usually removed after you have begun to swallow again normally.

You may feel afraid to swallow for a short while and may have a bad taste in your mouth. Mouthwashes can help relieve the bad taste. Gradually, you will be able to eat and drink fairly normally again. It is likely, however, that you will lose quite a lot of weight in the first few weeks after your operation. Try not to worry about it – the weight loss is normal and should slow down once you begin eating well again. The weight loss does not mean that your cancer has come back – few people return to the weight they were before the operation.

You may also have some diarrhoea for a while after the operation, which can usually be controlled with medicine if it continues.

We have booklets on nutritional support and dietary problems after surgery.

#### At home

Before you leave hospital you will be given an appointment to attend an outpatient clinic for your post-operative check up. This will be a good time to discuss any problems you have after your operation. But remember, you can usually ring your hospital doctor, specialist nurse or ward nurse any time if you have problems.

# Radiotherapy for oesophageal cancer

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells, while doing as little harm as possible to normal cells. Radiotherapy is directed at specific parts of the body and may be given externally or internally.

## External radiotherapy

External radiotherapy may be given before or after surgery. Depending upon the circumstances, it may also be given at the same time as chemotherapy.

The treatment is given in the hospital radiotherapy department as short daily sessions from Monday to Friday, with a rest at the weekend. The length of your course of radiotherapy treatment will depend on the type and size of the cancer. Your doctor will discuss the treatment with you.

## Planning your treatment

Planning is a very important part of radiotherapy and makes sure that it is as effective as possible. On your first visit to the radiotherapy department you will be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated. The treatment is planned by a cancer specialist (clinical oncologist) and may take a few visits.

The radiographer (the person who gives you your treatment) will make small marks on your skin, to show where the rays are to be directed. During the course of treatment this area should be kept as dry as possible to prevent the skin becoming red and sore. Your radiographer will explain how to look after the area being treated.

#### **Treatment sessions**

Before each session of radiotherapy, the radiographer will position you carefully on the couch and make sure that you are comfortable. The treatment only takes a few minutes. You will be left alone in the room but will be able to talk to the radiographer, who will be watching you from the next room.

Radiotherapy is not painful, but you do have to lie still for a few minutes while your treatment is being given. The treatment will not make you radioactive, and it is perfectly safe for you to be with other people, including children, after your treatment.

# Side effects of external radiotherapy

Radiotherapy can cause general side effects such as feeling sick (nausea) and tiredness, but is also likely to make the inside of your gullet inflamed, causing short-term soreness when you swallow. It is not unusual to feel worse before things start to feel better.

Some people can find this a very difficult time and they may feel rather depressed for a while. These side effects can be mild or more troublesome, depending on the strength of the radiotherapy dose and the length of your treatment. The clinical oncologist will be able to advise you on what to expect.

#### Sore throat and difficulty swallowing

The radiotherapy may make your throat very sore towards the end of the treatment, and you may not be able to swallow properly for a while. Medicines are available that may help to relieve the discomfort caused by the sore throat. You may be advised to have a feeding tube put into your stomach (known as a PEG tube) before the radiotherapy starts. Your doctor can advise you whether or not this will be necessary.

PEG stands for percutaneous endoscopic gastrostomy and is carried out under local anaesthetic. A flexible tube with a light at the end (endoscope) is passed down the throat and oesophagus into the stomach, to find a suitable area to insert the tube. A cut is then made in the skin and muscle over the stomach and a tube passed through a cut made in the stomach itself. The tube is usually held in place with a rubber or silicon disk (flange). Liquid feeds can be given through the tube.

Our booklet on nutritional support discusses PEG tubes and feeding in detail.

#### Dry mouth

If the radiotherapy is given to the upper end of the oesophagus, it may reduce the amount of saliva your salivary glands produce. This effect may be temporary, but occasionally can be permanent. This may make your mouth dry, which can make eating difficult.

#### Feeling sick - reduced appetite

Feeling sick (nausea) can usually be treated by anti-sickness drugs (anti-emetics), which your doctor can prescribe. If you don't feel like eating, you can replace meals with nutritious, high-calorie drinks, which you can get from most chemists. Our booklet on diet and cancer has some helpful hints on how to eat well. You can discuss any problems with your doctor.

