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Chronic Pancreatitis

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EUROPAC - European Register for Familial Pancreas Cancer and Hereditary Pancreatitis. The principal register in Europe providing advice and research in inherited pancreatic disorders.

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CHRONIC PANCREATITIS

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INTRODUCTION

This booklet is one of a series on pancreatic disorders written by Professor Neoptolemos. Its aim is to provide you, the patient, with useful information on the particular pancreatic problem you are suffering from, the procedures and tests you may need to undergo, and helpful advice on coping successfully with the problem. If you require any further information or advice or are unsure about anything, your doctor and or consultant will be able to help.

WHAT IS THE PANCREAS?

The pancreas is a solid gland measuring 20-25cm in length, 4-6cm in width and 3-4cm in depth. It is firmly attached in the back of the abdominal cavity behind the stomach. The pancreas is divided into 5 parts – the head, the uncinate process, the neck, the body and the tail. The head of the gland is closely attached to the duodenum which is the first part of the small intestine into which the stomach empties liquids and partially digested food. The head of the gland is situated just to the right of the midline of the abdomen and below the right rib-cage.

The uncinate process is an extension of the lower part of the head of the gland which surrounds important blood vessels. The body and tail of the pancreas lie at an angle so that the tail of the pancreas is situated beneath the extreme edge of the left rib cage. The tail of the gland is closely attached to the central part of the spleen with which it shares a common blood supply. Running behind the neck and uncinate process are many important blood vessels which supply the liver, the rest of the gut organs and the kidneys, including the aorta (an artery) which takes all the blood to the lower abdomen and legs, and the inferior vena cava (a vein) which returns blood from these areas.

WHAT DOES THE PANCREAS DO?

The pancreas does two important things:

- It makes enzymes which are necessary to digest food in the intestines
- It produces insulin to enable every part of the body to use glucose (sugar)

1. DIGESTION

Food is partly broken down by the acid and churning action of the stomach. After 1-2 hours food is slowly released into the duodenum through a valve called the pylorus. Here, and as it moves along the rest of the small bowel, the food is broken down into tiny particles. Nutrients are absorbed by the small intestine and used for energy and maintaining strong muscles and bones. Unwanted material passes into the large bowel (colon) and after 24 hours or so is excreted as stool via the rectum and anus.

Proper digestion of food which consists of carbohydrates (e.g. glucose/sugars), proteins (e.g. meat/eggs etc) and fat (e.g. butter) is not possible without the pancreas. Groups of glands in the pancreas (called acini) make 30 or so different enzymes each of which is responsible for breaking down clumps of different types of food into small particles for absorption. These enzymes are collected from the small glands in the pancreas into small ducts and finally into the main pancreatic duct to be released into the duodenum.

The enzymes when they are first made in the acini are not active (otherwise they would digest the pancreas as well!). When they pass into the duodenum however, they are made active by the juice of the duodenum. The main enzymes are called amylase for digesting carbohydrates, trypsin for digesting proteins and lipase for digesting fats.

Digestion is also assisted by enzymes made and released by the salivary glands (amylase), tongue (lipase), stomach (pepsin and lipase) and small intestine (peptidases).

The digestion of fat is very special. Fat needs to be dispersed before the pancreatic enzymes can properly break it down. This dispersion of fats is made by bile acids which are present in bile produced by the gall bladder. Bile acids act in exactly the same way as detergents which are used to wash up greasy dishes. Therefore, both bile acids and pancreatic enzymes are needed for fat digestion. If there are not enough pancreatic enzymes, fat is not digested and the stools (bowel motions) become pale and greasy. These greasy stools may become difficult to flush away from the toilet and may give off a strong offensive smell. Doctors call this steatorrhoea, which is a way of saying fatty stool.

2. INSULIN AND GLUCOSE METABOLISM

All the cells of the body use glucose as a source of energy in order to maintain their different functions (eg electrical activity of the brain and contraction of the heart and muscles). Sugar comes directly from digestion or is made in the liver from concentrated forms of sugar (glycogen). The level of sugar in the blood is kept constant by special control mechanisms involving hormones. There are many different types of hormones each with a specific task. Hormones act as messengers and work like a key opening the lock of a door.

