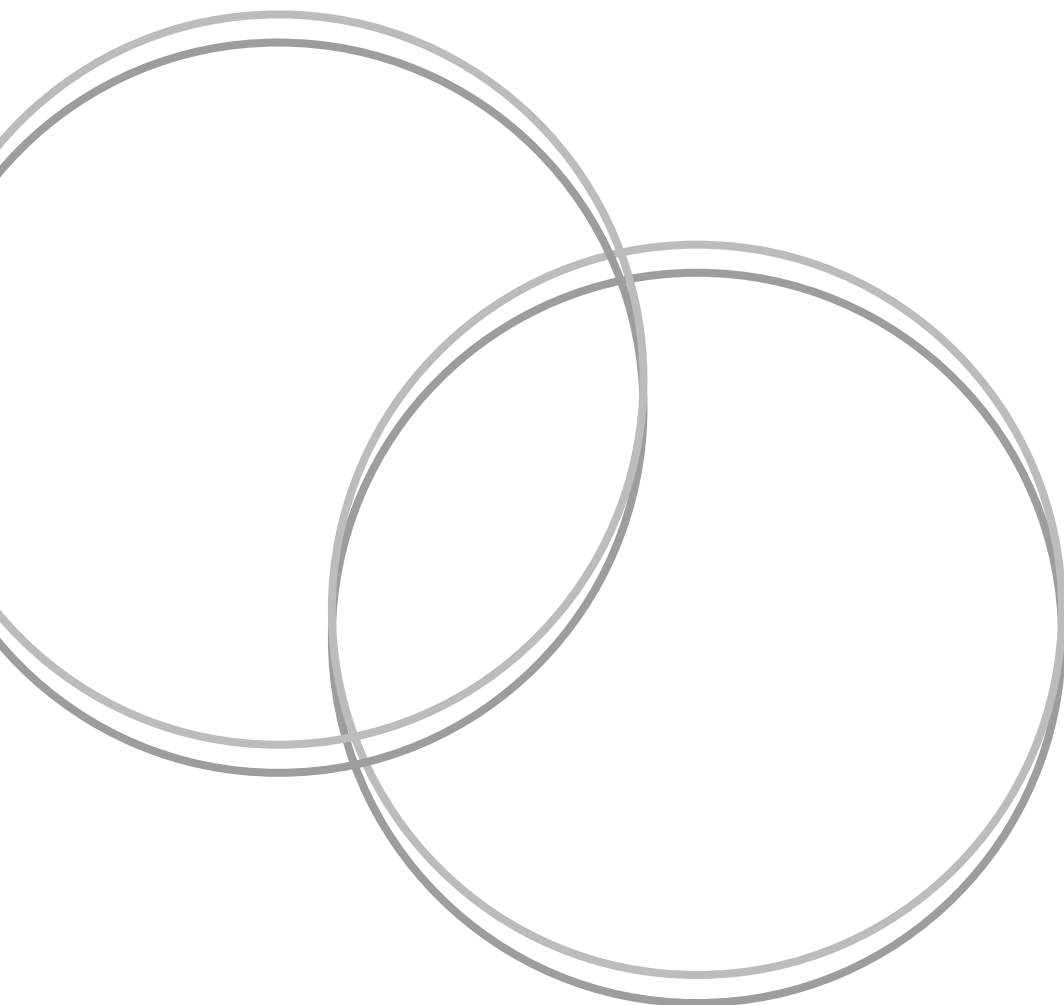


Total Pancreatectomy with Islet Autotransplant (TPIAT)

Information for patients



This information leaflet is for people who are being considered for Total Pancreatectomy with Islet Auto Transplant (TPIAT). Family and friends may also find it helpful.

This leaflet describes who is suitable for assessment, what happens in the assessment process, and in surgery and recovery. All of the assessment processes and the operation are done at the Churchill Hospital in Oxford.

TPIAT is a treatment option for a small group of patients who suffer with chronic pancreatitis. A successful TPIAT can reduce the pain of chronic pancreatitis and offers better blood sugar control from new diabetes caused by removing the pancreas.