#### Hair loss

When radiotherapy is used to treat the oesophagus, men may find that some of the hair on their chest may fall out.

#### Tiredness

As radiotherapy can make you tired, you should try to get as much rest as you can, especially if you have to travel a long way for treatment each day.

All these side effects should disappear gradually once your course of treatment is over, but it is important to let your doctor know if they continue.

# Internal radiotherapy (brachytherapy)

This is given by inserting a radioactive metal rod, known as a source, into the oesophagus. It is left there for between 30 minutes and a couple of days, depending on the amount of radiation that is needed. In this way more focused treatment is given to the inside of the oesophagus in a short time, rather than a course of external radiation given to a wider area over a longer time.

There are two ways of giving this type of treatment:

- through an endoscope
- through a nasogastric (NG) tube.

#### Endoscope

Your doctor will put the radioactive source in the oesophagus using an endoscope – similar to the one used to diagnose oesophageal cancer. You will be given a sedative to make you feel sleepy so that the endoscope can be easily passed into your oesophagus. The radioactive source is contained within a tube that is placed next to the cancer. The endoscope is then removed. When the treatment is finished the doctor uses the endoscope to remove the tube containing the radioactive source.

#### Nasogastric tube

A nasogastric tube (or NG tube) is a thin flexible, plastic tube that goes up your nose, down the back of your throat and into your stomach. Having a nasogastric tube put in can be unpleasant but should not be painful. The NG tube contains the radioactive source, which can be placed close to the cancer. When the period of treatment is over, the NG tube is removed.

Once the radioactive source has been removed, there is no remaining radiation within your body.

# Side effects of internal radiotherapy

As with external radiotherapy, internal radiotherapy causes temporary soreness when you swallow, which may develop a few days after treatment and last for a few days. Your doctor will recommend liquid medicines to help you swallow and to soothe the soreness. Unlike external radiotherapy, this treatment does not cause tiredness or nausea and there is no hair loss.

If you have to stay in hospital for a few days while the radioactive source is in place, your family or close friends will only be able to visit you for short periods each day. It is not advisable to allow children or pregnant women to visit while you are having this type of radiotherapy. These precautions can make you feel isolated, but they only last for the few days that the radioactive source is in place. Once it has been removed the radioactivity disappears.

# Chemotherapy for oesophageal cancer

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. They work by disrupting the growth of the cells. Chemotherapy drugs that are commonly used to treat oesophageal cancer are fluorouracil (also known as 5FU), cisplatin and epirubicin. These drugs may be given together and are known as the ECF regimen.

A tablet form of 5FU called capecitabine (Xeloda®) is sometimes used in place of the intravenous (drip) 5FU. The combination is then known as the ECX regimen.

# When it is given

If you are able to have surgery to remove your oesophageal cancer, chemotherapy is often given before the operation to help to reduce the chance of the cancer coming back. It may also be given if your doctors think that the tumour is too large to be removed by surgery, as the chemotherapy can sometimes shrink the cancer and make it easier to remove. Chemotherapy given before an operation is known as neo-adjuvant chemotherapy.

Chemotherapy may also be given after surgery if it was not possible to remove all of the tumour during the operation, or if there is a high risk that it may come back. Chemotherapy given after surgery is known as adjuvant therapy.

Chemotherapy is sometimes given alongside radiotherapy (known as chemoradiation). It is mainly used for squamous cell cancer (but can be used for adenocarcinoma too). Giving chemotherapy at the same time as radiotherapy may improve the effectiveness of radiotherapy. However, giving the two treatments at the same time also increases the side effects.

If the cancer has spread to other parts of the body, chemotherapy may be used as the main treatment. This aims to shrink the tumour, improving symptoms and extending good-quality life. In some people the chemotherapy will achieve this. Unfortunately, for other people the chemotherapy will not shrink the cancer and they will have the side effects of the treatment with little benefit.