Hormones are made in different places, are then secreted into the blood and will work on cells at many different sites. Insulin is a hormone which unlocks a special 'door' in the cells of the body to allow glucose to pass in to the cells. If insulin is lacking, then sugar diabetes develops. Instead of entering the cells of the body, the sugar stays in the blood which is very harmful at high concentrations. Insulin is made in special groups of cells called islets of Langerhans which are dispersed throughout the pancreas gland. Most of the islets (pronounced 'eye-lets') are in the tail of the gland. Most of the pancreas can be removed but there are usually enough islets remaining to make insulin sufficient to prevent sugar diabetes (also called diabetes mellitus) from occurring. As you are probably aware, diabetes can be treated by taking regular injections of insulin, which can be taken from the pancreas of animals (eg pork insulin) or made by genetic engineering (so called 'human' insulin).

Enzyme production and insulin production are independent. Because digestive enzymes and insulin are made by different parts of the pancreas, a problem with enzyme production does not mean necessarily that there will be a problem with insulin production. Similarly, if there is a problem with insulin production, this does not mean necessarily that there will be a problem with enzyme production.

Assuming that the pancreas was normal to begin with, increasing loss of the pancreas gland (by disease or surgery) usually results in more loss of enzyme production before there is obvious loss of insulin production. Another way of saying this, is that the insulin 'reserve' is much more than the enzyme 'reserve' of the pancreas.

SPECIAL INVESTIGATIONS FOR PROBLEMS WITH THE PANCREAS

Your doctor may need to do some tests to find out more about your particular problem. Perhaps you've already undergone one or more of them. The next section describes what these tests are, how and why they are done, and how they can help your doctor to treat your problem.

I. ULTRASONOGRAPHY OR ULTRASOUND (US) SCAN

This is a simple, painless and relatively quick investigation which can be used to obtain a 'picture' of the inside of the abdomen. The only preparation needed is for you to avoid eating for 6-8 hours prior to the test, as any fluid or food which is taken by mouth can obscure the pictures produced. Pictures are made using harmless sound waves. These waves bounce off interfaces between dense and less dense structures. The sound waves will not cross solid areas (such as bone) or areas containing air or other gas. Usually only a fairly simple picture of the pancreas, liver, bile ducts and gallbladder can be obtained.

The test is performed while you lie fully awake on a simple couch. A special jelly, a bit like vaseline is used to enable the 'probe', which produces and collects the sound waves, to be moved over the skin of the abdomen. The radiologist (or his assistant called a radiographer) moves the probe around and looks at a TV screen while this is done to see what pictures are being made. Although sound waves are generated during the procedure these cannot be heard.

II. COMPUTERISED TOMOGRAPHY (CT SCAN)

This is more complex and time consuming than an ultrasound scan but produces excellent pictures of the pancreas and other abdominal structures. As with ultrasound you need to avoid eating for 6-8 hours beforehand and is performed while you are fully awake.

You lie on a special couch attached to the CT scanner which looks like a large 'doughnut'. A CT scan uses X-rays which are emitted and collected through 360°. The couch is made to move through the doughnut as the X-rays are then put together by a computer to produce the pictures at different levels of the abdomen.

In order to make it easier to interpret the structures in the abdomen, you will be asked to swallow a liquid (or 'contrast'). This fills the stomach and the intestines. Another injection of a different contrast ('dye') is given into a vein (usually in the arm) during the second half of the procedure. This helps to show up the blood vessels.

An MRI scan is similar to a CT scan but uses magnetic resonance to image the pancreas instead of X-rays.

