

Pancreatitis Supporters Network

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The Pancreatitis Supporters Information Pack

PLEASE NOTE: All the contained information is advisory and under no circumstances should you change any medical regime without discussing the same with you Pancreatitis Specialist first. We take no liability for the contained advice.

By joining the Network you will help us be there, to provide this valuable information and website.

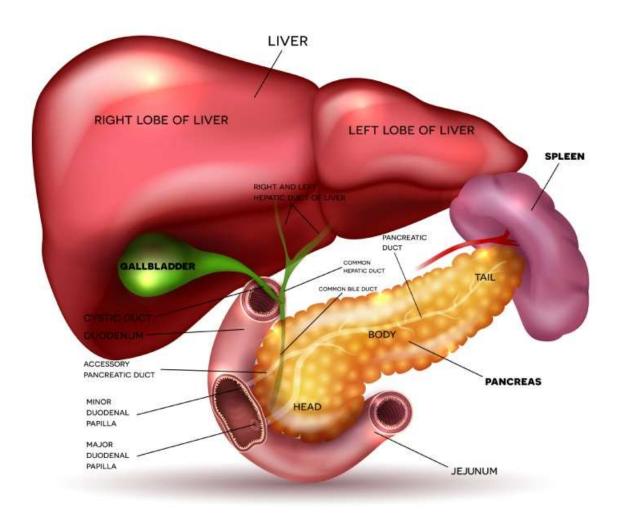
WHAT IS THE PANCREAS?

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 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

For the same reason if the main bile duct becomes blocked, then the bile cannot get into the duodenum, fat cannot be properly digested and the stools are again pale in colour. Because the bile made by the liver cannot go into the bowel it goes into the blood and out through the kidneys into the urine. This results in the eyes and skin becoming yellow and is known as yellow jaundice. As the bile is in the urine this now becomes dark in colour. Because the flow of bile is blocked (or obstructed), doctors call this condition obstructive jaundice. As the bile duct goes through the head of the pancreas yellow jaundice can be caused by disease of the pancreas (such as pancreatitis or cancer.

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.

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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 taste 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 of 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.

SPECIAL TESTS FOR PANCREATIC FUNCTION IN CHRONIC PANCREATITIS

TESTS FOR 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.

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 separate '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.

HOW CAN I MODIFY MY DIET AND DAILY ACTIVITIES TO HELP TREAT PANCREATITIS? ANSWER SUBMITTED BY THE PANCREATIC SOCIETY OF GREAT BRITAIN AND IRELAND.

The single most important change that any sufferer from chronic pancreatitis can make is to stop drinking alcohol. Even if your pancreatitis is not directly caused by alcohol, it is likely that drinking alcohol will harm the pancreas because it stimulates the production of a thick, sticky pancreatic juice which tends to clog the pancreatic ducts. This adds to the drainage already taking place in the pancreas. It is probably also helpful to stop smoking, because smoking stresses the body's natural defence mechanisms against inflammation and may contribute to the damage occurring in the pancreas. A well balanced diet is probably helpful. You need not restrict fatty food and in fact an adequate intake of fat may help to prevent weight loss. If you have access to a dietician, you should ask for advice on how to maintain an intake of 100 grams of fat and 100 grams of protein each day. If this diet causes symptoms such as diarrhoea or looseness of stools it is better to begin or increase the dose of pancreatic enzyme supplements rather than to cut down the amount you are eating.

Can vitamin supplements help? There is some evidence that antioxidants help to protect against inflammation in a wide variety of diseases. There are many vitamin preparations with added antioxidants available from chemists and Health Food shops. These preparations will certainly do no harm, and some patients find their pain is less severe or less frequent when they are taking them. Look out for formulations which contain vitamin C.

Questions to our Patron – Prof Mike Larvin



What is the relationship between alcoholism and Pancreatitis?

Q: By the way has there ever been any statistics on the causes of pancreatitis? **A:** The only 'survey' I have heard of was by Manchester Royal Infirmary for their Bioantox treatment and they could only find 20% alcohol related.

Q: The Digestive Diseases Foundation is quoting 70-80% as the cause in Acute attacks. Is this true? **A**: No-one really has good data. Almost everyone who develops it used to drink some alcohol so it is an easy assumption that this was the cause (as you and your wife know)! My own suspicion is that rich western style food, maybe social alcohol and possibly stress (oxidant and mental) all contribute to gradually knackering the pancreas. Add in a little genetic predisposition (this is becoming a hot topic) and it explains why some get it but most don't - despite the same risk factors. Undoubtedly some patients also have a mechanical element - sphincter dysfunction, gallstones recurrently passing by etc.

Q: What do you conclude from this long list?

A: Well just that we don't really know. What you read depends on location and social mix of the patients concerned. US, Germany and Scandinavia have a big proportion of alcohol related disease (notice that I avoid the term 'alcoholic' Pancreatitis' as most alcohol related disease occurs in social drinkers).

