

# **Pancreatic Cancer**

*J A S C A P*

**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**

JASCAP is a charitable trust that provides information on various aspects of cancer. This can help the patient and his family to understand the disease and its treatment and thus cope with it better.

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**Contact: Mr. Prabhakar K. Rao or Mrs. Neera P. Rao**

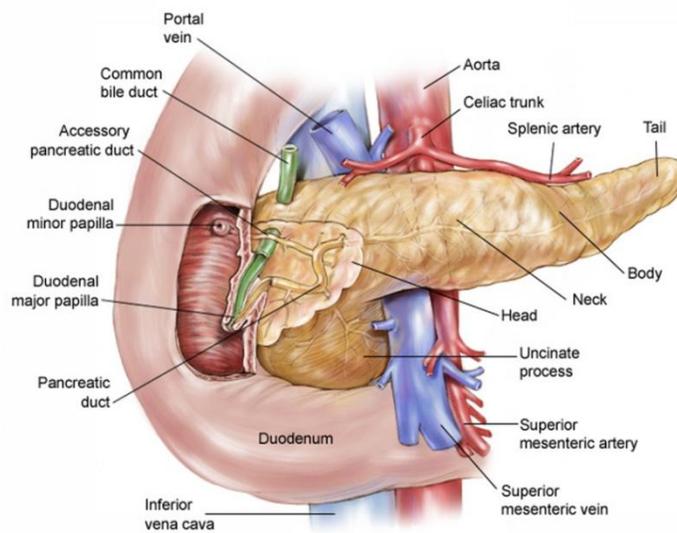
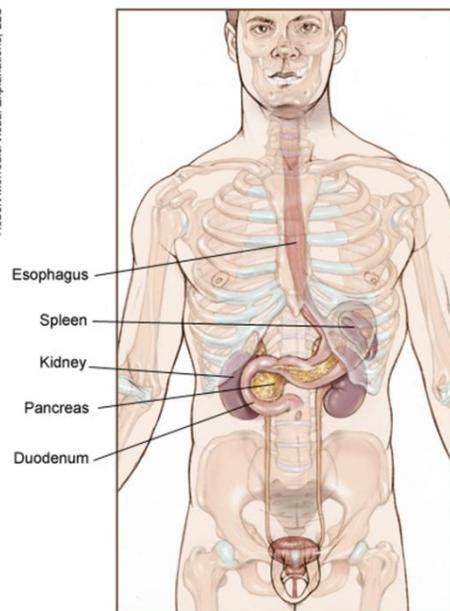
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# Pancreatic Cancer

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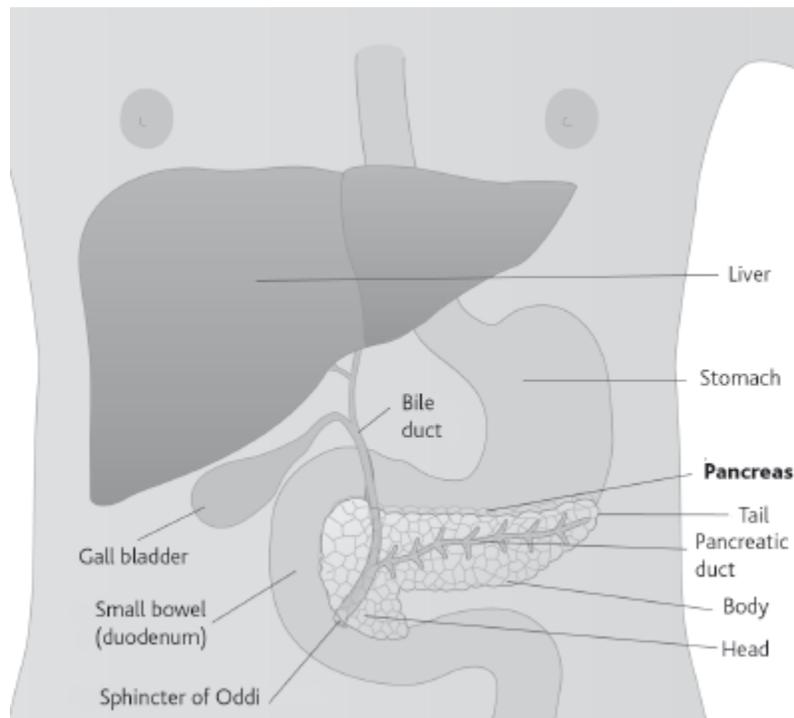
## The pancreas

The pancreas is part of the digestive system. It lies in the upper half of the abdomen, well above the tummy button (navel), on a level with the V where the ribs meet at the front. It's deep inside the abdomen, lying just in front of the spine. It is about 15cm (6 inches) long.

The large rounded section on the right-hand side of the body is called the head of the pancreas, the middle part is known as the body of the pancreas and the narrow part on the left-hand side of the body is called the tail of the pancreas. The head of the pancreas lies next to the first part of the small intestine, which is called the **duodenum**.

### *The position of the pancreas*

The pancreas produces a fluid which helps to digest food (pancreatic juice) and a hormone which enables the body to use sugars and store fats (**insulin**). The digestive juices produced by the pancreas flow down a tube (the pancreatic duct) into the duodenum. The bile duct drains bile from the liver, into the duodenum, and joins the pancreatic duct at the **sphincter of Oddi** just as it enters the duodenum.