It is helpful to discuss with your cancer specialist the benefits and side effects of chemotherapy in your particular situation. If you have a cancer that has spread, and you decide that you do not want to have chemotherapy, your doctor can still prescribe medicines that may help to control symptoms caused by the cancer.

# How it is given

Before any chemotherapy is prescribed, you may need to have a test to check how well your kidneys are working (kidney function). This is because the dose of one of the chemotherapy drugs is decided according to your kidney function. This may involve just a blood test or you may be asked to collect all of your urine for 24 hours and to give a blood sample.

You may be asked to attend the hospital for an EDTA test, which is a specialised test that measures kidney function. An EDTA (ethylene diamine tetraacetic acid) test involves giving you an injection of a mildly radioactive liquid and taking two blood samples.

It is usual for chemotherapy treatment to consist of a combination of two or more drugs. These are often given by injection into a vein in your arm (intravenously). It may mean staying in hospital for a few days, or you may be able to be treated as a day patient. The treatment is generally repeated every three weeks, but in the three week interval while you are at home, one of the drugs – fluorouracil or 5FU – may be given continuously through a fine plastic tube (called a central line) put into a vein in your chest.

The central line is either stitched or taped firmly to your chest, and can be kept in the vein for many months. Sometimes, a tube may be put into a vein in the crook of your elbow instead of into the chest. This is known as a PICC line (peripherally inserted central catheter).

A small pump can be attached to the central line or PICC line to allow a continuous dose of one of the chemotherapy drugs to be given day and night, while you are at home. The pump can be carried round in a small bag, that is worn around the waist or over the shoulder.

Most of the chemotherapy drugs for oesophageal cancer are given by injection into a vein in your arm (intravenously) or through a central line or PICC line. Research is now in progress using a tablet called capecitabine (also known as Xeloda®), instead of giving fluorouracil through the central line.

#### Side effects

Chemotherapy drugs may cause unpleasant side effects, but these can usually be well controlled with medicines. Not all drugs cause the same side effects and some people may have very few side effects. Your doctor will tell you about any problems that your treatment may cause.

#### Lowered resistance to infection

While the drugs are acting on the cancer cells in your body, they also temporarily reduce the number of normal white cells in your blood. When these cells are reduced, you are more likely to get an infection and you may tire easily. Your blood will be tested regularly during chemotherapy and, if necessary, you may be given antibiotics to treat any infection.

If your temperature goes above 38°C (100.5°F), or you suddenly feel unwell, even with a normal temperature, you may have an infection. Contact your chemotherapy nurse or doctor at the hospital straight away.

#### Anaemia

If the level of red blood cells (haemoglobin) in your blood is low you will probably feel very tired and lethargic. You may also become breathless. These are all symptoms of anaemia – a lack of haemoglobin in the blood.

Anaemia can be very successfully treated by blood transfusions. These should help you to feel more energetic and ease the breathlessness.

#### Bruising and bleeding

Platelets are a type of blood cell which help to clot the blood. If the number of platelets in your blood is low you will bruise very easily and may bleed heavily from even minor cuts or grazes. If you develop any unexplained bruising or bleeding, contact your doctor or the hospital immediately.

Our information on platelet transfusions explains this in more detail.

#### Feeling sick

Some of the drugs used to treat oesophageal cancer can make you feel, or be, sick (nausea and vomiting), but there are very effective anti-sickness drugs (anti-emetics) to prevent this. It is helpful to avoid eating immediately before and after your chemotherapy. If the sickness is not controlled or continues, even with anti-sickness treatment, let your doctor know. They can prescribe other medicines that may be more effective.

#### Tiredness

Chemotherapy affects people in different ways. Some people find they are able to lead a fairly normal life during treatment, but many find they have to take things much more slowly. Tiredness can build up over a course of treatment, and if you have a lot of chemotherapy, it can last for several months or more after your treatment has finished. It is best to cope with tiredness by planning ahead. Try to fit in rest periods and don't do things that you don't need to do. Accept help from others when you need to. There may be times when you feel less tired. A little activity can sometimes help with the symptoms of fatigue.