(I think this is a very important point to get across to a lot of the medical profession who automatically class us as being alcoholics! – Editor)

Question to Mike Larvin on Pregnancy and Pancreatitis plus Cystic Fibrosis (CF)

Q. My reason for writing, is that my Niece has been trying for a long time to have a child, and no results. She is wondering if the combination of a CF gene and the Pancreas condition prevents her from becoming pregnant? She is too upset to search this information on her own (she also suffers from depression), so she has asked for my help. Please provide as much medical information, or sources, on this topic (asit relates to preventing pregnancy) as possible. (Left Anon by Editor)

A. Poor nutrition can occur if enzyme replacement is not given/taken for either condition, so infertility can be a result of that. I can't really add much here as I am not an expert in non-pancreatic elements of CF. She should also consider that it is best to have depression treated fully before aiming for pregnancy maybe, but there is no alternative to seeing her GP with a view to a specialist consultation at her local CF clinic - they will know what to advise. Even though she is only a carrier (you need two genes to develop CF but we know some carriers do have problems pancreatic and otherwise, it is unfortunately not as exact a science as we would like. I would encourage the lady to make sure her niece seeks a professional CF opinion unless her GP can help with this.

ANTIOXIDANT THERAPY FOR PANCREATITIS

BIO ANTOX INFORMATION SUMMARY

February 1995 (edited due to lack of space. Full article in Archives on The Pancreatitis Supporters Network website).

BIO ANTOX - This preparation allows substantial reduction in daily tablet intake by combining the essential amino acid methionine, antioxidant vitamins and trace element selenium.

Detailed background evidence, to support the use of antioxidants in pancreatitis, is given in the summary which follows. It is stressed that treatment should be part and parcel of a shared care protocol, so that blood antioxidant and free radical marker profiles can be checked at intervals to ensure compliance and adequacy of dosage.**PROPRIETARY NAME: BIO ANTOX** MANUFACTURER: Pharm Nord and distributed by Pharma Nord (UK) Ltd. Spital Hall, Mitford, Morpeth NE16 3PN

PRESENTATION: Tablets (150 in a box) typically containing:

containing.	
selenium (organic)	75 ug
methionine	400 mg
beta carotene	3 mg
vitamin C	150 mg
vitamin E	47 ug
LICENSED INDICATIONS:	None

CURRENT STATUS: Pharma Nord have given Pancreato Biliary Consultants an undertaking that Bio-Antox, the formulation of which is based entirely on the work of the Manchester group, will not be available "over the counter". The same company markets a range of food supplements, one of which is called Bio Antioxidant, but this should not be confused with Bio Antox. Both contain micronutrients and vitamins but the formulations of each markedly differ.

Sources as ultraviolet light, substance abuse (for example alcohol or cigarettes), and, above all, environmental pollutants. The notion that antioxidant supplementation might be protective to a population by increasing its defence against pro oxidant factors, is gaining ground, as witnessed by a plethora of studies in the field of atherosclerosis. The therapeutic corollary was exploited by the Manchester group almost a decade ago and has been validated by placebo controlled trials, while sporadic reports from other groups are beginning to offer independent endorsement of this treatment.

DEVELOPMENT OF ANTIOXIDANT THERAPY: Background - There is increasing evidence that habitually poor diets render body organs vulnerable to oxidative stress, and hence tissue injury, when free radical load exceeds antioxidant defence capability. In general terms this load may derive from such dissimilar

QUESTIONS TO BE ANSWERED

- Q: What need is met by this therapy?
 A: Treatment of patients with chronic or recurrent acute pancreatitis
- Q: What happens now?
 A: Patients are treated with anal-gesics, or may go on to near-total pan-createctomy resulting in malabsorption and diabetes.
- Q: Is quality improved?
 A: Yes patients on this treatment do not have pain.
- Q: What does the treatment cost?
 A: Less than 15 pounds per month per patient.
- Q: Can cost savings be made?
 A: Yes though not quantified, the cost of treatment with antioxidants is likely to be much less than present treatments.

Advice to Health Authorities and GP^{*}s Will increase quality and effective-ness. May result in reduced costs. Worth considering in specification.

(WARNING: Do not self dose with these ingredients as without proper monitoring some of these ingredients are POISONOUS! We no longer have a group supporting this treatment but if they set up another helpline in the future, we will include it here).

TRANS FATTY ACIDS

First, a little about trans fat. I would like to climb up on the soapbox, but I'll save that for another time.

Trans Fatty Acid's (TFA's) main use is to extend the shelf life of a product. Foods containing trans-fat have a much longer shelf life because it doesn't spoil. It's secondary purpose is to change a liquid oil into a solid. This is why shortening is white and solid, but pure corn oil is a liquid. The following list contains the most common foods containing TFA's. It is by no means complete. It will identify some of the obvious foods to watch out for.

Trans Fat List:

Margarine, vegetable shortening, pastries, peanut butter, French fries (except those made at home from fresh potato's, fried in pure vegetable oil), most fast food, most cookies (Internet cookies are OK), most frozen dinners (low fat included), most snack foods, most cakes

(prepared and boxed, I would. like to give the Dough Boy an extra hard poke in the belly), most potato chips, most crackers, most restaurant food (because it is usually prepared with shortening), some candies, some ice creams, some pizza (depends on ingredients used), most vending machine foods.