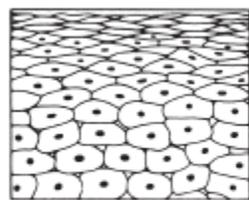


The position of the pancreas

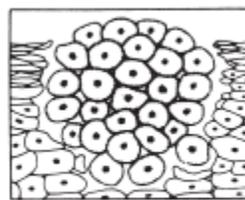
## What is cancer?

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**.



Normal cells



Cells forming 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.

## Risk factors and causes of pancreatic cancer

Pancreatic cancer is not a common type of cancer and affects 7000 people in the UK each year. Although the cause of pancreatic cancer is unknown, research into this is ongoing all the time. Like other cancers, cancer of the pancreas isn't infectious and can't be passed on to other people.

There are a number of factors that can increase your risk of developing pancreatic cancer. These are:

### ***Age***

Pancreatic cancer occurs mainly in people aged between 60 and 80 and is rare below the age of 50. About 6 in 10 are diagnosed in people over 70. Some of the rarer types, such as neuroendocrine and papillary cancer (see types), may affect people in their 20s and 30s.

### ***Smoking***

People who smoke are more at risk of developing cancer of the pancreas. Up to a third of all pancreatic cancers may be linked to smoking. People who chew tobacco are also at an increased risk.

### ***Inflammation of the pancreas***

People who have chronic pancreatitis – where the pancreas becomes inflamed – are more likely to develop pancreatic cancer. One of the main causes of chronic pancreatitis is drinking large amounts of alcohol over long periods of time. However, other types of pancreatitis are more likely to cause cancer (see section below on inherited faulty genes).

### ***Diet***

A diet that contains large amounts of fat, sugar, red or processed meat may increase your risk of developing pancreatic cancer. Your risk may also be increased if you don't eat many fresh fruit and vegetables.

### ***Diabetes***

There may be a small increase in the risk of developing cancer of the pancreas if you have diabetes. However diabetes is very common and the vast majority of people with it won't develop pancreatic cancer.

### ***Inherited faulty genes***

Most cancers of the pancreas are not caused by an inherited faulty gene, and so members of your family are very unlikely to be at an increased risk of pancreatic cancer because you have it.

Some people who have the faulty breast cancer genes BRCA1 or BRCA2, or the bowel conditions FAP (familial adenomatous polyposis) or HNPCC (hereditary non-polyposis colorectal cancer), have a higher risk of developing pancreatic cancer.

There is a rare inherited condition called hereditary pancreatitis, where family members develop pancreatitis because of a faulty gene. People with this condition have an increased risk of developing pancreatic cancer.

Members of families with a tendency to have large numbers of unusual moles (Familial Atypical Multiple Mole Melanoma – FAMMM), also have an increased risk of cancer of the pancreas.

The genetic changes which cause these cases of pancreatic cancer have not yet been found, and so currently there is no genetic test available for pancreatic cancer.

## How common is the Pancreatic Cancer in India?

Pancreatic cancer is one of the rare cancers diagnosed in India. The incidence (newly diagnosed cases of Cancer in a year) of Pancreatic cancer for men and women from the Indian subcontinent is about 1 person per 1,00,000 population<sup>1</sup>.

In India, between the years 2001-2003, across five urban centers - Mumbai, Delhi, Chennai, Bhopal and Bangalore, – and one rural center - Barshi, a total of 728 cases of Pancreatic cancer were registered (1.65% of all cancers) for males across all age groups; while 466 cases of Pancreatic cancer were registered (1.05% of all cancers) for females across all age groups. Considering all men, women and children with all types of cancers together, a grand total of 1,194 cases of Pancreatic cancer (1.35% of all cancers) were registered at the six centers mentioned above, between the year 2001-2003<sup>2</sup>.

The TATA Memorial Hospital (T.M.H.) in Mumbai, India registered a grand-total of 19,127 cases of all types of cancer patients in the year 2006 for men, women and children combined, out of which 133 (0.7% of the total cases) were diagnosed with the Pancreatic cancer. Out of the total 133 patients diagnosed with Pancreatic cancer, mentioned above at the T.M.H., 90 (68%) were males and 43 (32%) were females<sup>3</sup>.

## Types of pancreatic cancer

Cancers of the pancreas are divided into groups according to their position within the pancreas and the type of cell that the cancer has started from.

Between 7 and 8 out of 10 of all pancreatic cancers occur in the head of the pancreas (see diagram of the pancreas).

Nearly all pancreatic cancers start from the cells in the inner lining of the pancreatic ducts. These are the channels through which the digestive juices produced by the pancreas flow out into the small bowel. This type of cancer is called **adenocarcinoma**.

There are other very rare tumours that can affect the pancreas. These include:

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<sup>1</sup> Globocan 2008: Cancer incidence and mortality rates worldwide

<sup>2</sup> Population based cancer registry 2001-2003 Mumbai, Delhi, Chennai, Bhopal, Barshi and Bangalore, Indian Cancer Society.

<sup>3</sup> TATA Memorial Hospital Registry Data for 2006

a group of conditions called neuroendocrine tumours, which produce hormones

a type of lymphoma – a cancer arising from lymphatic tissue in the pancreas

pancreatic sarcoma, which develops in the tissue that holds together the cells of the pancreas.