III. ERCP

This is a special investigation for taking pictures of the bile ducts and pancreatic duct. It provides complementary and usually essential information to that given by ultrasound or CT. The full name of ERCP is rather a mouthful: endoscopic retrograde cholangiopancreatography! It involves inserting a special flexible telescope (the duodenoscope) into the mouth, down the gullet and into the stomach and then into the duodenum opposite the opening of the bile duct and pancreatic duct. A small tube (cannula) is then pushed into the opening (ampulla of Vater) and contrast ('dye') is injected into the ducts. You lie on an X-ray table to enable pictures of the ducts to be taken while the contrast is injected. Sometimes it is necessary to cut a small part of the opening using an electric current passed down a needle which has been inserted into the telescope to permit the cannula to go into the ducts properly. If your doctor decides you should have an ERCP it is essential that you don't eat or drink anything for at least 8 hours before the test.

Usually a plastic tube is put into a vein of the right forearm or the back of the hand before you go to the X-ray department. You may need a drip of intravenous fluids and be given one or more antibiotics in the drip.

You will be asked to sign a consent form agreeing to this procedure because it is complicated. Normally you are taken on a trolley to the X-ray department and, after being checked by a nurse, asked to move onto the X-ray table. You will be asked to lie on your left side with your left arm behind your back and be given a throat spray of local anaesthetic. This tastes awful but the feeling quickly goes and it will stop any coughing during the procedure. A second spray may then be given under the tongue, which contains a substance to help the ampulla of Vater open up during the procedure. At this stage you are given a strong sedative by injection.

This is enough to make most patients very sleepy but not fully unconscious. It is very important that you are as relaxed as possible before and during the procedure. The telescope is easily passed into the mouth and stomach. There is then a strange sensation as air is introduced into the stomach. Belching should be avoided as the air helps the endoscopist to pass the tip of the telescope into the duodenum. Most patients usually do not remember anything of the procedure. The results may be explained to you or a relative on the ward but the best time to discuss the findings is at the next out-patient visit or the next day on the ward. If you are an out-patient, full details will also be sent to your GP. The results are not always easy to interpret and are usually combined with other tests to provide an overall diagnosis. It is always necessary for a friend or relative to drive you home if you have had an ERCP as an out-patient because it takes several hours for the effects of the drugs to wear off.

Is ERCP safe?: ERCP is safe with no complications in about 95% of cases. There are occasionally complications from ERCP however, the most common of which are abdominal pain, acute pancreatitis, biliary infection and bleeding. It will be necessary to keep you in hospital overnight if there has been a complication. In most cases, the complications improve, and patients are soon discharged. Very occasionally the complication is serious, and death may result in a very small proportion of cases. For these reasons, an ERCP must be:

- Performed by a specialist
- Performed for a good reason

IV. ENDOLUMINAL ULTRASOUND (EUS)

This is an endoscopic procedure rather like ERCP. Instead of x-ray pictures of the pancreas and bile ducts, EUS takes pictures by ultrasound. There are no complications with this procedure.

V. NEEDLE BIOPSY

Occasionally a small piece of tissue from the pancreas needs to be taken to help make a diagnosis. This can be done during ERCP, an ultrasound scan or a CT scan. During the latter procedures, local anaesthetic is injected into the skin. A fine needle is then introduced and its tip positioned using pictures from the scan before any tissue is taken.

Is needle biopsy safe? This is perhaps surprisingly safe but complications such as bleeding or acute pancreatitis can occur, but only very occasionally.

TESTS FOR SUGAR DIABETES

The urine can be tested for sugar using a simple technique of dipping a special strip of paper into a sample. Depending on the amount of sugar, it changes colour (normally there is no sugar in the urine). Urine testing is often used as a screening test.

More precise tests involve measuring the actual glucose level in the blood by taking a blood sample from an arm vein. The blood glucose level can also be measured using another special paper strip dipped into a drop of blood obtained by pricking the pulp end of a fingertip. This latter method (and sometimes urine testing) is used by patients who are known diabetics to adjust their own insulin requirements.

A patient who is thought to be developing diabetes can be tested by a glucose tolerance test. This involves taking a glucose drink following an overnight fast and then measuring the blood glucose level from blood samples taken over the next 2-3 hours.