TFA Free Foods:

All fat free foods, Meats, Eggs, Milk, Fruits, Vegetables, Fish, Most candy, Soft drinks, Coffee, Tea, Vegetable oil, Chocolate, Grilled foods, Most cheeses, Yogurt, Most breads, No fat mayonnaise, Ketchup's, Mustard.

Specific TFA Free Foods:

Krusteze brand cake and muffin mix, Certain Pringles Potato chips, Smart Balance spread (new and patented for not containing TFA"s, and for being able to help balance fat metabolism), Kraft or Henry's no fat salad dressing, These specifics were included because in these food categories it's hard to find any products that are TFA free. If anyone finds more please let me know and I'll add them to the list. If the theory holds and the condition of the pancreas improves, small amounts of other natural fats, such as monounsaturated, polyunsaturated, and saturated, may be beneficial. Some research indicates that a balanced fat diet is very important to the overall health of an individual.

A Final Thought:

Human evolution has been taking place for some 4 or 5 million years. During that long span our digestive systems slowly adapted to the foods that were consumed. Now we have been introduced to hydrogenated oils. It is killing or making sick those who cannot adapt to it. Given a few thousand years we won't have to worry about hydrogenated oil because those not able to adapt to it will be gone.

PANCREATIC ENZYME SUPPLEMENTS

(We are often asked how many enzymes should we be taking, I hope the below article, from Liverpool University Hospital"s Web site will help).



There are many preparations available. These preparations differ considerably in their effectiveness of action. The better preparations consist of capsules containing scores of small granules. The enzyme preparations can also be divided into two types depending upon their strength of action: regular and high dose. The capsules need to be taken during each meal and with any snack.

Requirements vary enormously from patient to patient: **typically 20-30 high-dose capsules per day** are required but this can be lower or much higher. The requirements vary greatly 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 intestines but which also varies 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 of the enzyme preparations (called methacrylic copolymer). The problem does not arise with preparations without this covering. The latter preparations are therefore recommended. 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 them-selves to suit their own individual needs.

AN ANSWER TO PANCREATIC PAIN?

Written by William D Broadfoot FISTC, MCIM [Heavily edited by the Editor!]

The author is a Fellow of the Institute of Scientific and Technical Communicators and is also a Chartered Consultant who is working alongside two Bristol based doctors (AJR MacDonald and TW Coates) to help them introduce a new method of pain relief known as Transcutanous Spinal Elec-troanalgesia (TSE for short)

The X-Pain machine is fundamentally different to the well-established "TENS" machine and indeed has more in common with the surgical technique known as Spinal Cord (Dorsal Column) Stimulation which has been practiced since 1967 to provide sufferers of acute pain with measure of relief. Over a 28 year period there has been no indication of any possible side effects related to the transmission of electricity to this area.

In a major scientific breakthrough it was discovered that when injury was caused to any part of the body, spinal cord interneurones (nerve cells) exhibit a dramatic behavioural change which is manifest by the production of c-FOS protein. Once spinal cord interneurones have been triggered by news of an injury it would appear that these nerve cells can subsequently remain active for decades - and certainly long after the injured part has healed completely. As a result - and for reasons which remain obscure - spinal cord interneurones continue to send warning messages to the brain which results in millions of people suffering completely unnecessary pain for much of their lives.

Since electricity was first generated and harnessed for use; its pain-relieving properties have been noted and applied. Transcutanous Electrical Nerve Stimulation (TENS) devices use electrical stimulation to excite AB [Editor's note: The B here is the Greek symbol] fibres in the area where pain is experienced. They are arguably the modern equivalent of applying a hot water bottle or ice pack (or healers' hands) to the apparent seat of the pain.

All these methods have an indirect effect on the mechanism of the spinal cord interneurones. *However they have to be applied to the correct place [My italics, Editor],* and therefore considerable skill is required by the practitioner. When pain is felt in the elbow, for example, the tender region which requires treatment may well be in the neck. If the patient has two elbows in trouble and a knee as well, several regions require simultaneous treatment *[rather like acupuncture: Editor].*

The only way to do this was to aim for the spinal cord itself. The key to success, the two Bristol doctors discovered, was to determine the precise intensity, frequency and pulse width of electrical input to the spinal area which would cause the spinal cord interneurones to become dormant.

To achieve this they placed two electrodes at the top and base of the spine. Obviously, electrical energy takes the most direct route and will therefore flow parallel to the spine. The electrical energy which reaches the spinal cord is minute in terms of duration so there is no stimulation of the peripheral nerves in the area - in other words, no localized pain.

The doctors then developed a simple portable pulse generator which the patient adjusts until a slight warming sensation is felt. There is no discomfort. One patient who was treated by doctors using this device suffered recurring spasms of pain for over 40 years since being struck in the stomach by a rifle butt during the Korean War. Other patients using the X-Pain device have experienced almost immediate relief where the original cause of the injury has long healed or is 'on the mend'.