#### Sore mouth and loss of appetite

Some chemotherapy drugs can make your mouth sore and cause small ulcers. It is important to rinse your mouth regularly to keep it clean. Using a child's soft toothbrush can be helpful. If you don't feel like eating during treatment, you could try replacing some meals with nutritious drinks or a soft diet.

Our booklet on eating well provides useful tips on coping with eating problems. Our information on mouth care during chemotherapy and diet in this section may be helpful.

#### Hair loss

Unfortunately, some chemotherapy drugs will make your hair fall out. If you lose your hair it will start to grow back within three to six months of finishing your treatment. People who lose their hair often cover up by wearing wigs, bandanas, hats or scarves. If you are being treated as an inpatient, or you are on income support, you can get a free wig from the NHS. If not, you can still get a subsidised wig from the hospital. Ask the team looking after you if a wig specialist is available to visit you. If your hair falls out it is important to protect your scalp from the sun.

#### Numbness or tingling in hands or feet

This is due to the effect of cisplatin on nerves and is known as peripheral neuropathy. Tell your doctor if you notice these symptoms. This problem usually improves slowly over a few months after the treatment is over

#### Diarrhoea

Some of the chemotherapy drugs used to treat oesophageal cancer can cause diarrhoea. This often starts several days after the chemotherapy. If you are taking chemotherapy tablets at home it is important to tell your doctor if you have diarrhoea more than 4–6 times a day, as your treatment may need to be stopped.

Your doctor can give you medicine to help slow down and stop the diarrhoea. It may help to follow a low-fibre diet if you can. It is important to drink plenty of fluids if you have diarrhoea.

#### Sore hands and feet

Soreness of the palms of the hands or soles of the feet can occur when 5FU or capecitabine are given over a long period of time, or when they are given continuously through a pump. It is known as palmar-plantar syndrome. A vitamin can be prescribed to help control this side effect and simple moisturising creams can often help to relieve symptoms.

Chemotherapy affects people in different ways. Some find they are able to lead a fairly normal life during their treatment, but many find they become very tired and have to take things much more slowly. Just do as much as you feel like and try not to overdo it.

Our booklet on chemotherapy discusses this treatment and its side effects in more detail.

# Research - clinical trials for oesophageal cancer

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.

Clinical trials may be carried out to:

- test new treatments, such as new chemotherapy drugs, gene therapy or cancer vaccines
- look at new combinations of existing treatments, or change the way they are given, in order to make them more effective or to reduce side effects
- compare the effectiveness of drugs used for symptom control
- find out how cancer treatments work
- see which treatments are the most cost-effective.

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

# Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits in doing this. Trials help to improve knowledge about cancer and develop new treatments. You will also be carefully monitored during and after the study. Usually, several hospitals around the country take part in these trials. It is 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.

## Blood and tumour samples

Many blood samples and bone marrow or tumour biopsies may be taken to find out what is wrong with you. You may be asked for your permission to use some of your samples for research into cancer. Some samples may be frozen and stored for future use, when new research techniques become available.

The research may be carried out at the hospital where you are treated, or it may take place at another hospital. This type of research takes a long time, so you are unlikely to hear the results. The samples will, however, be used to increase knowledge about the causes of cancer and its treatment. This research will, hopefully, improve the outlook for future patients.

# Living with gullet cancer

# Relieving difficulty in swallowing when you have oesophageal cancer

If you find swallowing difficult there is much that can be done to help make it easier. Your doctor may suggest one or more of the following treatments:

# Stretching (dilatation)

This involves the doctor stretching the oesophagus, using a tube to enlarge the space for food and fluid to pass through. Stretching is also often done after radiotherapy or surgery and you may need to have the procedure repeated. It is a simple and quick procedure, which may be carried out under general or local anaesthesia.

## Intubation or stenting

A plastic or wire mesh tube (a stent) can be put into the oesophagus using an endoscope. The procedure is similar to oesophagoscopy. The tube helps to keep the oesophagus open and should enable you to eat more comfortably. It is important to take care with your diet to ensure the tube does not become blocked. Drinking fizzy drinks after eating will help to keep the tube clean and clear. Information on diet is available from the Oesophageal Patients Association.