TESTS FOR PANCREATIC ENZYME PRODUCTION

These tests are not as accurate as determining blood glucose levels because many factors are involved in the digestion of food by pancreatic enzymes. Few patients actually require such a test since the clinical outcome is the most important factor. This means that if a patient has greasy stools and is losing weight, then pancreatic enzyme supplements (tablets or capsules) are required. The number of tablets or capsules will be increased by the doctor, or the patient will be instructed by the doctor to do so until the symptoms disappear.

Nevertheless, confirmatory tests are usually required. None of these tests is ideal and different institutions use different tests. The precise details of these are not required but may include the following:

- a. Faecal Elastase Test: Elastase is one of the enzymes produced by the pancreas to digest protein. There is always a small extra amount produced which means that it can be measured in the stool. The extra amount of elastase produced is related to the amount of normal pancreatic function. The faecal elastase test is used for screening and monitoring. More complicated tests may also need to be used.
- b. PLT or Pancreato-Lauryl Test: A standard meal is taken following an overnight fast along with a test 'food' (with PLT). One or more blood tests or a urine test is then made to see if the test 'food' has been digested (by the pancreatic enzymes) and then absorbed.
- c. Triolein breath test: This is a more specific test for fat digestion and absorption and is fairly simple to perform. Triolein is a fat which contains a minute trace of radioactive carbon. The amount of fat metabolised is determined by taking a simple breath test at a fixed time following ingestion of a small amount of triolein.
- d. Faecal fat test: This is an excellent way of determining fat digestion but involves collecting stools for 1-3 days. As you can imagine this is not popular with either patients or the laboratory staff who have to make the measurement. (At the same time pancreatic enzymes present in the stool can also be measured).
- e. Secretin test: This is performed in specialist units and is very accurate (like the faecal fat test). After an overnight fast a special tube is passed through the nose into the stomach and the farthest part of the duodenum. The tube has two separates 'pipes' which drain fluid from the stomach and duodenum. The fluid from the duodenum contains the pancreatic enzymes and bicarbonate. Following the first 30-40 minutes an injection into a vein is given to stimulate the pancreas to produce enzymes and bicarbonate. The injection contains the hormones CCK-PZ (cholecystokinin-pancreozymin) and secretin, further collections of fluid are then made to see how well the pancreas has been stimulated. The whole test lasts 3-4 hours and is carried out as an out-patient procedure.

CHRONIC PANCREATITIS II

This section of the booklet deals with the particular problem you have with your pancreas – "Chronic Pancreatitis". So what is it, what causes it, and how can it be treated?

What Is Chronic Pancreatitis and What Causes It?

This refers to an inflammation of the pancreas which is continuous. The inflammation is usually of a lowgrade so that there is no fever but often there is some pain. Because of the continuous inflammation, scar tissue develops within the pancreas. At first this may result in loss of part of the enzyme-making part of the pancreas. After a variable period of time (which could be after some weeks or months but is usually after many years), the insulin-making part of the pancreas may become destroyed. For reasons that are not understood, many patients with chronic pancreatitis develop calcium deposits in the pancreas tissue and may form calcium stones in the pancreatic ducts. Blockage of the ducts by scar tissue or stones will stop enzymes being delivered to the gut and impair digestion. The pancreatic duct may enlarge if it is blocked.

The cause of chronic pancreatitis is usually due to alcohol drinking but there are other causes such as narrowing of the pancreatic duct and pancreas divisum (see below). In many cases, the cause remains unknown. If alcohol is thought to be the cause, it is essential that all alcohol drinking is stopped.

The main symptoms of chronic pancreatitis are:

- Poor Digestion
- Sugar Diabetes
- Pain
- Weight Loss

There are many causes for abdominal pain so that it is essential to establish a diagnosis of chronic pancreatitis by investigation. Most patients can be treated by medical treatment only, but a few will require surgery.

i. NARROWING OF THE PANCREATIC DUCT:

There are many different reasons why the pancreatic duct becomes narrowed. For this reason, it is important not only to show that the pancreatic duct is narrow but also the cause for this. Surgery is often required to deal with pancreatic duct narrowing.

ii. PANCREAS DIVISUM:

The pancreas develops as two separate buds from the intestinal tube during embryological development of the foetus in the womb. These buds each have a separate pancreatic duct. The two buds eventually combine together before birth to form a solid single organ. When this occurs, the separate pancreatic ducts also combine. In about 5-10% of healthy individuals, the pancreatic tissue combines but the two pancreatic ducts remain divided and they empty separately into the duodenum. This situation is called pancreas divisum because the pancreatic ducts remain divided.