This is particularly true of neck and back sufferers who have sufferers an injury to their spine sometime previously. The same is true to people who suffer from painful limbs, stress aches, migraines, headaches, postoperative pains, arthritis, menstrual pains, and 'modern living' complaints such as repetitive stress injury and M.E.

The X-Pain method of pain relief is not an anesthetic. It will not provide relief for patients suffering from any pain generating condition. Equally, it will not hide the symptoms of heart attacks, or angina, or where there is inflammation to any organ brought about by disease. Such pains are ongoing and the signals will continue to be sent to the brain regardless of any TSE treatment.

People who have a medical condition which requires the use of a Pacemaker or other implanted electrical stimulator would not use the TSE method - nor should pregnant women, without first seeking medical advice. The closest competitor to the TSE method is the widely practiced method of the "TENS" machine.

TSE offers five distinct advantages when compared to this form of treatment:-

- TSE provides longer lasting relief from pain (possibly even permanent relief in some cases).
- The pain relieving benefits do not diminish the more you use the TSE machine.
- TSE takes less time to use
- TSE provides simultaneous relief of pain across the entire body rather than one place.
- TSE does not require anatomical knowledge to site the electrodes correctly.

In summary, TSE would appear to represent a major advance in pain therapy. *(Editor in this article refers to The Pancreatitis Supporters Network.)*

******Unfortunately there is a dispute between the manufacturers on this product and as a result production has been suspended.******



Acticare TSE Dr Alex Macdonald co-inventor of TSE Available from: <u>http://www.acticare.com</u> (When produced) Article refers to the original ENM/X-Pain Device now refined with more features and called Acticare



Forms of Pancreatitis

(As taken from University Hospital Website, Liverpool)

I think this is a marvellous description of all the forms of Pancreatitis;

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.

PANCREATITIS 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 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 this can eventually lead to chronic pancreatitis.

The treatment involves enlarging the narrowed pancreatic duct opening and can occasionally be done by endoscopic sphincterotomy (see above). An open surgical operation can also be performed that involves opening the duodenum and is called trans-duodenal sphincteroplasty.

The operation may involve enlarging both the biliary and pancreatic sphincters (see above) and is therefore called a double sphincteroplasty. If the pancreatic duct is very distended then this can be drained into a piece of bowel and the operation is called a Roux-en-Y lateral pancreato-jejunostomy. If the head of the pancreas is damaged by the pancreatitis sometimes it may be necessary to remove a part of the pancreas (Beger's operation).

AUTOIMMUNE PANCREATITIS

This is a rare condition that causes chronic pancreatitis. The actual cause of the condition is not known. In the pancreas of this condition there are many cells of the type that make antibodies and other cells involved with immunity. This is why it is called autoimmune pancreatitis. The diagnosis is extremely difficult to make. There is often obstructive jaundice and a swelling in the head of the pancreas. It is therefore not surprising that it is often confused with a tumour in the head of the pancreas. In fact the correct diagnosis is usually only made after major surgery to remove the head of the pancreas (Kausch-Whipple operation). The condition will respond to a course of steroids and pancreas enzyme supplements.

IDIOPATHIC

This is a loosely applied term used by doctors to mean "the cause is specific to an individual person" – in other words the cause is not known for certain. Many patients initially diagnosed as "idiopathic" turn out to have a known cause – such as autoimmune pancreatitis or hereditary pancreatitis

The pancreatitis can begin in children or young adults and is referred to as juvenile-onset idiopathic pancreatitis. Alternatively it may first begin in older adults and is referred to as late-onset idiopathic pancreatitis. There may be a genetic basis to the pancreatitis. This often involves an alteration to a gene called SPINK-1 or an alteration to a gene called the cystic fibrosis gene, which is also called the CFTR gene. Inheritance in pancreatitis is explained in more detail below.

DOES CHRONIC PANCREATITIS RUN IN FAMILIES?

In general, the answer is NO as it is mainly due to alcohol. Nevertheless alcohol is not the problem in one in three patients and in these cases, there may be a genetic basis for the pancreatitis. Therefore, although it is quite rare, it is possible for pancreatitis to run in families and falls into two types: hereditary pancreatitis and some forms of idiopathic pancreatitis.

INHERITED PANCREATITIS

Inherited pancreatitis happens because they have an altered gene which predisposes to pancreatitis. What are genes?

Each person has exactly the same number of genes as every other person. The total number of genes is 30,000. Genes are in the nucleus of each cell of the body. Genes are like the blueprints in a factory. These blueprints (or genes) enable the cell to make proteins which then organise the two other types of basic molecule (carbohydrates and fats) to create particular types of cell and hence the different organs (such as liver, arms and legs and so on). In the cells of different organs only some of the 30,000 genes in the nucleus are selected for use. This number varies from 6,000 to 10,000 genes in any particular cell. The different combination of genes used as blueprints for making proteins is how the human body can be organised in such a complicated way (compared to a simple worm that has only 900 genes).