## Symptoms and Diagnosis

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### Symptoms of pancreatic cancer

Pancreatic cancer may not cause any symptoms for a long time, and symptoms may be vague to begin with. The most common symptoms caused by cancer of the pancreas are described below. Some people may have only one of these symptoms.

#### ***Pain***

This often begins with discomfort or pain in the upper abdomen, which sometimes spreads to the back. In the beginning the pain may come and go, but later on it can be more persistent. In some people the pain is worse while lying down and it's relieved by sitting up or bending forward

#### ***Weight loss***

It's common for people with pancreatic cancer to have some weight loss and loss of appetite.

#### ***Jaundice***

This is yellowing of the skin and the whites of the eyes, itchy skin, dark yellow urine, and pale bowel motions. It can be caused by different illnesses including cancer of the pancreas. Jaundice can occur if the cancer develops in the head of the pancreas, and blocks the bile duct that carries bile from the liver to the intestine. The resulting build-up of bile in the body causes the symptoms mentioned above.

#### **Other symptoms include:**

- indigestion
- sickness
- bloating after meals
- feeling extremely tired.

**Remember, most pain in the abdomen is not caused by cancer of the pancreas. However, you can arrange to see your doctor if you are worried.**

### How pancreatic cancer is diagnosed

Usually people begin by seeing their GP when they develop symptoms. It can be difficult for a GP to diagnose pancreatic cancer as the symptoms may be vague and can be

caused by other conditions. However, your GP will normally look at your eyes and the colour of your skin to detect any jaundice, test your urine for bile and take a blood sample if needed. Your doctor may also examine your abdomen to feel for any swelling in the area of the liver. After this, further tests or x-rays may be arranged.

Your GP will refer you to hospital for these tests and for specialist advice and treatment.

At the hospital, the specialist will ask you about your general health and any previous medical problems, before examining you. You may have a blood test and a chest x-ray to check your general health.

## **Further tests for pancreatic cancer**

To help make the diagnosis, you'll probably have a number of tests. After a diagnosis is made, more tests may be needed to find out about the size and position of the cancer, and whether it has spread to other parts of the body. The results will help your doctor to decide on the best treatment for you.

While tests are useful, no one test can tell the whole story. Even the most modern scans can't always pick up tiny areas of cancer. Occasionally, other medical conditions can cause similar results, making it difficult to decide what is and is not cancer. Doctors often have to piece together information from different tests and examinations, along with your symptoms and medical history, and then put all this information in context.

Usually, only tests that give the most helpful information about the illness are used. The following tests are often used to diagnose cancer of the pancreas:

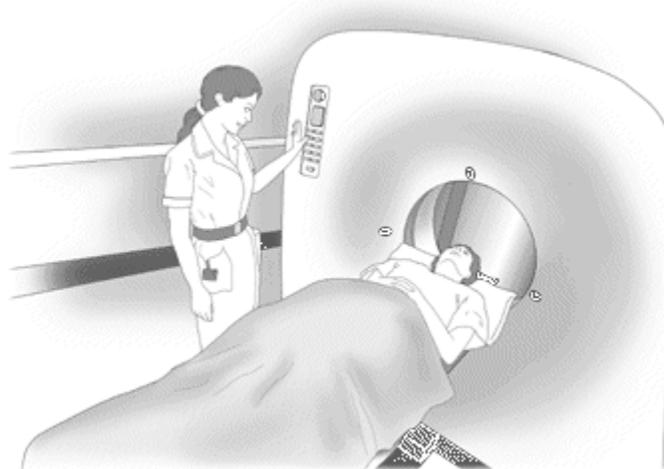
- Blood tests
- CT scan
- Ultrasound scan
- MRI scan
- ERCP
- EUS (endoscopic ultrasound)
- Biopsy
- Laparoscopy
- Waiting for your test results

### ***Blood tests***

Many cancers of the pancreas produce a substance called CA 19-9, which can be measured in the blood. CA 19-9 is known as a tumour marker. Measuring the level of CA 19-9 in the blood can help to diagnose a cancer of the pancreas, and also to see how it responds to treatment. This test is not enough on its own to make a diagnosis, and needs to be used alongside other tests such as scans.

### ***CT scan***

A CT (computerised tomography) scan takes a series of x-rays which builds up a three-dimensional 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 is very unlikely to harm you and will not harm anyone you come into contact with. You'll be asked not to eat or drink for at least four hours before the scan.



Having a CT scan

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

CT scans can be used to guide a biopsy, in which a small amount of tissue is taken for examination under a microscope. You'll be told if this is planned.

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

### ***Ultrasound scan***

Ultrasound uses sound waves to look at internal organs, such as the pancreas and the liver. You'll usually be asked not to eat or drink anything for at least six hours before the test.

Once you are lying comfortably on your back, a gel is spread on to the area to be scanned. A small device that produces sound waves is passed over the area. The sound waves are then converted into a picture by a computer. This test only takes a few minutes.

As with CT scans, an ultrasound can be used to guide a biopsy, in which tissue is taken for examination under a microscope.

### ***MRI scan***

An MRI (magnetic resonance imaging) scan is similar to a CT scan, but uses magnetic fields instead of x-rays to build up a series of cross-sectional pictures of the body.

During the test you will be asked to lie very still on a couch inside a metal cylinder that's open at both ends. The whole test may take up to an hour and is painless – although the machine is very noisy. You'll be given earplugs or headphones to wear.