## Laser treatment

Laser treatment can sometimes be used to remove enough of the tumour to allow food to pass down the oesophagus. This treatment can sometimes be given with a local anaesthetic, in which case you go home the same day. The procedure may be done under sedation and occasionally a general anaesthetic. It is carried out using an endoscope so is similar to having the oesophagoscopy. The procedure takes about 15 minutes.

It may take two or three sessions of laser treatment to clear your oesophagus enough for you to be able to swallow normally. Further treatments may be needed after 4–6 weeks. You are unlikely to feel any pain after the procedure; although there may be some temporary swelling in your oesophagus, which may make swallowing more difficult at first. You may also have some discomfort in your abdomen. If you have any pain, tell your doctor or nurse.

## Alcohol injection

Alcohol injection aims to shrink enough of the tumour to allow food to pass down the oesophagus. Using an endoscope the tumour is injected with small amounts of ethanol alcohol. This usually makes it easier for people to swallow, though it can take a few days to work.

## Photodynamic therapy

Photodynamic therapy (PDT) uses low-powered lasers combined with a light-sensitive drug to destroy cancer cells. In the UK it is only carried out in a few specialist hospitals.

Photodynamic therapy is given in two stages. First you will be given a drug that makes the cells of the cancer more sensitive to light (a photosensitiser). This is usually given as an injection into a vein in your arm (intravenously). For the second part of the treatment a laser is shone onto the cancer, using an endoscope. The laser activates the photosensitiser to destroy the cancer cells.

The treatment will make you sensitive to light and you will need to take precautions to avoid exposure to sunlight for a few days. PDT may also make the area in the oesophagus become temporarily inflamed and swell up. At first, this can make swallowing more difficult.

Although PDT is an established treatment to relieve the difficulty in swallowing caused by oesophageal cancer it is not widely used as a 'first line' treatment. However, in December 2006, The National Institute for Health and Clinical Excellence (NICE) produced guidance for doctors on PDT as a treatment for early (stage one) oesophageal cancer. It was thought that PDT might be a possible alternative to surgery for some people.

The guidance says that more evidence is needed before we can really know how effective PDT is for early oesophageal cancer. We don't yet know enough about how well it works and how it compares in the long-term with surgery. In the meantime, doctors may offer PDT for stage one cancer as long as they discuss the possible risks and benefits with people. NICE suggests that doctors use PDT within research trials if possible and also make sure that patients are followed up to check their progress.

# Advice on diet for people affected by oesophageal cancer

While you are waiting for treatment it is important to eat well, using food supplements if necessary. You may be able to see a hospital dietitian for advice at the time of diagnosis and

after surgery. If you are unable to swallow at all, you should let the hospital know immediately.

If you have had surgery that has not removed a major part of your stomach, you can start to eat as soon as your doctor says you can. You will usually start with a soft diet while you are still in hospital, and will often be advised to remain on this for a few weeks. This will naturally exercise the surgical join and help keep the passage open as it heals.

Gradually you will be able to start eating solid foods again, as long as there are no large lumps and you chew the food well. You may feel rather worried about eating solid foods at first but this will lessen as you become more used to a normal diet again. Your doctor or specialist nurse can give you further advice about this. Some people may have an allergic reaction to milk for a while.

When you eat, acidic liquid flows into the stomach to help digest the food. This can cause an uncomfortable feeling of indigestion because of the new position of your stomach.

If you have had part of your stomach removed, you will find that you feel full very quickly because your stomach will be smaller. To help prevent these problems, eat little and often rather than trying to eat large meals. It can also help to chew food well and eat slowly.

Bouts of diarrhoea are fairly common after any operation for cancer of the oesophagus. From time to time you may need to cut out some foods, such as fruit, vegetables, cereals and reduce the amount of milk you drink (or eat in food) to help deal with this problem.

If you have had radiotherapy, or a tube fitted in your oesophagus, you will probably need a softer diet. Avoid foods which may block the tube or which you may have difficulty in swallowing; such as raw fruit and vegetables, tough meat or crusty bread. Complan® and any powdered food supplement must be very thoroughly mixed. It is also a good idea to eat slowly and to have plenty to drink during and after meals.