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. An alteration in a gene that gives rise to a disease is often referred to as a mutation (this is a Latin word that simply means "changed"). Patients and their families with inherited pancreatitis require the care of a specialist surgeon, paediatrician or gastroenterologist and genetic counselling.

HEREDITARY PANCREATITIS

In this type of inherited pancreatitis there is a tiny variation in the cationic trypsinogen gene. The trypsinogen gene provides the blueprint to make a protein called trypsinogen. Trypsinogen is not active in any way and itself is quite harmless. During a meal trypsinogen is secreted into the main pancreatic duct and then into the duodenum. Trypsinogen is then made very active by the removal of a protective cap at one end of the molecule. Once this cap has been removed it is now called trypsin, which is also an enzyme and is now very active. As mentioned above trypsin is also an enzyme and is used to digest the proteins in foods such as meat.

What happens in hereditary pancreatitis is that the protective cap of trypsinogen is removed in the pancreas. This unfortunately results in active trypsin in the pancreas. This activation occurs before it has had a chance to be secreted into the duodenum. This activated trypsin then begins to attack other proteins actually within the pancreas and causes acute pancreatitis.

The gene is officially called the PRSS1 gene and the two commonest alterations (or gene mutations) are called R122H and N29I. There are however 20 or so different mutations that have been discovered. 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. The altered gene can be passed on by either the father or the mother and only one altered gene needs to be passed on to cause pancreatitis. The technical term for this kind of inherited disease is autosomal dominant. ("Autosomal" refers to the fact that is not linked to the sex genes and "dominant" means that the altered gene is stronger than the normal gene). 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 will not be affected at all. We call this 80% penetrance because the disease will only "penetrate" into 80% of people with altered gene.

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 PRSSI genes. This means that another gene is affected and scientists are trying to find out which one this is.

Idiopathic Pancreatitis

Up to half of all patients with idiopathic pancreatitis (see above) have inherited one of two other altered genes that can trigger pancreatitis. One is called SPINK-1 and the other is called CFTR.

In order to protect the pancreas against accidental conversion of trypsinogen to trypsin, humans have been equipped with a safety mechanism called SPINK-1. This is a special enzyme that destroys any active trypsin in the pancreas and hence stops pancreatitis from occurring. Unfortunately some individuals have an alteration in SPINK-1 called the N34S mutation, which destroys the safety mechanism.

About one in fifty people have the N34S mutation but less than 1% of these people ever get acute pancreatitis. In other words this altered gene has less than 1% penetrance, or very low penetrance. This means that there is some other reason as well for the pancreatitis. This means that even though the N34S mutation was inherited from either the mother or the father, the parents are usually not affected. Also this means that the disease is very either the mother or the father, the parents are usually not affected. Also this means that the disease is very unlikely to be passed on to the children even though there is a fifty-fifty chance that the N34S mutation will be passed on to the children even though there is a fifty-fifty chance that the N34S mutation will be passed on to them.

Some patients have an alteration in the gene that causes cystic fibrosis, known as the CFTR gene. This gene provides the blueprint that makes a protein also called CFTR. This protein regulates the passage (or conductance) of small molecules through the outer surface (or membrane) of the cell. An alteration in both genes (the one from the mother and the one from the father) causes the disease called cystic fibrosis. For all of these reasons the full name of the gene is the cystic fibrosis transmembrane conductance regulator 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. People with idiopathic pancreatitis only have one CFTR gene mutation (either from the mother or from the father). This type of genetic disease is therefore called autosomal recessive. We do not understand why some people with only one CFTR gene mutation develop pancreatitis. Scientists are trying to find out why this happens.

In these rare forms of pancreatitis, the symptoms begin as acute pancreatitis and usually progress to chronic pancreatitis. This also applies to a number of other causes of acute pancreatitis but gallstones never cause chronic pancreatitis unlikely to be passed on to the children even though there is a fifty-fifty chance that the N34S mutation will be passed on to them.

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USEFUL ORGANISATIONS

PANCREATITIS SUPPORTERS NETWORK

The only worldwide registered charity working for the patient.

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.

Write to: Mr. Jim Armour, Chairman, The Pancreatitis Supporters Network, PO Box 8938, Birmingham, B13 9FW.

Tel: (+44) 075394250434

email psn@pancreatitis.org.uk website http://www.pancreatitis.org,uk

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. Write to: Mr Ross Carter Secretary - Pancreatic Society of Great Britain and Ireland

Consultant Surgeon - Glasgow Royal Infirmary

84 Castle Street, Glasgow, G4 0SF

Tel: 0141 211 5129 Fax: 0141 211 4991

rcarter@clinmed.gla.ac.uk

MRI PANCREATITIS SUPPORT GROUP

MRI Pancreatitis Support Group, Pancreato-biliary administrator, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9WL. Provides support and advice to patients with pancreatitis in the Manchester region. Contact Margaret O'Brien

Tel: 01457 873859.

Write to: MRI Pancreatitis Support Group, Pancreato-biliary administrator, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9WL.