The cylinder is a very powerful magnet, so before going into the room you should remove all metal belongings including jewellery. You should also tell your doctor if you have ever worked with metal or in the metal industry or if you have any metal inside your body (for example, a cardiac monitor, pacemaker, surgical clips, or bone pins). You may not be able to have an MRI because of the magnetic fields.

Some people are given an injection of dye into a vein in the arm, but this usually does not cause any discomfort.

You may feel claustrophobic inside the cylinder, but you may be able to take someone with you into the room to keep you company. It may also help to mention to the staff beforehand if you do not like enclosed spaces. They can then offer extra support during your test.

### ***ERCP***

ERCP (endoscopic retrograde cholangio pancreatography) enables the doctor to take an x-ray picture of the pancreatic duct and the bile duct. The bile duct can be unblocked during this procedure if necessary.

Before the test, you will be asked not to eat or drink anything for about six hours so that the stomach and small bowel (duodenum) are empty. You will be given an injection to help you to relax and some local anaesthetic will be sprayed on to the back of your throat. The doctor will then pass a thin, flexible tube, known as an endoscope, into your mouth, through your stomach and into the duodenum.

Looking down the endoscope, the doctor can find the opening where the bile duct and the pancreatic duct drain into the duodenum. A dye that can be seen on x-ray is then injected into these ducts to show up any abnormalities or any blockage of the duct.

You'll usually be given an injection of antibiotics before the test, to prevent any infection.

Most people are ready to go home a couple of hours after their test. It's a good idea to arrange for someone to collect you from the hospital as you shouldn't drive for several hours after a sedative.

### ***EUS (endoscopic ultrasound)***

A newer test that is sometimes used instead of an ERCP, is an endoscopic ultrasound (EUS). This is a similar procedure to an ERCP, but involves an ultrasound probe being passed down the endoscope, to take an ultrasound scan of the pancreas and surrounding organs. Ultrasound uses high-frequency sound waves to build up a picture. Biopsies can also be taken during an EUS.

### ***Biopsy***

If your doctor strongly suspects that you have cancer of the pancreas, they'll usually suggest that you have a biopsy to confirm the diagnosis. This involves removing some cells or a small piece of tissue, from the tumour, to be looked at under a microscope.

A biopsy can be taken in a number of ways. It may be possible to insert a needle through the skin of the abdomen to take a small piece of tissue, using an ultrasound or CT scan for guidance. You'll be given an injection of local anaesthetic to numb the area so that you feel little or no pain from the insertion of the needle.

Another way is to take some cells during an ERCP or an EUS.

### ***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 area of the pancreas and see whether an operation will be possible.

The doctor makes a small cut (about 2cm/1inch) in the skin and muscle near the navel and carefully inserts a thin, fibre-optic tube (laparoscope) into your abdomen. The doctor can then examine the area and take a sample of tissue (biopsy) for examination under the microscope. Sometimes gas is pumped into the abdomen to make it easier for the doctor to see the pancreas. The gas will not harm you and it will gradually disappear after the laparoscopy.

If the above tests do not give a definite diagnosis, an operation to look inside the abdomen (called a laparotomy) may be done under a general anaesthetic. It's rare for a laparotomy to be needed as most people can have a laparoscopy.

ERCP, biopsy and laparoscopy can cause problems for some people. Your specialist should discuss any possible risks with you before you have any of these procedures.

### ***Waiting for your test results***

It will probably take several days for the results of your tests to be ready and this waiting period will obviously be an anxious time for you. It may help if you can talk things over with a relative or close friend. You may wish to ring our information service or another support organisation for emotional support.

## Staging of pancreatic cancer

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

Generally, pancreatic cancer is divided into four stages: small and localised (stage one); spread into surrounding structures (stages two or three); or spread into other parts of the body (stage four). If the cancer has spread to distant parts of the body this is known as secondary cancer (or metastatic cancer).

A commonly used staging system is described below.

**Stage 1** This is the earliest stage. The cancer can only be found inside the pancreas itself, although it may be quite large. There is no cancer in the lymph nodes close to the pancreas and no sign that it has spread to anywhere else in the body.

**Stage 2** The cancer has started to grow into the duodenum or bile duct, or other tissues or organs close to the pancreas. There is no cancer in the nearby lymph nodes.

**Stage 3** The cancer can be any size and may have spread into the tissues surrounding the pancreas.

**Stage 4** These cancers are divided into 4A and 4B.

**4A** means the cancer has grown into organs close to the pancreas, such as the stomach, spleen, large bowel or large blood vessels nearby. Cancer may or may not be present in the lymph nodes.

**4B** means the cancer has spread to other body organs such as the liver or lungs.

### ***TNM staging system***

Another staging system known as the TNM system is commonly used. This can give more precise information about the extent of the cancer.

**T** describes the size of the tumour.

**N** describes whether the cancer has spread to the lymph nodes.

**M** describes whether the cancer has spread to another part of the body (secondary or metastatic cancer).

## Treatment for pancreatic cancer

Types of treatment  
Benefits and disadvantages  
Treatment decisions  
Giving your consent

## Second opinion

### ***Types of treatment***

The type of treatment you will be offered depends on the particular type of cancer of the pancreas you have, the stage of the cancer, its size, and your general health. The treatment will be planned by a team of specialist doctors and other healthcare professionals. This is known as a multidisciplinary team (MDT), and may include:

- a surgeon who specialises in treating cancer of the pancreas
- a clinical oncologist – a doctor who treats cancer with radiotherapy
- a medical oncologist – a doctor who treats cancer with chemotherapy
- a pathologist – a doctor who specialises in how disease affects the body
- a radiologist – a doctor who analyses x-rays and scans
- a specialist nurse who gives information and support to people with pancreatic cancer.