Pancreas divisum is not harmful in the vast majority of cases. Very occasionally one of the ducts becomes narrowed and sometimes this may eventually lead to chronic pancreatitis.

The treatment involves enlarging the narrowed pancreatic duct opening and sometimes removing a part of the pancreas.

OTHER CAUSES OF CHRONIC PANCREATITIS

Sometimes the cause is not known for certain. Doctors use the loosely applied term idiopathic to mean "the cause is specific to an individual person."

Another factor which may predispose to chronic pancreatitis in later life is a condition called annular pancreas. The problem arises during embryological development of the two pancreatic buds as described above (see pancreas divisum). In simple terms, the head of the pancreas become partly or totally wrapped around the duodenum. This can cause an obstruction to the flow of food in very young babies. Alternatively, the flow of pancreatic juice along the pancreatic duct may be hindered leading to an attack of pancreatitis. This may be difficult to recognise but once it is, surgery is required.

DOES CHRONIC PANCREATITIS RUN IN FAMILIES?

In general, the answer is NO. There is, however, a very rare form of chronic pancreatitis, which can run in families. The features of this are no different from other types of chronic pancreatitis except it does tend to afflict young members of a family. Treatment of this condition is identical to the treatment of other types of chronic pancreatitis.

There are two main groups of patients in whom pancreatitis can be inherited. This happens because they have a gene which predisposes to pancreatitis. Each person has exactly the same number of genes as every other person. There are 100,000 genes in every cell of the body but only 10,000 genes are selected for use in any particular cell. Genes are always in pairs, so that one set comes from the mother and one set comes from the father. There are tiny variations in each gene. These tiny variations are essential to make every person an individual. Occasionally a tiny variation in a gene can give rise to a disease condition. Patients and their families require the care of a specialist surgeon, paediatrician or gastroenterologist and counselling from a geneticist.

Hereditary Pancreatitis

In this type there is a tiny variation in the cationic trypsinogen gene (which makes trypsin and is used to digest protein) results in active trypsin in the pancreas. This activation occurs before it has had a chance to be secreted into the duodenum. The gene is officially called the PRSS1 gene and the two commonest alterations (or gene mutations) are called R122H and N29I. Affected individuals tend to develop pancreatitis as children, adolescents or young adults. There may be other members of the family with sugar diabetes. Not all members of the family will be affected in the same way. On average only half the individuals will carry the altered gene. This is called a dominant mutation. This means that half the children of an affected parent will have the gene passed on to them. Even then, some members of the family (about 20%) with the altered gene (or mutation) will not be affected at all. The presence of the gene can be tested for by a single blood test. Genetic counselling is required before any tests can be performed. Some families with Hereditary Pancreatitis have a normal set of PRSS1 genes. This means that another gene is affected and scientists are trying to find out which one this is.

Idiopathic Pancreatitis

Some patients have an alteration in the gene that causes cystic fibrosis (the CFTR gene). One in 20 of the normal population has a CFTR gene mutation but only a tiny handful has idiopathic pancreatitis. Individuals with cystic fibrosis disease have both of the CFTR genes altered. We do not understand why some people with only one CFTR gene mutation develop pancreatitis. Scientists are trying to find out why this happens.

MEDICAL TREATMENT OF CHRONIC PANCREATITIS

- Stop all alcohol drinking if this is the cause. (NOTE: Even if not this is a trigger for attacks The PSN) If a patient works in an alcohol related industry such as a brewery or bar or pub, a change of employment is recommended. A change of lifestyle is often very helpful. Attendance at a drug addiction unit also can be very helpful.
- Ideally smokers need to stop smoking altogether (see page * "Does Chronic Pancreatitis Cause Cancer)?"
- Pancreatic enzyme supplements (see page *). These help digestion and may reduce the pain.
- If sugar diabetes is present, then insulin treatment will be required (see page *).
- Mild pain-relieving tablets are acceptable.