PANCREAS RESEARCH FUND

Specifically supports basic and clinical research of all diseases of the pancreas. Write to: Professor JP Neoptolemos - Division of Surgery and Oncology, Royal Liverpool University Hospital, Daulby Street, Liverpool, L69 3QA Tel: 0151 706 4175 http://www.liv.ac.uk/surgery/about.html

j.p.neoptolemos@liv.ac.uk

DIGESTIVE DISORDERS FOUNDATION

Supports research into digestive diseases. Write to: 3, St Andrew's Place, London, NW1 4LB Tel: 0207 486 0341 http://www.digestivedisorders.org.uk

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, Division of Surgery and Oncology, Royal Liverpool University Hospital, Daulby Street, Liverpool, L69 3QA.

http://www.liv.ac.uk/surgery/europac.html europac@liv.ac.uk

BENEFITS HELP

Although we will do what we can to help over the telephone, it is often more appropriate for you to get a LOCAL help centre to assist you in filling in the forms when claiming for Disability Living Allowance or Attendance Allowance etc.

We can give general hints and tips on how to claim these, and other benefits but nothing beats having someone sit beside you while you fill one of these forms in.

The following are the Head Offices of a number of Organisation who should be able to help and if you call them they should be able to give you a local branch to where you live.

ADVICEUK

12th Floor New London Bridge House, 25 London Bridge Road, London, SE1 9ST AdviceUK can provide details of your local advice agency. Tel: 020 7407 4070 Web Site: <u>www.adviceuk.org.uk</u> general@adviceuk.org.uk

AGE CONCERN
 Freepost (SWB30375), Ashburton, Devon, TQ13 7ZZ.
 Age Concern can provide you with details of a local Age Concern Branch.
 Tel: 0800 00 99 66
 Web Site: www.ageconcern.org.uk

email@email.com

CITIZENS' ADVICE

Myddelton House,115-123 Pentonville Road, London, N1 9LZ. Citizens' Advice can provide details of local Citizens' Advice Bureau. Tel: 020 7833 2181 Web Site: <u>www.citizensadvice.org.uk</u>

DIAL UK

Park Lodge, St Catherine's Hospital, Tickhell Road. Balby, Doncaster. DN4 8QN DIAL is a national network of disability information and advice services. They can provide a list of local DIAL groups in England and Wales. Tel/Textphone:01302 310123 Web Site: <u>www.dialuk.org.uk</u> <u>enquiries@dialuk.org.uk</u>

✤ LAW CENTRES FOUNDATION

Duchess House, 18-19 Warren Street, London, W1T 5LR. The Law Centres Federation can provide a list of local law centres in England and Wales. Tel: 020 7387 8570 <u>info@lawcentres.org.uk</u>

DISABILITY ALLIANCE

Universal House, 88-94 Wentworth Street, London, E1 7SA.

Tel: 020 7247 8776 (textphone also available)

Fax: 020 7247 8765

Rights Advice Line: 020 7247 8763 (textphone available).

This Organisation produces a variety of publications on specifically how to claim a benefit. It is worthwhile buying a copy of the one relating to the benefit you are trying to claim as these show the language and format needed for a successful claim. ALWAYS be prepared to APPEAL or even the next stage TRIBUNAL. At each of these stages get a copy of what basis you were turned down on in the first place.

Web Site: www.disabilityalliance.org

office@dial.pipex.com

SPECIALIST PANCREATIC CENTRES

Find your specialist and get your GP to do a letter of referral. Your GP cannot refuse to do this under Choose and Book and The Patients Charter. Both of which can be found in the LINKS tab. Some will do a one-off private consultation for about £150 BUT you MUST specify at your initial consultation that you want all tests and treatment under the NHS.

Aberdeen Royal Infirmary Foresterhill Aberdeen AB24 2ZN
St Bartholomew's Hospital West Smithfield London Greater London EC1A 7BE
Trust Headquarters, A Floor Belfast City Hospital Lisburn Road Belfast BT9 7AB
Queen Elizabeth Hospital Birmingham Mindelsohn Way Edgbaston Birmingham B15 2WB
Royal Blackburn Hospital, Haslingden Road Blackburn Lancashire BB2 3HH
Marlborough Street Bristol Avon BS2 8HW
Addenbrooke's Hospital Hills Road Cambridge Cambridgeshire CB2 0QQ
St David's Hospital Cowbridge Road East Canton Cardiff CF11 9XB
Mercy University Hospital Grenville Place Cork Ireland
University Hospital Clifford Bridge Road Coventry West Midlands CV2 2DX
Royal Derby Hospital Uttoxeter Road Derby Derbyshire DE22 3NE
St Vincent's University Hospital Elm Park Dublin 4
Ninewells Hospital Dundee DD1 9SY
51 Little France Crescent Old Dalkeith Road Edinburgh EH16 4SA
Glasgow Royal Infirmary 84 Castle Street Glasgow G4 0SF
Frimley Park Hospital NHS Foundation Trust Portsmouth Road Frimley Surrey GU16 7UJ
Du Cane Road London Greater London W12 OHS
Anlaby Road Hull East Yorkshire HU3 2JZ