The MDT may also include other healthcare professionals, such as:

- a dietitian
- a physiotherapist
- an occupational therapist
- a psychologist or counsellor.

Many pancreatic cancers are not diagnosed until the cancer is quite advanced. Cancer of the pancreas can be very difficult to treat. It may not be possible to cure it, although early-stage cancer can sometimes be cured with surgery.

The most effective treatment for early-stage cancer of the pancreas is surgery to remove part, or all, of the pancreas. This is a major operation and is only suitable for people whose cancers are small and have not spread, and who are fit. If the cancer is too large, or has already spread beyond the pancreas when it's diagnosed, this kind of surgery is not possible. Learning that your cancer has spread, and therefore that certain treatments are not suitable for you, is distressing news to cope with. Your doctor will advise you about the treatments that are most likely to help in your situation.

If the cancer has spread and is causing a blockage of the bile duct or the bowel, surgery can sometimes be used to relieve the blockage and ease the symptoms.

Chemotherapy can be used in a number of different ways. It may be used after surgery for early-stage pancreatic cancer to try to reduce the chances of the cancer coming back. It can also be used to shrink cancers that have spread into the area around the pancreas, or to treat cancers that have spread to other parts of the body, such as the liver. For cancers that have not spread beyond the pancreas but can't be removed by an operation, chemotherapy and radiotherapy may be given separately or together. Sometimes you may be asked to take part in a clinical trial of a new drug or treatment.

Chemotherapy may also be given to help reduce some of the symptoms of pancreatic cancer. Radiotherapy can be helpful in controlling pain.

An important part of the care of all people with pancreatic cancer is the use of treatments to control symptoms and make you feel more comfortable, known as supportive care.

### ***Benefits and disadvantages***

Many people are frightened at the idea of having cancer treatments, because of the side effects that can occur. Some people ask what would happen if they did not have any treatment.

Although many of the treatments can cause side effects, these can usually be well controlled with medicines. Treatment can be given for different reasons, and the potential benefits will vary depending upon each person's situation.

### **Early-stage pancreatic cancer**

In people with early-stage pancreatic cancer, surgery is often done with the aim of curing the cancer. Additional treatments such as chemotherapy may also be given to reduce the risks of it coming back.

### **Advanced pancreatic cancer (metastatic)**

If the cancer is at a more advanced stage, the treatment may only be able to control it, leading to an improvement in symptoms and a better quality of life. However, for some people, the treatment will have no effect upon the cancer and they will get the side effects without any of the benefits.

### ***Treatment decisions***

If you have been offered treatment with the aim of curing your cancer, deciding whether to accept the treatment may not be difficult. 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 to go ahead with treatment.

Making decisions about treatment in these circumstances is always difficult, and you may need to discuss the possible treatment options in detail with your cancer specialist. Many people find it helpful to have a relative or friend with you.

### ***Giving your consent***

Before you have any treatment, your doctor will explain the aims of the treatment to you. They will usually ask you 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. 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 types of treatments that may be appropriate
- 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 very complex, so it's not unusual for people to need repeated explanations.

It's 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 to your appointment.

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

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

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

### ***Second opinion***

Usually a number of cancer specialists work together as a team. They will use national treatment guidelines to decide on the most suitable treatment for you. Even so, you may want to have another medical opinion. Either your specialist, or your GP, will be willing to refer you to another specialist for a second opinion, if you feel it 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 give you useful information.

If you do go for a second opinion, it may be a good idea to take a friend or relative with you. It can also help if you have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

## **Surgery for pancreatic cancer**

- Removal of the cancer (resection)
- After your operation
- Bypass surgery

### ***Removal of the cancer (resection)***

Occasionally, it's possible to remove all of the cancer with surgery. This is a major operation, only suitable for people with early-stage pancreatic cancer. This type of surgery should be done by specialist surgeons who are trained and experienced in pancreatic surgery, so you may need to be referred to a specialist centre to have this

type of treatment. It is important to discuss the benefits and the risks with your surgeon before making the decision to go ahead with any surgery.

Depending on where the cancer is, and how much of the pancreas is involved, all, or part of the pancreas may need to be removed during surgery.

Removal of the whole pancreas is called **pancreatectomy**

Removal of the lower end (body and tail) of the pancreas is called **distal pancreatectomy**

Removal of the head of the pancreas, the lower end of the stomach, most of the duodenum (the first part of the small bowel), the common bile duct, gall bladder and the surrounding lymph nodes is called a **pancreatoduodenectomy** or a **Whipple's operation**.

A Whipple's operation in which the lower end of the stomach is not removed is called a **pylorus-preserving pancreatoduodenectomy** (PPPD).

Your specialist may suggest that you have a laparoscopy to see which type of surgery is possible in your case.

Occasionally, even if the cancer can't be completely removed, the surgeon may remove some of the cancer (a partial resection) to reduce symptoms and control the cancer for a while.