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About the pancreas:

The pancreas is a gland about 18 to 25cm long, in the back of your abdomen (belly), behind your stomach. It is spongy and shaped like a tadpole with a head, body and tail. It lies across the abdomen.

The head of the pancreas is the largest part. It lies on the right-hand side of the abdomen, where the stomach joins the first part of the small intestine (duodenum). Here is where the stomach empties broken-up food into the small intestine, where it is mixed with digestive juices (enzymes) from the pancreas.

The tail of the pancreas is the narrowest part and lies all the way to the left side of the abdomen, next to the spleen.

What does the pancreas do?

The pancreas has two main functions: enzyme production (exocrine) and hormone production (endocrine).

Exocrine cells in the pancreas produce enzymes that help with digestion. The enzymes are drained out into the duodenum through pancreatic ducts, and help to digest fats, carbohydrates, and proteins in food.

Endocrine cells make hormones. Hormones are chemicals that enter the blood stream and carry out a particular job. Lots of hormones act as 'messengers' between different systems in the body. The most well-known of hormones made by the pancreas are insulin and glucagon. Islet cells make up just 2% of the pancreas and produce insulin and glucagon that flow into the blood stream to maintain stable levels of sugar (glucose) in the blood. When you digest food and drink, carbohydrate is broken down into glucose. Glucose passes into your blood and is used by all the cells of the body.

What is Chronic Pancreatitis?

Chronic pancreatitis is inflammation of the pancreas that does not heal or improve. It gets worse over time and leads to permanent damage due to fibrosis (production of scar tissue). Because of this damage the pancreas is unable to make enough digestive enzymes for proper digestion of food. This leads to weight loss and frequent pale, greasy stools which contain large amounts of undigested fat (steatorrhea). The damage can also affect the islet cells, so less insulin is made, leading to diabetes.

What are the treatment options for Chronic Pancreatitis?

Treatment depends on the symptoms being experienced. Treatment is mostly for pain management and nutritional support. Pancreatic enzyme replacement (Creon, pancrex) helps to digest food. For those patients who develop diabetes, tablets or insulin injections will help to manage blood sugar levels.

If you and your doctors decide that removing the pancreas is the best way to manage your symptoms and reduce the number of flare-ups and hospital admissions for pain, then a TPIAT could be suitable for you.

It is important to understand that a total pancreatectomy (removing a whole pancreas) removes the body's means of making insulin, and so having diabetes after the operation is inevitable. This can be thought of as developing type 1 diabetes.

The standard treatment for type 1 diabetes is 1 or 2 injections of long-acting, background (basal) insulin every day, with injections of more rapid-acting insulin with food.

What is Total Pancreatectomy with Islet Auto Transplant (TPIAT)?

A TPIAT is when your pancreas is removed and the islet cells are separated (isolated) from it. These islet cells are then infused back into you.

A total pancreatectomy (removal of a whole pancreas) is done with open surgery through a large cut across the top of the abdomen. The first part of the small bowel (duodenum), as well as the gallbladder and part of the bile duct are also removed. Once the pancreas is taken out, it is sent to our specialist laboratory and the islet cells (insulin, glucagon and other hormone producing cells) are carefully removed from the pancreas using special enzymes that digest the rest of the pancreas.

After the islet cells have been isolated and checked, they are put into a bag, like a fluid drip bag, and this is taken back to the operating theatre. While the islets are being prepared, the surgical team re-join your bowel and bile duct together.

The islets will be dripped into a big vein in your liver, so the surgeons will also place a temporary line directly into the vein. The islet fluid is dripped through this temporary line into the big liver vein.

The techniques used for isolating islet cells from a pancreas are well established in Oxford and carried out by a highly trained and experienced team.

However, in some people, chronic pancreatitis makes the pancreas become too hard and fibrous. In this case, and despite every effort, it is impossible to remove enough islet cells for transplanting back. Unfortunately, it is impossible to predict this in advance.