It is sometimes suggested that the nerves of the pancreas which are responsible for taking the sensation of pain to the brain should be destroyed. This usually involves an injection into the back to destroy the nerves around the pancreas. Most pancreatic surgeons do not recommend this as any effect is short-lived and can make any further surgery very difficult.

SURGICAL TREATMENT OF CHRONIC PANCREATITIS

This is necessary if there are surgical complications of chronic pancreatitis or if the pain becomes severe.

Once it is necessary to be taking strong pain killers on a regular basis, then surgery will be required. If a patient is already receiving regular pethidine or morphine, attendance at a drug addiction unit may also be necessary following surgery.

The chances of achieving a good result following surgery for pain are at least 80% in the first instance. There is, however, no guarantee of success and some patients may develop a recurrence of pain sometime after surgery. This may necessitate further surgery. For these reasons, it is essential that the patient and relatives and friends remain committed to addressing all the social problems as well as the medical problems involved. Patience and optimism are required by all.

The underlying disease process will largely dictate the choice of operation. Some operations can be relatively simple – for example removal of a single pancreatic stone, enlarging a narrowing of the pancreatic duct or performing an internal drainage operation for a dilated pancreatic duct. In principle, however, a resection of part of the pancreas (partial pancreatectomy) will be required if there has been severe pain.

Operations have become more 'conservative' in recent years. This means that only the affected pancreas tissue is removed and that other nearby organs such as the duodenum, stomach and spleen are left untouched. This is so-called "designer-pancreatic surgery".

This type of surgery is particularly demanding and requires a specialist pancreatic surgeon to undertake the procedure. Although it is nearly always intended to preserve the spleen, this may prove excessively difficult at operation when it becomes necessary for reasons of immediate safety to the patient to remove the spleen (splenectomy).

In addition to relieving pain, the principal aims of designer-pancreatic surgery are to improve drainage of the pancreas, reduce the risk of developing sugar diabetes (diabetes mellitus), and maintain important normal anatomy.

Common operations include the following:

- A. **Beger's operation**: The head of the pancreas is removed preserving the duodenum. The base of the removed pancreatic tissue (which contains the bile duct and pancreatic duct) is drained into the small bowel by a special procedure (Roux-en-Y).
- B. **Peustow Procedure:** In this operation no tissue is removed but the dilated main pancreatic duct is drained into the small bowel by a Roux-en-Y procedure. This operation is used if the pancreas is not badly affected apart from obstruction to the pancreatic duct.
- C. **Frey's procedure:** This is almost identical to the Peustow operation but some tissue is removed from the head of the pancreas although less than in Beger's operation.

Other operations include the following:

- A. Kausch-Whipple's Operation: Some surgeons offer this operation instead of a Beger's operation or if there is concern about the presence of a small cancer. Part of the stomach is removed along with the pylorus, the duodenum and the head of the pancreas.
- B. **Pylorus-Preserving Kausch-Whipple's Operation:** In this procedure the stomach and pylorus are preserved whilst removing the duodenum and head of the pancreas.
- C. Bilateral Thoracoscopic Sympathectomy (BITS): In some cases in which surgery has failed to control pain even though all the pancreas has been removed it may be helpful to undergo the BITS procedure. This involves cutting the pain nerves from the pancreas as they travel through the chest. The operation is done using fine instruments and telescopes. This is so called 'keyhole' surgery. The operation lasts only 30 minutes and may be performed as an outpatient.
- D. Left Pancreatectomy: In this operation the left part of the pancreas is removed. This operation is performed if the head and neck of the pancreas are completely normal. The spleen is normally preserved, but may need to be removed sometimes.
- E. **Conservative Total Pancreatectomy:** In this operation 95% of the pancreas is removed. A small amount of pancreas tissue is preserved near the duodenum to maintain its blood supply. The spleen is also preserved if possible. This operation is performed if the whole of the pancreas is badly affected. Designer total pancreatectomy may be necessary especially if:
 - there has been previous pancreatic surgery or
 - the patient already has sugar diabetes