Kings College Hospital	
	Denmark Hill London SE5 9RS
Leeds General Infirmary	Great George Street Leeds West Yorkshire LS1 3EX
Leicester Royal Infirmary	Infirmary Square Leicester Leicestershire LE1 5WW
Liverpool	The Royal Liverpool University Hospital Prescot Street Liverpool Merseyside L7 8XP
Luton	Luton and Dunstable Hospital The L&D Hospital NHS Foundation Trust Lewsey Road Luton Bedfordshire LU4 0DZ
Manchester Royal Infirmary	Oxford Road Manchester Greater Manchester M13 9WL
Marsden	The Royal Marsden Hospital Fulham Road London Greater London SW3 6JJ
Newcastle	Freeman Hospital Freeman Road High Heaton Newcastle upon Tyne Tyne and Wear NE7 7DN
Newcastle	Mr Jeremy French - Department of HPB Surgery, Freeman Hospital,Newcastle, NE7 7DNe-mail: jeremy.french@nuth.nhs.uk24Tel: 00 44 191 2231525/ 00 44 191 2448750Fax: 00 44 191 223 1191
North Manchester General	Delaunays Road Crumpsall Manchester Greater Manchester M8 5RB
Nottingham University Hospitals	NHS Trust – City Campus Nottingham City Hospital Hucknall Road Nottingham Nottinghamshire NG5 1PB
Oxford	John Radcliffe Hospital Headley Way Headington Oxford Oxfordshire OX3 9DU
Plymouth Hospitals NHS Trust	Derriford Road Crownhill Plymouth Devon PL6 8DH
Royal Free	The Royal London Hospital Whitechapel Road London Greater London E1 1BB
Royal London	Whitechapel Road London E1 1BB
Sheffield	Royal Hallamshire Hospital Glossop Road Sheffield S10 2JF
Southampton General Hospital	Tremona Road Southampton Hampshire SO16 6YD
Stoke	Royal Infirmary Princes Road Stoke on Trent ST4 7LN
Swansea	Morriston Hospital West Glamorgan SA6 6NL
UCL	University College London Gower Street London WC1E 6BT

EXTRACT FROM CHOOSE AND BOOK

NHS – Uk Only

WHAT IS CHOOSE AND BOOK?

Choose and Book is a service that lets you choose your hospital or clinic and book your first appointment. When you and your GP agree that you need an appointment, you can choose which hospital or clinic you go to. You will also be able to choose the date and time of your appointment.

WHAT DOES CHOOSE AND BOOK MEAN FOR ME?

As well as giving you a choice of hospital, date and time for your appointment, Choose and Book will also give you the ability to:

- ✓ plan and manage your appointments around any existing appointments, if you are currently undergoing treatment;
- ✓ fit your treatment in with your other commitments, at home and at work;
- ✓ choose appointments that fit with your carer's schedule; and
- ✓ check the status of your referral and change or cancel your appointments easily over the phone or on the internet.

HOW DOES CHOOSE AND BOOK WORK?

When you and your GP agree that you need an appointment with a specialist, Choose and Book shows your GP which hospitals or clinics are available for your

treatment. Your GP discusses with you the clinically appropriate options that are available for treating your medical condition.

If you know where and when you would like to be seen, you may be able to book your appointment before you leave the practice. You will be given confirmation of the place, date and time of your appointment.

You may want more time to consider your choices. If so, you can take the Appointment Request letter away with you and book your appointment later. Your Appointment Request letter lists your unique booking reference number, your NHS number and a list of hospital or clinic options for you to choose from. Your GP practice will also give you a password with your Appointment Request letter.

You can then decide how you wish to book your appointment; via the telephone, using the national number on the letter or via the internet. Please note that whilst the vast majority of appointments can be booked this way, in some cases you will need to telephone your chosen hospital directly to make your appointment. This is because the hospital appointments system does not link to Choose and Book.

CAN I BOOK ALL MY APPOINTMENTS THROUGH CHOOSE AND BOOK?

When you and your GP agree that you need an appointment with a specialist, you can book your first hospital or clinic appointment using Choose and Book. Any follow up appointments are arranged by the hospital themselves.

THE BENEFITS OF CHOOSE AND BOOK:

You can choose any hospital in England funded by the NHS (this includes NHS hospitals and some independent hospitals). More information about hospitals is available on the NHS Choices website;

You can choose the date and time of your appointment;

You experience greater convenience and certainty. With Choose and Book, the choice is yours; and There is a reduced risk that correspondence gets lost in the post as most of the communication is done via computers.

For more information please go to their website: <u>http://www.chooseandbook.nhs.uk/patients/whatiscab</u>

Extract from The Patients Charter – NHS – UK Only

Patients and the public - your rights and NHS pledges to you

Everyone who uses the NHS should understand what legal rights they have. For this reason, important legal rights are summarised in this Constitution and explained in more detail in the Handbook to the NHS Constitution, which also explains what you can do if you think you have not received what is rightfully yours. This summary does not alter your legal rights.