### ***After your operation***

After your operation, you may stay in an intensive care ward for the first couple of days. You will then be moved to a general ward. You'll be encouraged to start moving around as soon as possible. This is an essential part of your recovery, and even if you have to stay in bed it's important to do regular leg movements and deep breathing exercises. A physiotherapist or nurse will explain these to you.

### **Drips and drains**

A drip into a vein in your arm (intravenous infusion) will be used to give you fluids until you are able to eat and drink again.

You may have a fine tube that passes down your nose, into your stomach or small intestine. This is called a nasogastric tube and it allows any fluids in the stomach to be removed so that you don't feel sick. You may need this for up to five days.

Often a small tube (catheter) is put into the bladder, and urine is drained into a collecting bag. This will save you having to get up to pass urine and is usually taken out after a couple of days.

You may also have one or more drainage tubes in your wound, to collect any extra fluid or blood, or to drain bile or pancreatic fluid. These will be removed when the amount of fluid draining has reduced.

## Pain

After your operation, you'll probably have some pain and discomfort for a few days.

### **Pain can usually be controlled effectively with painkillers.**

It's important to let your doctor or the nurses on the ward know if you are in pain, or if your drugs are not completely relieving your pain, so that the dose can be increased or the painkillers changed as soon as possible.

## Insulin and enzyme replacement

People who have had their whole pancreas removed will need to either take tablets to regulate their blood sugar, or have daily insulin injections to replace the insulin normally produced by the pancreas. They will need this for the rest of their life. They may also need to take capsules containing the special proteins (enzymes) normally produced by the pancreas, to help with digestion.

If you've had a part of your pancreas removed, immediately after the operation the remaining pancreas may not be able to produce enough enzymes to help with digestion, or enough insulin to control your blood sugar. You may need to have insulin given by injection into a vein (intravenously). This is usually only until the remaining pancreas recovers and starts to produce insulin again. You may also need to take capsules containing digestive enzymes normally made by the pancreas.

## *Bypass surgery*

Sometimes, surgery is carried out to treat a blockage in the first part of the small bowel (duodenum), if the blockage is causing vomiting. During the operation, a piece of the small bowel (the jejunum) is connected to the stomach, to bypass the duodenum. This is called a **gastrojejunostomy**. It is often done at the same time as a bile duct bypass.

## Chemotherapy for pancreatic cancer

Why chemotherapy is given

How it is given

Side effects

### ***Why chemotherapy is given***

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells.

If a pancreatic cancer has been completely removed with surgery, chemotherapy may be given afterwards to try to reduce the chance of the cancer coming back. This is known as **adjuvant chemotherapy**. If the cancer can only be partially removed you may still be given chemotherapy, to shrink the remaining tumour.

If the cancer can't be removed at all but has not spread beyond the pancreas, chemotherapy can't cure the cancer, but may shrink it down and control it for a time.

If the cancer has spread, chemotherapy may be used to try and shrink the cancer and relieve symptoms.

Chemotherapy may be given together with radiotherapy to increase its effectiveness. This is known as **chemoradiation**.

### ***How it is given***

Chemotherapy drugs are usually given by injection into a vein (intravenously) either in your arm or through a plastic tube (a central line), into your chest.

The chemotherapy drugs used to treat pancreatic cancer include gemcitabine (Gemzar®), 5-fluorouracil (5FU), cisplatin, mitomycin, oxaliplatin (Eloxatin®) and capecitabine (Xeloda®).

It's unusual for more than one chemotherapy drug to be given at the same time in the treatment of pancreatic cancer. Combinations of drugs are sometimes used as part of research trials. Sometimes gemcitabine is given in combination with a drug called erlotinib (Tarceva®). Erlotinib is a biological therapy that works by interfering with the way that cancer cells grow and divide.

The length of time that chemotherapy is given for will depend on the drugs that are used, and how well the treatment is working. This will be monitored by your doctor at regular appointments, and you will have regular blood tests and occasional scans. Any decision to use chemotherapy will be reached after a discussion between you and your doctor.

After you have had your chemotherapy there is usually a rest period of a few weeks, which allows your body to recover from the side effects of the treatment. Chemotherapy is usually given to you as an outpatient, but occasionally it may mean spending a few days in hospital.

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

A number of research trials are being carried out to try to improve the results of treatment for pancreatic cancer. You may be asked to take part in a trial.

### ***Side effects***

Chemotherapy can sometimes cause unpleasant side effects, but it can also make you feel better by relieving the symptoms of the cancer. Most people have some side effects, but these can often be well controlled with medicines. Some of the possible side effects are described here, along with some of the ways in which they can be reduced.

#### **Reduced resistance to infection**

While the chemotherapy is acting on the cancer cells in your body, it also temporarily reduces the number of white blood cells. When these cells are reduced you are more likely to get an infection. During chemotherapy, your blood will be tested regularly and, if necessary, you will be given antibiotics to treat any infection.

### **Sore mouth**

Some chemotherapy drugs can make your mouth sore and cause small ulcers. Regular mouthwashes are important and your nurses will show you how to use these properly. 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 has some useful tips on coping with eating problems.

### **Diarrhoea**

Some drugs used to treat cancer of the pancreas can irritate the lining of the digestive system and cause diarrhoea for a few days. Your doctor can give you medicine to slow down your bowel, and reduce the diarrhoea. You may also be able to help to control it by eating a low-fibre diet. This means avoiding wholemeal bread and pasta, raw fruit, cereals and vegetables for a few days after each treatment.