Other conditions that may complicate chronic pancreatitis are pseudocysts and ascites:

- A. **Pseudocyst:** (Pronounced 'Sue-doe-cyst') This is a cystic swelling which lies in the pancreas or next to the pancreas and which contains high concentrations of pancreatic enzymes. Often pseudocysts disappear without any specific treatment. If a pseudocyst remains or enlarges, it may cause nausea, vomiting, pain and weight loss, in which case, treatment is necessary. There are different ways to treat large pseudocysts but usually the most appropriate method is by surgery. Sometimes it is possible to insert a tube into the pseudocyst under local anaesthetic in the X-ray department and drain the fluid away without surgery. It is often better in chronic pancreatitis however to remove the cyst rather than simply drain it.
- B. Ascites: (Pronounced 'ass-eye-teas'). This refers to a discharge of pancreatic juice into the general cavity of the abdomen. Ascites may occur if the pancreatic duct or a pseudocyst ruptures and leaks at a certain point. Treatment may involve surgery and/or the use of a special drug called octreotide which suppresses the secretion of pancreatic juice.

DOES CHRONIC PANCREATITIS LEAD TO CANCER?

Unfortunately, it does appear that some patients with chronic pancreatitis are more likely to develop pancreatic cancer, as they become older.

The risk is greatest amongst smokers and those with Hereditary Pancreatitis. These risk factors are 'independent' and therefore all patients are recommended not to smoke. The risk appears to increase with age and with the duration of symptoms. The risk is lowest in those under 30 years old and highest in those over 70 years of age.

LIVING WITHOUT A PANCREAS

There are some patients who have had either their pancreas removed or who still have pancreatic tissue but which is not functioning at all. Both types of patient are perfectly able to lead a normal life provided they take regular enzyme supplements and insulin injections.

PANCREATIC ENZYME SUPPLEMENTS

There are many preparations available. These preparations differ considerably in their effectiveness of action. Modern preparations consist of capsules containing scores of small acid-resistant granules. The enzyme preparations can also be divided into two types depending upon their strength of action: regular and high strength. The capsules need to be taken during each meal and with any snack. Requirements vary enormously from patient to patient partly because of the different level of secretion by any functioning pancreas and partly because there are still some enzymes secreted by the salivary glands, tongue, stomach and small intestine but which also vary greatly from person-to-person.

In a few cases of children and adults with cystic fibrosis, a serious problem with the large bowel (colon) has been reported. This condition is called fibrosing colonopathy and causes narrowing of the bowel. It seems to be related to the use of a particular acid-resistant coating (called methacrylic acid copolymer) in some enzyme preparations. The problem does not arise with preparations without this coating. The ingredients are always listed on the pack leaflet or label. Once patients are accustomed to taking enzyme supplements, they are usually allowed to adjust the number they take themselves to suit their own individual needs.

INSULIN

There are many types of insulin available including human insulin obtained by genetic engineering. Precise dosing and frequency of injections is an individual matter. Being under the care of a diabetic specialist is obviously important in the first instance.

GASTRIC ACID SUPPRESSING TABLETS

Medication of this sort is often prescribed to be taken once or twice a day. Pancreatic juice normally counters the acid of the stomach. In the absence of the pancreas, there may be excess acid which can cause dyspepsia. There is also some evidence that taking this type of medication helps the action of pancreatic enzyme supplements which means that fewer capsules are required each day.

LIVING WITHOUT A SPLEEN

Pancreatic surgery sometimes necessitates removal of the spleen. This is much more of a problem in children than adults. Without the spleen there is a small but real risk of developing a serious infection caused by certain bacteria especially pneumococcus. All children and adults without a spleen therefore require regular pneumococcal vaccination. All patients should also receive vaccination for meningococcus groups A and B, and children less than 4 years old require Haemophilus influenzae type b vaccination. Children may also need to take a daily antibiotic. Since the risk is much less in adults, daily antibiotics are not prescribed usually. Nevertheless, if any infection develops, then appropriate antibiotics (such as penicillin or erythromycin) must be taken over-and-above any other types of antibiotic that are required.