In this situation, the islets are either destroyed and discarded using Human Tissue Authority approved methods, or sometimes the islets can be used for ethically approved research relating to pancreatitis.

Using your islets for research if they cannot be transplanted will have been discussed in detail with you before the operation. You will have full control of whether your islets are used in this way or not. If you decide you would like them to be used for research, you will be asked for separate research consent.

Once the islets have been infused, they lodge in the tiny blood vessels of the liver where they recover from the operation and make a new blood supply. Once they have a blood supply, they are able to start making hormones to help to maintain healthy blood sugar levels.

Why bother with the islets?

We go through the effort of isolating islet cells and injecting them into the liver because if they take, they can help to manage both high and low blood glucose levels.

There is evidence from people with type 1 diabetes that if the body can make even a tiny amount of insulin for itself, this is associated with a longer, healthier life with diabetes.

There is also a possibility that the hormones that the islet cells make as well as insulin (such as glucagon) may also protect against low blood glucose (hypoglycaemia).

Finally, there is evidence which suggests that those receiving an islet auto transplant after total pancreatectomy may have a longer life expectancy compared to those who have the pancreas removed but do not receive an auto transplant.

Assessment for TPIAT

Why?

Assessment for TPIAT is organised by a nurse specialist. They are your main point of contact during the assessment and after the TPIAT.

Total pancreatectomy with islet auto transplant is a major operation, and it is important that the assessment team are sure that you will benefit from it.

The surgery can take between 8 to 10 hours to complete and the health effects of living without a pancreas are significant. We want you and your family to be fully aware of what a TPIAT means, and to make sure it is the right treatment for you.

After the assessment, a team of healthcare professionals will review all the results and discuss your case to decide if you are suitable for TPIAT.

What is involved in assessment?

Surgical assessment for pancreatectomy:

This first appointment is with a pancreas surgical consultant and the nurse specialist to discuss TPIAT. This is to see if you are likely to benefit from being put forward for the full TPIAT assessment.

We will also talk about possible outcomes, problems, and effects of a TPIAT in general terms.

Test of islet function and assessment by Diabetes Consultant:

Since removing a pancreas takes away the body's ability to make enough insulin and will leave you with diabetes, it is important to meet and be assessed by a diabetes consultant. This is to discuss using insulin injections and what the long-term effects of diabetes are.

Insulin doses are worked out by checking your blood glucose level and adjusting the insulin dose based on that level. Mealtime doses are adjusted according to the carbohydrate content of the food to be eaten.

Standard glucose testing is with finger-prick testing. This is when you prick a clean fingertip with a small needle and drop the blood onto a testing strip.

Your islet cell function will be tested with a meal tolerance test (MTT). This will take place during your clinic appointment.

- You will need to be nil by mouth from midnight the night before.
- You are allowed to have water.
- You will have a blood test, followed by a glucose and protein supplement to drink, then blood samples will be taken 90 minutes later.
- You must not have anything else to eat or drink (apart from water) until the test is complete.

However, it has been nationally agreed that people having a TPIAT would be eligible to use some form of continuous glucose monitoring (CGM) that is available on prescription. This involves a small sensor unit that is worn on your arm or abdomen (tummy) and checks blood sugar levels without needing a finger prick.

We strongly recommend looking at the Diabetes UK and JDRF websites and other Type 1 Diabetes (T1) resources at the back of this leaflet. Examples of CGM systems are Freestyle Libre 2 (R) and Dexcom One (C).

Abbott's website has more information on the Freestyle Libre® www.freestyle.abbott/uk-en/home and there is information about Dexcom One (C) on their website www.dexcom.com/en-gb/dexcom-one-cgm-system#more.

There is a very good online course to learn more about how to manage T1 diabetes at www.bertieonline.org.uk. You will need to do this course as part of the diabetes assessment.

We have seen that people can find it difficult to take on information immediately after the surgery when they are trying to recover!

So it is important that you learn about diabetes **before** you come in for the surgery. You will need to know how to take care of your new diabetes straight after the operation.

Anaesthetic assessment by Consultant Anaesthetist:

TPIAT surgery is long and complicated and we need to make sure that you are fit enough to cope with the long anaesthetic.