### **Feeling sick**

Some of the drugs may make you feel sick (nauseated) and you may sometimes be sick. There are now very effective anti-sickness drugs (anti-emetics) to prevent or reduce nausea and vomiting. Your doctor can prescribe these for you. Let your doctor or nurse know if your anti-sickness drugs are not helping you, as different types can be used.

Some anti-emetics can cause constipation. Let your doctor or nurse know if this is a problem.

### **Hair loss**

Ask your doctor whether the drugs you are taking are likely to make your hair fall out. Not all drugs cause hair loss and certain drugs are more likely to make your hair thin. If your hair does fall out, it will start to grow back once your treatment is over.

### **Skin**

Chemotherapy can affect the skin and nails, causing dryness and flaking. Some drugs make your skin more sensitive to the sun, so it is important to cover up and use a high-factor sun cream (SPF 15 or greater).

**Although these side effects may be hard to bear at the time, they will gradually disappear over a few weeks once your treatment has finished.**

## **Radiotherapy for pancreatic cancer**

Radiotherapy treats cancer by using high-energy x-rays to destroy as many cancer cells as possible, while doing as little harm as possible to normal cells.

Radiotherapy is used less often than surgery or chemotherapy. It is sometimes used to treat cancer of the pancreas which has not spread but can't be removed by surgery. In this situation it may be used together with chemotherapy (known as **chemoradiation**) to shrink the cancer and keep it under control for as long as possible.

Radiotherapy is also sometimes given to relieve symptoms such as pain. The radiotherapy can shrink the tumour and so relieve pressure which may be causing pain.

The dose of radiotherapy used to relieve symptoms is usually lower so you may have a shorter course of treatment and less chance of side effects.

Radiotherapy is given in the hospital radiotherapy department. How the treatment is given can vary a lot, depending on your particular needs. Sometimes a single treatment is all that is needed, but usually a course of therapy is given in daily sessions from Monday–Friday, with a rest at the weekends. Each session lasts only a few minutes. The course of treatment may last for a number of weeks. Your doctor will discuss your treatment with you in detail beforehand.

Planning your treatment

Having treatment

Side effects

### ***Planning your treatment***

To ensure that you receive maximum benefit from your radiotherapy, it has to be carefully planned. This is done using a CT scanner, which takes x-rays of the area to be treated. Treatment planning is a very important part of radiotherapy and it may take a few visits to complete.

Marks may be drawn on your skin to help the radiographer, who gives you your treatment, to position you accurately and to show where the rays are to be directed. These marks must stay visible throughout your treatment, but they can be washed off once it is over. At the beginning of your radiotherapy you will be told how to look after the skin in the area to be treated.

### ***Having treatment***

Before each session of radiotherapy the radiographer will position you carefully on the couch, either sitting or lying, and make sure that you are comfortable. During your treatment, which only takes a few minutes, you will be left alone in the room, but you will be able to talk to the radiographer, who will be watching you carefully from the next room. Radiotherapy is not painful but you have to be still for a few minutes while your treatment is being given.



The radiographer watches on a monitor while treatment is given

### **Side effects**

Radiotherapy for cancer of the pancreas can cause side effects such as feeling sick (nausea), vomiting, diarrhoea and tiredness. These side effects can be mild, or more troublesome, depending on how much treatment you are having. Your cancer specialist will be able to advise you what to expect.

Our radiotherapy booklet tells you more about this treatment and its side effects.

## **Supportive care (controlling symptoms) for pancreatic cancer**

Your doctor may suggest certain treatments or procedures to relieve any uncomfortable symptoms caused by the cancer. Treating symptoms is known as **supportive care**.

Our booklet on controlling the symptoms of cancer gives information about the methods of treating different symptoms.

- Treating jaundice
- Bypass surgery
- Nerve block (coeliac plexus)

### ***Treating jaundice***

If the tumour blocks the bile duct, causing jaundice (see symptoms), and it's not possible to remove it, your doctors may suggest you have a procedure to relieve the blockage and allow bile to flow into the small bowel again. The jaundice will then clear up. There are three ways of doing this. These are ERCP, PTC (percutaneous transhepatic cholangiography) and bypass surgery.

### **ERCP and PTC**

In ERCP and PTC, a tube called a **stent** is placed into the inside of the blocked bile duct to hold it open. The ERCP method is often used when ERCP is first carried out as an investigation (see further tests).

You'll be asked not to eat or drink anything for six hours before the procedure, so that the stomach and duodenum are empty. You will be given a sedative by injection, and the endoscope will be passed through your mouth (as described on the further tests page).

A dye will be used, as before. X-rays are taken, and by looking at the x-ray picture the doctor will be able to see the narrowing in the bile duct. The narrowing can be stretched and a tube put in through the endoscope, allowing the bile to drain.

The tube may need to be replaced later if the jaundice comes back or if an infection occurs.

The PTC method is similar to ERCP in that a dye is used to show up the blockage on x-ray. Instead of the tube being inserted through an endoscope, a needle is inserted

through the skin just below your rib cage and a fine guide wire passed through the liver and into the blockage in the bile duct. The tube is then passed along this wire.

As with ERCP, you will be asked not to eat or drink for at least six hours beforehand, and you will then be given a sedative. You will also have a local anaesthetic so you should not feel pain as the needle or wire is passed through your skin, although moving the wire into the correct position in the bile duct can be painful. To help prevent any infection you will be given antibiotics before and after the procedure. It is likely that you will stay in hospital for a few days afterwards.