The Constitution also contains pledges that the NHS is committed to achieve. Pledges go above and beyond legal rights. This means that pledges are not legally binding but rep Access to health services:

- You have the right to receive NHS services free of charge, apart from certain limited exceptions sanctioned by Parliament.
- You have the right to access NHS services. You will not be refused access on unreasonable grounds.
- You have the right to expect your NHS to assess the health requirements of your community and to commission and put in place the services to meet those needs as considered necessary, and in the case of public health services commissioned by local authorities, to take steps to improve the health of the local community.
- You have the right, in certain circumstances, to go to other European Economic Area countries or Switzerland for treatment which would be available to you through your NHS commissioner.
- You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.
- You have the right to access certain services commissioned by NHS bodies within maximum waiting times, or for the NHS to take all reasonable steps to offer you a range of suitable alternative providers if this is not possible. The waiting times are described in the Handbook to the NHS Constitution.

THE NHS ALSO COMMITS:

- to provide convenient, easy access to services within the waiting times set out in the Handbook to the NHS Constitution (pledge);
- to make decisions in a clear and transparent way, so that patients and the public can understand how services are planned and delivered (pledge); and
- to make the transition as smooth as possible when you are referred between services, and to put you, your family and carers at the centre of decisions that affect you or them (pledge).

QUALITY OF CARE AND ENVIRONMENT:

- You have the right to be treated with a professional standard of care, by appropriately qualified and experienced staff, in a properly approved or registered organisation that meets required levels of safety and quality.
- You have the right to expect NHS bodies to monitor, and make efforts to improve continuously, the

THE NHS ALSO COMMITS:

- to ensure that services are provided in a clean and safe environment that is fit for purpose, based on national best practice (pledge);
- to identify and share best practice in quality of care and treatments (pledge); and that if you are admitted to hospital, you will not have to share sleeping accommodation with patients of the opposite sex, except where appropriate, in line with details set out in the Handbook to the NHS Constitution (pledge).

NATIONALLY APPROVED TREATMENTS, DRUGS AND PROGRAMMES:

- You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you.
- You have the right to expect local decisions on funding of other drugs and treatments to be made rationally following a proper consideration of the evidence. If the local NHS decides not to fund a drug or treatment you and your doctor feel would be right for you, they will explain that decision to you.
- You have the right to receive the vaccinations that the Joint Committee on Vaccination and Immunisation recommends that you should receive under an NHS-provided national immunisation programme.
- If you are detained in hospital or on supervised community treatment under the Mental Health Act 1983 different rules may apply to treatment for your mental disorder. These rules will be explained to you at the time. They may mean that you can be given treatment for your mental disorder even though you do not consent.
- You have the right to express a preference for using a particular doctor within your GP practice, and for the practice to try to comply.
- You have the right to make choices about the services commissioned by NHS bodies and to information to support these choices. The options available to you will develop over time and depend on your individual needs. Details are set out in the Handbook to the NHS Constitution.

THE NHS ALSO COMMITS:

- to inform you about the healthcare services available to you, locally and nationally (pledge); and to
 offer you easily accessible, reliable and relevant information in a form you can understand, and
 support to use it. This will enable you to participate fully in your own healthcare decisions and to
 support you in making choices. This will include information on the range and quality of clinical
 services where there is robust and accurate information available (pledge).
- Involvement in your healthcare and in the NHS:
- You have the right to be involved in discussions and decisions about your health and care, including your end of life care, and to be given information to enable you to do this. Where appropriate this right includes your family and carers.

THE NHS ALSO COMMITS:

- to provide you with the information and support you need to influence and scrutinise the planning and delivery of NHS services (pledge);
- to work in partnership with you, your family, carers and representatives (pledge);

- to involve you in discussions about planning your care and to offer you a written record of what is agreed if you want one (pledge); and
- to encourage and welcome feedback on your health and care experiences and use this to improve services (pledge).

COMPLAINT AND REDRESS:

- You have the right to have any complaint you make about NHS services acknowledged within three working days and to have it properly investigated.
- You have the right to discuss the manner in which the complaint is to be handled, and to know the period within which the investigation is likely to be completed and the response sent.
- You have the right to be kept informed of progress and to know the outcome of any investigation into your complaint, including an explanation of the conclusions and confirmation that any action needed in consequence of the complaint has been taken or is proposed to be taken.
- You have the right to take your complaint to the independent Parliamentary and Health Service Ombudsman or Local Government Ombudsman, if you are not satisfied with the way your complaint has been dealt with by the NHS.
- You have the right to make a claim for judicial review if you think you have been directly affected by an unlawful act or decision of an NHS body or local authority.
- You have the right to compensation where you have been harmed by negligent treatment.

The NHS also commits:

- to ensure that you are treated with courtesy and you receive appropriate support throughout the handling of a complaint; and that the fact that you have complained will not adversely affect your future treatment (pledge);
- to ensure that when mistakes happen or if you are harmed while receiving health care you receive an appropriate explanation and apology, delivered with sensitivity and recognition of the trauma you have experienced, and know that lessons will be learned to help avoid a similar incident occurring again (pledge); and
- to ensure that the organisation learns lessons from complaints and claims and uses these to improve NHS services (pledge).