The Anaesthetic Consultant (a doctor who looks after you during the operation) will make a plan of how to manage any other medical conditions you have at the time of surgery, and they will decide if any further tests are needed before we go ahead.

This appointment includes a detailed assessment of your fitness and sometimes you will need a test called CPET; a cardiopulmonary exercise test. There is a video explaining this test here:

www.youtube.com/watch?v=Vs4MWnRjKJ4&feature=youtu.be.

How Psychiatrist assessment by Consultant Psychiatrist:

Chronic pancreatitis is a long-term condition and TPIAT surgery has lifelong implications.

Long term conditions can affect your ability to function as well as you would like, and this can effect your psychological wellbeing. It is crucial to take a holistic, all-round approach to your care so that the right decisions about your treatments are made.

A consultant psychiatrist will see you as part of the assessment process to explore this with you. Pain can have a strong effect on mood, and tackling negative thoughts can help with this.

Pain Consultant assessment:

Pain is a complicated physical and psychological experience. People can experience pain even if there is little or no damage or injury.

The pain consultant will discuss your pain and your expectations of the surgery to see if it is likely to reduce your pain. They will also review your pain killers as some of them may not be helpful and could make it harder for you to recover after the operation.

Diet and physical activity before surgery

The fitter you are before surgery, the better. Try to eat as well as possible in the weeks before your operation and be as active as you can. People with chronic pancreatitis can struggle to maintain a healthy weight.

If you exercise regularly, you should carry on with this. If you don't usually exercise, try to move about as much as possible. Try setting yourself small targets each day, such as increasing the number of times you go up and down the stairs. We may suggest that you see a physiotherapist in the months leading up to surgery to help you with your fitness.

Consent

It is very important that we have your consent for surgery. We cannot go ahead without it. We need to make sure that you understand what is being done and the risks involved. The doctor will go over this with you. You are free to remove your consent and decide not to go ahead at any time.

Please ask any questions you have at any time. The TPIAT specialist nurse can help you feel ready and confident about the procedure.

A TPIAT will only be offered to you if the all the team think that you are suitable for it. If there is not complete agreement, then your case is rediscussed with all the team, and a decision is made.

TPIAT procedure

If you are considered suitable, a date for the operation will be decided as soon as possible. It will be necessary for you to come to a pre-op assessment clinic in the weeks before the surgery. This is for final checks on blood pressure and to take an ECG (an electric trace of the heart to check its function) and blood tests.

The operation

On the day you will be seen by an Anaesthetist to discuss what will happen with the anaesthetic, pain relief after the operation, and to go over any specific issues and risks for you.

To do the operation safely, the surgeons must be able to see the pancreas clearly. For this reason, a large cut (roof top incision) is made across your upper abdomen. Once the surgery is completed, this incision is sewn together under the skin (using dissolvable stitches) and the top layer of the skin is closed and covered with skin glue.

The skin glue acts as a wound dressing. This usually means that there are no stitches or staples to remove. However, some patients may need closing with staples that will need removing later. It is sometimes necessary to remove the spleen as part of the operation.

The spleen helps the body fight against bacterial infections. If you do not have a spleen, you will still be able to cope with most infections, but in a serious infection such as sepsis could develop more quickly. If your spleen is removed, you will need to have some vaccinations and you may have to take a low dose of daily antibiotics to help prevent infections to which you would be particularly vulnerable.

The operation is quite long, so at the end the surgeon will telephone a relative or friend of your choice to explain what was found and what has been done.

Will the islet cells always be isolated from the pancreas?

In some patients, chronic pancreatitis causes the pancreas to become very hard and fibrous. While every effort will be made to recover as many islet cells as possible, it is impossible to tell in advance how successful this will be and sometimes the isolation is unsuccessful.

What to expect after the operation

After you wake up after the operation, you will be taken to the Churchill Overnight Recovery Unit (CORU) for the first 24 hours. Your recovery from anaesthetic and the operation can be closely monitored here.