Sometimes, if the tube can't be passed into the bile duct from the duodenum during ERCP, a combination of ERCP and PTC is carried out.

### ***Bypass surgery***

Surgery is sometimes recommended to deal with a blockage of the bile duct. This involves joining the gall bladder or bile duct to the small bowel (see diagram of the pancreas). This bypasses the blocked part of the bile duct and allows the bile to flow from the liver into the bowel. This operation is called a **cholecystoenterostomy**. In some hospitals, it's possible to do this procedure during laparoscopy.

### ***Nerve block (coeliac plexus)***

If the pain caused by cancer of the pancreas can't be properly controlled with painkilling drugs, your doctor may suggest that you have a nerve block. A nerve block stops pain messages from getting to the brain by blocking the nerves themselves. There are different ways in which this can be done – injecting an anaesthetic such as alcohol into the nerve or, occasionally, cutting the nerve.

In people with cancer of the pancreas, persistent pain in the abdomen and back can be caused by the tumour pressing on the coeliac plexus (a complicated web of nerves at the back of the abdomen). A coeliac plexus nerve block is usually a very effective way of treating this type of pain.

Before the procedure you'll be given a sedative to help you relax, usually by injection into a vein in your arm (intravenously). The nerve block may be carried out with a CT scan to help the doctor to put the needle into the right place. You will be given an injection of local anaesthetic to numb the skin beforehand. A long, fine needle is inserted through your back and into the nerve, which is then injected with alcohol.

Afterwards, for a day or two, your blood pressure may be low, making you feel light-headed and dizzy, particularly when you stand up. Sometimes the nerve can be cut rather than injected, but for this you will need a general anaesthetic. For this reason, a block involving cutting the nerve is usually carried out when a person is having other surgery, such as bypass surgery.

## Follow-up after treatment for pancreatic cancer

After your main treatment is finished, your doctor will ask you to go back to the hospital for regular check-ups. These are a good opportunity to discuss any worries or problems you may have.

You should also see your GP or hospital doctor if, between your follow-up visits, you have any new symptoms that you can't readily explain, which last more than a week or is not getting better.

## Research - clinical trials for pancreatic 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, to make them more effective or to reduce side effects
- compare the effectiveness of drugs used to control symptoms
- 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.

You don't have to take part in a trial. If you decide not to take part your decision will be respected and you do not have to give a reason. There will be no change in the way that you are treated by the hospital staff and you will be offered the standard treatment for your situation.

### ***Blood and tumour samples***

Many blood samples and bone marrow or tumour biopsies may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you are taking part in a trial you may also be asked to give other samples which may be frozen and stored for future use, when new research

techniques become available. These samples will have your name removed from them so you can't be identified.

The research may be carried out at the hospital where you are treated, or it may be at another hospital. Completing this type of research and interpreting the results can take many years. 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.

### ***Current research***

If you have advanced pancreatic cancer (stage 3 or 4) you may be asked to take part in a trial called FRAGEM. This trial is comparing giving the chemotherapy drug gemcitabine together with the drug dalteparin (Fragmin®), with gemcitabine given on its own. Dalteparin is a type of drug that helps to thin the blood and prevent blood clots forming (an anti-coagulant). It is being tried as a possible treatment for pancreatic cancer, alongside chemotherapy, because people with pancreatic cancer are at an increased risk of developing a blood clot.

If you can't have surgery to remove your tumour, but it hasn't spread to another part of the body, you may be asked to take part in a trial that is looking at the benefits of giving radiotherapy with a biological therapy called cetuximab (Erbix®). The trial, called PACER, is looking to see if cetuximab will help to improve treatment with radiotherapy and to see what side effects the combination will cause. Cetuximab is a type of biological therapy called a monoclonal antibody. It works by locking onto receptors on the surface of the cancer cells and interfering with the way that the cells grow and divide.

## **JASCAP resources**

### **Talking about your cancer**

Practical advice and guidance for cancer patients to help them communicate with family, friends, carers and health professionals about emotional and practical issues arising from a diagnosis of cancer and cancer treatment.

### **Talking to children about cancer**

Practical advice and guidance to help parents with cancer talk to their children about their cancer.

### **Talking to someone with cancer**

Practical advice and guidance for friends, carers and family members to help them talk to their friend or relative with cancer, and provide emotional and practical support.

***Note: JASCAP has booklets on each of 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 \_\_\_\_\_

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4. \_\_\_\_\_

Answer \_\_\_\_\_

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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**

This JASCAP booklet is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through JASCAP is not a substitute for professional care and should not be used for diagnosing or treating a health problem or a disease. If you have, or suspect you may have, a health problem you should consult your doctor.

## 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](mailto:pkrjascap@gmail.com), [abhay@abhaybhagat.com](mailto: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](mailto:dkgoswamy@sify.com)

BANGALORE: MS. SUPRIYA GOPI,  
455, I CROSS,  
HAL III STAGE,  
BANGALORE – 560 075  
PHONE : 91-80-2528 0309 .  
e-mail : [supriyagopi@yahoo.co.in](mailto:supriyagopi@yahoo.co.in)

HYDERABAD: MS. SUCHITA DINAHER & DR. M. DINAHER, 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](mailto:suchitadinaker@yahoo.co.in)