Removal of the spleen sometimes causes the number of platelets in the blood to increase. This increases the risk of developing unwanted blood clots. Regular blood tests are therefore needed. If the number of platelets in the blood rises excessively, it is common practice to prescribe low-dose aspirin which reduces the risk of undesirable clotting.

CAN I DRINK ALCOHOL?

• Alcohol is not recommended for patients who have chronic pancreatitis.

- CAN I SMOKE?
 - Smoking is not recommended in general. Specifically it is not recommended in patients with chronic pancreatitis because of the added risk of pancreatic cancer.

DOCTORS DEALING WITH PANCREATIC DISEASE THAT YOU MAY MEET

All surgeons are called 'Mr' and other medically qualified doctors are called 'Dr'. Either may be called 'Professor' if they work for a University. Senior doctors are called 'consultants' and the junior doctors are called house officers, senior house officer and registrar. In University departments, they are also called 'lecturer' (registrar) and 'senior-lecturer' or 'reader' (consultants)

• General physician:

A consultant medical doctor who works in a hospital and who is broadly specialised including 'gut' problems.

- General surgeon:
 A consultant surgeon who works in a hospital and who is broadly specialised including 'gut' problems.
- Gastroenterologist:

A physician who is highly specialised in 'gut' problems and is usually an 'endoscopist'.

- Endocrinologist: A physician who is highly specialised in glandular problems including glandular problems including sugar diabetes.
- Specialist surgeon:
- A general surgeon who is highly specialised a so called PB-specialist is a pancreato-biliary surgeon.
 Endoscopist:

This may be a gastroenterologist or a surgeon who is able to undertake endoscopy (examination of the stomach or bowel using a flexible telescope). A few endoscopists can also perform ERCP, a specialist form of endoscopy that examines the bile ducts and pancreatic ducts.

- Radiologist: A consultant who only specialises in taking X-rays and scans of various sorts at the request of other specialists. A few radiologists are also expert endoscopists.
- Paediatrician:

A consultant who specialises in the care of children and who may be called to investigate a pancreatic problem in young children or teenagers.

Geneticist:

A consultant who specialises in diseases which may be inherited. This is the only type of consultant who is properly qualified to provide counselling in cases where pancreatitis may run in families.

Dietician:

This is a specialist who is not a doctor but is an expert in advising on various types of diet.

USEFUL ORGANISATIONS

Pancreatitis Supporters Network

This is a support group which has members throughout the UK. The Network provides information and support to patients with pancreatitis and their relatives. This is a registered charity. For further information, write to

Mr Jim Armour Chairman, Pancreatitis Supporters Network PO Box 8938 Birmingham B13 9FW Tel. 0121 449 0667

Pancreatic Society of Great Britain and Ireland

This is a professional organisation of specialist doctors involved in the care of patients with pancreatic disease. The Society is allied to the European Pancreatic Club and the International Association of Pancreatology. For further information write to:

Mr. R. Charnley Secretary, Pancreatic Society of Great Britain and Ireland Department of Surgery Freeman Hospital Newcastle-upon-Tyne NE7 7DN

Pancreas Research Fund

Specifically supports clinical and basic research of diseases of the pancreas. Write to: Pancreas Research Fund Department of Surgery Royal Liverpool University Hospital Daulby Street Liverpool L69 3GA

Digestive Disorders Foundation

3 St Andrew's Place London NW1 4LB Tel : 0171 486 0341

EUROPAC:

European Register for Familial Pancreas Cancer and Hereditary Pancreatitis. The principal register in Europe providing advice and research in inherited pancreatic disorders. Write to: EUROPAC Co-ordinator Department of Clinical Services Alder Hey Children's Hospital Eaton Road Liverpool L12 2AP

Europac@liv.ac.uk www.liv.ac.uk/surgery/europac.html