# After treatment for oesophageal cancer

After your treatment is completed, you will have regular check-ups and possibly scans. You will probably continue to have these for several years. Many people find that they get very anxious for a while before the appointments. This is natural and it may help to get support from family, friends or a support organisation.

These appointments are a good opportunity to discuss with your doctor any concerns or problems you may have. If you notice any new symptoms between check-ups, or are anxious about anything, contact your doctor or specialist nurse for advice.

After your treatment you may find that you feel more tired than usual and have a poor appetite. You are quite likely to feel very full; even after eating just small amounts. It can take several months to feel better after treatment and up to a year to adjust to the changes in your digestive system. It may be many months before you are able to eat a more normalsized meal and the diarrhoea stops. If you find you have difficulties with swallowing again after treatment it does not necessarily mean that the cancer is coming back; it can be caused by the treatment itself. Your doctor may suggest dilatation to deal with this problem. For people whose treatment is over apart from regular check-ups, our booklet on adjusting to life after cancer treatment gives useful advice on how to keep healthy and adjust to life after cancer.

#### Work

It can be hard to judge the best time to go back to work. Your decision if and when to go back is likely to depend mainly on the type of work that you do and whether or not your income is affected. It is important to do what is right for you.

Getting back into your normal routine can be very helpful and you may want to return to work as soon as possible. Many people find that going back to work as soon as they feel strong enough gives them an opportunity to forget their worries, as they become involved with their job and colleagues again. Talk to your employer about your situation – it may be possible for you to work part-time or job share.

On the other hand it can take a long time to recover fully from treatment for oesophageal cancer, and it may be many months before you feel ready to return to work. Do not feel pressurised into taking on too much, too soon.

Your consultant or GP will be able to help you decide when and if you should return to work.

# Living with and after cancer

# **Emotional effects**

Information on the emotions you might experience as a result of your cancer diagnosis, ways that you might manage them and other sources of support.

## Relationships and communication

Advice on how to talk to other people, talking to children, relationships and sexuality

Note: JASCAP has booklets on the above subjects.

# Questions you might like to ask your doctor or surgeon

You can fill this in before you see the doctor or surgeon, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1.	 
Answer	
2.	 
Answer	 
3.	 
Answer	 
4.	 
Answer	 
5.	 
Answer	 

# JASCAP : We need your help

We hope that you found this booklet useful.

To help other patients and their families we need and intend to extend our Patient Information Services in many ways.

Our Trust depends on voluntary donations. Please send your donation by Cheque or D/D payable in Mumbai in favour of "JASCAP".

#### Note for Reader

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## JASCAP

JEET ASSOCIATION FOR SUPPORT TO CANCER PATIENTS, C/O ABHAY BHAGAT & CO., OFFICE NO.4, "SHILPA", 7<sup>TH</sup>. ROAD, PRABHAT COLONY, SANTACRUZ (East), MUMBAI - 400 055. PHONE: 91-22-2617 7543 & 91-22-2616 0007 FAX: 91-22-2618 6162, e-mails: pkrjascap@gmail.com, abhay@abhaybhagat.com

- AHMEDABAD: MR. D.K.GOSWAMY, 1002, LABH, SHUKAN TOWER, NEAR JUDGES' BUNGALOWS, AHMEDABAD - 380 015. PHONE : 91-79-6522 4287. Mob : 93270 10529 e-mail : dkgoswamy@sify.com
- BANGALORE: MS. SUPRIYA GOPI, 455, I CROSS, HAL III STAGE, BANGALORE – 560 075 PHONE : 91-80-2528 0309 . e-mail : supriyakgopi@yahoo.co.in
- HYDERABAD: MS. SUCHITA DINAKER & DR. M. DINAKER, M.D., FLAT NO. G4, 1<sup>ST</sup>. FLOOR, "STERLING ELEGANZA", STREET NO.5, NEHRUNAGAR, SECUNDERABAD – 500 026. PHONE : 91-40-2780 7295. e-mail : suchitadinaker@yahoo.co.in