When you wake up, you will have the following:

- **Nasogastric tube:** this goes into your nose, down your throat and into your stomach. It drains stomach fluid that could make you feel sick while your stomach heals from the surgery. The tube is usually removed after a few days.
- **Urinary catheter:** a soft tube that goes into the bladder to drain out urine. This allows close monitoring of how much urine you make, and is usually removed after a few days.
- **Central line:** a thin tube put into one of the big veins in your chest or neck. This allows you to have more than one drip at the same time, including pain killers and insulin.
- **Intravenous lines in arms or hands:** also called cannulas. These allow for extra medication or fluids.
- **Arterial line:** this is a thin tube that is put into an artery on the inside of your wrist. This lets us constantly measure your blood pressure and take certain blood tests.
- **Drains in the abdomen:** these are tubes with a pot or bag on the end that are put in during the operation to drain extra fluid away from where the pancreas has been removed. They are removed once they are draining only very small amounts of fluid.
- **Wound infusion catheters in abdomen:** these tubes deliver local anaesthetic to the wound bed to help with pain relief.

Once CORU are happy you are recovering well, you will be taken to the Transplant Ward.

Eating and Drinking after the operation

For the first few hours after surgery you won't be able to eat or drink anything. You may be able to have a few sips of water after a few hours.

You will slowly start to drink and eat normally again, starting with clear fluids such as water and squash. You can then try other drinks, including fruit juice, tea, coffee, and milk.

Next you can try softer foods, which you should chew very well. Once you are managing this, you can slowly have more normal food.

The surgical team will let you know when you can start eating. Sometimes patients need to be fed through a tube to begin with. This is to give your digestive system time to recover. How quickly you start eating and drinking will depend on your recovery.

Some patients may not be able to start eating very quickly. If you have a leak from where the bile duct or stomach are joined to the small intestine you may need to have food through a line in a vein (intravenously) for a few days.

You will see a dietitian after your surgery. They can give you advice on what to eat, how to maintain or put on weight, and how to use pancreatic enzyme supplements. They can also give food advice for diabetes.

Will I need insulin after the operation?

An insulin infusion is started during the operation, as soon as the pancreas is removed, to control your blood glucose levels. You will have this infusion until you are eating and drinking. At this point injections will be started.

Occasionally patients can be on minimal doses of insulin or stop it completely, but most patients should expect to be on insulin injections after the operation.

Even after a successful islet auto transplant, insulin is still needed. You will continue to take insulin until the diabetes team are confident that the islets have bedded into their new location in the liver and have formed a new blood supply. If they do not, the islets will still try to function, but without a blood supply they will go through cell death (necrosis) and the transplant will fail.

Insulin will usually be continued for at least 3 months after the operation even when the islet cells appear to be functioning well.

Most patients will need to continue insulin treatment for the long term.

Studies of people who have had a TPIAT suggest that around 70% of patients will need insulin treatment at 1 year after the operation, and around 80% of patients will need insulin treatment at 2 years after the operation.

Pain control after the operation

Pain is very common after an operation. We will do everything we can to try and reduce the pain you may have, but it can be difficult to control. This can be due to long-term use of painkillers to manage chronic pancreatitis.

Pain can be managed in several ways (not all techniques are always possible and you will make a plan with your anaesthetist):

- Spinal injection of morphine before surgery starts as part of the anaesthetic – this is an injection in the small of your back to put a long-acting pain killer near the nerves that feel pain from the abdomen. It lasts until about a day after the operation.
- Epidural infusion – a continuous infusion of local anaesthetic. It is in the same place as the spinal injection and it can stay in for a few days.
- Wound infusion catheters – these send a small amount of local anaesthetic straight to the wound in your abdomen. These can stay in for a few days.
- Patient controlled analgesia (PCA) – this is a pump infusion of strong painkillers which gives a small dose with the push of a button. The PCA can also give a small, constant, background infusion of strong painkiller if needed.

These stronger painkillers are slowly reduced in the days after the operation.

If you are unable to reduce your pain killers in hospital, then the reduction will continue after discharge home. It is usually managed by your GP or local pain management team.

Going to the toilet

The urinary catheter that was put in during the operation will be taken out once you can get out of bed to use the toilet. Your bowels will not start working normally for a few days. When they do you may have diarrhoea (runny stool), or constipation (problems emptying your bowels). But this should settle down. Constipation can be caused by the pain relief medicine.

Physiotherapy

The day after the operation you will be helped out of bed and into a chair. You will also be encouraged to walk short distances with help from a physiotherapist or nurse as soon as you can.

Walking soon after surgery helps improve blood circulation, prevent blood clots and infections, and encourages your bowels to start working.

You will be encouraged to do deep breathing exercises and coughing which help to prevent chest infections.

Diabetes Nurse Specialists

This team of nurses will visit you regularly on the ward to teach you about:

- Insulin injection techniques and rotation of injection sites.
- Blood glucose monitoring – finger prick testing, ketone testing, use of Freestyle Libre.
- Glucagon administration (for your next of kin / family to learn).
- Hypoglycaemia management (low blood glucose).
- Hyperglycaemia (high blood glucose) / ketone management.
- Safe use of insulin and what to do when you are unwell.

Special considerations

Feeling tired

Feeling tired is common following pancreas surgery and is to be expected. You may need a nap during the day after you get home. It usually takes six to twelve weeks until energy levels return to normal.

Diarrhoea

After the removal of your pancreas, you can have malabsorption. This is when you do not properly digest food because without a pancreas you will not be able to make the enzymes needed.

Undigested fat stays in the bowel and causes diarrhoea and poor nutrition. To digest food properly you will have to take pancreatic enzyme replacements with all food.

Sometimes anti-diarrhoea medication is needed to slow down the number of your bowel motions. The TPIAT team will advise you on this.

Smaller appetite

It is common to have a smaller appetite after surgery. We advise trying to eat smaller meals to stimulate your appetite.

It can help to think about eating as an important medicine to help recovery. If you don't want full meals, try eating smaller portions until you feel ready to try more. Your body needs fuel to heal properly.

Alcohol

You can drink moderate amounts of alcohol after recovering from a TPIAT, and we suggest checking with your doctor before doing so.

Alcohol can also affect your blood glucose levels and make them more difficult to manage.

Numbness

It is normal to have numbness in the skin below the wound scar, because the nerves that give the skin sensation have been cut. This numbness should get better over time, but there will most likely be some permanent numbness below your scar. Sometimes you can have pain and funny feelings around your wound as the nerves repair.

Exercise

We highly recommend to take regular exercise to improve your strength after the surgery. But you must not lift anything heavier than about 2kg for 6 weeks. Please check with your doctor before restarting heavy exercise.

Driving

You will need to let the DVLA and your insurer know that you now have diabetes.

It may be several weeks before you feel able to drive after the surgery. It is recommended to wait 6 weeks after abdominal surgery. It would be wise to contact your insurer to make sure they are happy with this.

Important information

We advise you to contact your GP / diabetes team / specialist nurse if you have:

- A temperature above 38°C
- Uncontrolled blood sugars
- Redness or leakage from wound
- Increased pain around your wound.

Useful websites

www.diabetes.org.uk

www.jdrf.org.uk

www.mytype1diabetes.nhs.uk

www.freestylelibre.co.uk

www.bertieonline.org.uk

Contact details of TPIAT Clinical Nurse Specialists

Email: posttransplantnurses@ouh.nhs.uk

Telephone: 01865 228 662

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Authors: Mr. Michael Silva, Consultant HBP surgeon; Dr. Zehanah Izmeth, Consultant Psychiatrist; Dr. Alistair Lumb, Consultant Diabetologist; Prof. Paul Johnson, Lead Islet Isolation; Dr. Tim McCormick, Consultant Pain specialist; Dr. David Hallsworth, Consultant Anaesthetist; Mr. Venkatesha Udupa, Consultant HBP surgeon; Mrs. Jenny Fox, CNS; Ms Kate Onyett, TNP



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